UNDER ONE ROOF; INTERGENERATIONAL CARE FOR PEOPLE WITH DEMENTIA IN SINGAPORE-CHINESE FAMILIES - A CASE STUDY DESIGN

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy in the Faculty of Biology, Medicine and Health

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6.2.2 Recommendations for Practice---------------------------------- 241
6.2.3 Recommendations for Policy----------------------------------- 242
6.2.4 Limitations and Recommendations for Future Research--------- 243
6.2.5 Study Limitations -------------------------------------------- 244

6.3 Methodological Reflections for Future Work------------------- 244
6.4 Concluding Remarks------------------------------------------ 247

REFERENCES---------------------------------------------------------- 248

APPENDICES
Appendix 1: PRISMA Checklist----------------------------------- 266
Appendix 2: Search Strategy and Outcome------------------------ 268
Appendix 3 - Summary on the Number of Abstracts Identified by Each Search--- 269
Appendix 4: Detailed List of Studies with Extracted Data – an example -------------- 281
Appendix 5: Checklists and Appraisal of the 21 Articles--------------- 283
Appendix 6: Summary and textual description of selected studies ----------- 290
Appendix 7: Synthesis of Results ----------------------------------- 307
Appendix 8: Interview Guide -------------------------------------- 386
Appendix 9: Questionnaire (English version) ---------------------- 391
Appendix 10: Questionnaire (Chinese version) --------------------- 396
Appendix 11: University of Manchester Research Ethics Committee [ref: 14207] ---- 401
Appendix 13: Approval Letter ------------------------------------- 404
Appendix 14: Participant Information Sheet (English version) --------- 405
Appendix 15: Participant Information Sheet (Chinese version) -------- 408
Appendix 16: Participant Information Sheet for Adolescents ----------- 411
Appendix 17: Consent Form (English version) ---------------------- 414
Appendix 18: Consent Form (Chinese version) ------------------- 415
Appendix 19: Parent / Guardian Consent Form (English version) -------- 416
Appendix 20: Parent / Guardian Consent Form (Chinese version) ------ 418
Appendix 21: Assent Consent Form --------------------------------- 420
Appendix 22: Participant Reply Form ----------------------------- 422
Appendix 23: Case Study Protocol Template------------------------ 423

[83,709 words]
LIST OF FIGURES
Figure 1: Dementia sub-types --------------------------------------------------- 17
Figure 2: Overview of the literature search and retrieval process ------------ 26
Figure 3: The multiple case study design ---------------------------------------- 47
Figure 4: Example of a genogram and ecomap ------------------------------------- 53
Figure 5: Version 1: Genogram and Ecomap with Olive on 5th April 2015 ----------- 83
Figure 6: Version 2 Genogram and ecomap of Family 1 -------------------------- 84
Figure 7: Version 1: Ecomap with Pete on 4th October 2015 --------------------- 85
Figure 8: Final Genogram and Ecomap of Family 1 ------------------------------- 86
Figure 9: Version 1: Genogram and Ecomap with Clive on 8th April 2015 -------- 109
Figure 10: Version 1: Genogram and Ecomap with Joy on 12th July 2015 -------- 110
Figure 11: Version 1: Ecomap with Kit on 12th July 2015 ------------------------ 111
Figure 12: Final Genogram of Family 2 ----------------------------------------- 112
Figure 13: Final Ecomap of Family 2 ------------------------------------------- 113
Figure 14: Version 1: Genogram and Ecomap with Ben on 6th June 2015 -------- 129
Figure 15: Version 2 Genogram of Family 3 ------------------------------------- 130
Figure 16: Version 2 Ecomap of Family 3 --------------------------------------- 131
Figure 17: Final Genogram of Family 3 ----------------------------------------- 132
Figure 18: Final Ecomap of Family 3 ------------------------------------------- 133
Figure 19: Version 1 of Genogram of Family 4 ------------------------------- 148
Figure 20: Version 1 of Ecomap of Family 4 ------------------------------------- 149
Figure 21: Final Genogram and ecomap of Family 4 ----------------------------- 150
Figure 22: Version 1 of Genogram of Family 5 ------------------------------- 172
Figure 23: Version 1 of Ecomap of Family 5 ------------------------------------- 173
Figure 24: Version 1 of Ecomap of Family 5 ------------------------------------- 174
Figure 25: Final Genogram and Ecomap of Family 5 ----------------------------- 175
Figure 26: A model of Intergenerational Family Connections (IFC) --------------- 213, 216

LIST OF TABLES
Table 1: The search terms or keywords used in the PICo search --------------- 25
Table 2: Participant Demographics ------------------------------------------- 67
Table 3: Summary of Total Research Contacts ------------------------------- 69
Table 4: Research contacts with all members of Family 1 ------------------- 72
Table 5: Research contacts with all members of Family 2 ------------------- 89
Table 6: Acrylic paintings by Clive --------------------------------------- 100, 180
Table 7: Examples of Clive’s co-created drawings with Dolly --------------- 101
Table 8: Research contacts with all members of Family 3 ------------------- 116
Table 9: Research contacts with all members of Family 4 ------------------- 136
Table 10: Digital photographs of the interview venues at the workplace ----- 137
Table 11: Research contacts with all members of Family 5 ------------------- 153

LIST OF PHOTOGRAPHS
Photograph 1: HDB apartment block which Family 1 resided in --------------- 71
Photograph 2: Lift lobby on the first floor of the apartment -------------- 71
Photograph 3: Living room of Family 1 ----------------------------------- 72
Photograph 4: HDB apartment block which Family 2 resided in --------------- 88
Photograph 5: Lift lobby on the second floor of the apartment block leading to the twelfth floor ------------------------------------------ 88
Photograph 6: Living room and dining area of Family 2 --------------------- 88
Photograph 7: Dolly examining a bird’s nest during her morning walk --- 96
Photograph 8: Dolly examining the papaya tree with fruits during her morning walk --- 96
Photograph 9: Dolly making payment at the cash register ----------------- 96
Photograph 10: Dolly buying groceries at NTUC--------------------------- 96
Photograph 11: Dolly buying groceries at NTUC

Photograph 12: Dolly buying groceries at NTUC

Photograph 13: Going for walks

Photograph 14: Going out for a meal at a café

Photograph 15: Accompanying Kit to the army camp for his National Service enlistment

Photograph 16: Accompanying Dolly for an activity organized by the Residents’ Community Centre (RC)

Photograph 17: Street showing the semi-detached house which Family 3 resided in

Photograph 18: Semi-detached house on the right side which Family 3 resided in

Photograph 19: Ben accompanying Pam during her activities with therapists at the ‘Dusk to Dawn Service’

Photograph 20: HDB apartment block which Family 4 resided in

Photograph 21: Living room of Family 4

Photograph 22: HDB apartment block which Family 5 resided in

Photograph 23: Living room of Family 5

Photograph 24: Seating arrangement for interviews at the dining area of Family 5

Photograph 25: Relabelled ‘pill box’ in Chinese characters using analogy

Photograph 26: Statues and artefacts of Buddha in the prayer room which Margaret offered prayers to

Photograph 27: Margaret and Mindy preparing Margaret’s medication in the “pill boxes”

Photograph 28: Chinese characters on red coloured rice paper pasted on the left side of the living room wall in Family 1’s apartment

Photograph 29: Family 4’s apartment

Photograph 30: Hexagonal shaped object hung above the front entrance of Family 5’s apartment

Photograph 31: The two huge drums at the bottom right hand corner are for Taoist devotees to burn incense paper as offerings to their ancestors

Photographs 32 to 34: Chinese deities at the prayer alter in the living room of Family 1

Photograph 35: Ancestral tablet on the altar in the living room of Family 1’s apartment

Photograph 36: Prayer altar in the prayer room of Family 5

Photograph 37: Spacious kampong house with garden space for meaningful family interaction and support

Photograph 38: Housing Development Board high-rise apartment block comprising multiple small apartment units with shared common spaces

Photograph 39: Doing Chinese New Year Shopping together

Photograph 40: Clive and Dolly engaging in their routine daily activity

LIST OF DIAGRAMS

Diagram 1: Seating arrangement for interviews at the sofa area for Family 1

Diagram 2: Seating arrangement for interviews at the dining area for Family 2

Diagram 3: Seating arrangement for interviews at the sofa area for Family 3
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSEES</td>
<td>American Bibliography of Slavic and East European Studies</td>
</tr>
<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
</tr>
<tr>
<td>ASSIA</td>
<td>Applied Social Sciences Index And Abstracts</td>
</tr>
<tr>
<td>BEHAVE-AD</td>
<td>Behavioural Pathology in Alzheimer's Disease Rating Scale</td>
</tr>
<tr>
<td>BNI</td>
<td>British Nursing Index</td>
</tr>
<tr>
<td>CES-D</td>
<td>Center for Epidemiological Studies–Depression</td>
</tr>
<tr>
<td>CRD</td>
<td>Centre for Reviews and Dissemination</td>
</tr>
<tr>
<td>COREQ</td>
<td>Consolidated Criteria for Reporting Qualitative Research</td>
</tr>
<tr>
<td>CINAHL</td>
<td>Cumulative Index to Nursing and Allied Health Literature</td>
</tr>
<tr>
<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of Mental Disorders-IV</td>
</tr>
<tr>
<td>EPPI</td>
<td>The Evidence for Policy and Practice Information and Co-ordinating Centre</td>
</tr>
<tr>
<td>EMBASE</td>
<td>Excerpta Medica Database</td>
</tr>
<tr>
<td>GHQ</td>
<td>General Health Questionnaire</td>
</tr>
<tr>
<td>HDB</td>
<td>Housing and Development Board</td>
</tr>
<tr>
<td>SIGLE</td>
<td>System for Information on Grey Literature in Europe</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
</tr>
<tr>
<td>STROBE</td>
<td>Strengthening the Reporting of Observational Studies in Epidemiology</td>
</tr>
<tr>
<td>U.S.A.</td>
<td>United Sates of America</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
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ABSTRACT

**Background:** The family-centred cultural construct of filial responsibility forms the core foundation of the traditional mosaic of a typical intergenerational Singapore-Chinese family. Due to modernization, several generations co-habiting within the same household or living in separate households have shrunk to smaller-sized immediate and extended families residing in mostly high-rise apartments. This change has impacted on the social norm of traditional intergenerational Singapore-Chinese caregiving. Currently, there are gaps in understanding the intergenerational Singapore-Chinese families and caregiving in dementia. Only a few studies to date have discussed the intersection on intergenerational family care, but an in-depth exploration of intergenerational Singapore-Chinese families’ cultural beliefs and values is an important consideration when attempting to understand the family and determine their support and maintenance of relational bonds. **Aims:** The aim of this longitudinal, case study research using a participatory approach was to better understand the everyday caregiving experience of intergenerational Singapore-Chinese families within the context of each family unit living together in Singapore ‘under one roof’. Family biographies were co-constructed with five intergenerational families living ‘under one roof’ during repeated and scheduled visits with each participating family over a period of between six to 15 months. The interviews included the completion of a 23-item structured questionnaire, co-construction of a genogram and ecomap with each family, drawings, audio recordings and digital photographs of the home environment, items and activities. **Results:** Narrative analysis of the five intergenerational cases resulted in the emergence of three themes that explained and explored the various dynamics in the data, namely: i) Family values, and its supporting sub-themes of culture; religion; and filial piety; ii) Family support, and its supporting sub-themes of timeliness; internal support network; and external support network; and iii) Family bonds, and its supporting sub-themes of relational; closeness and conflict; and challenges. Data analysis also generated a meta-theme ‘Intergenerational Family Connections’ which was supported by three properties: i) Strongly held beliefs and practices; ii) Shared space; and iii) Supporting family togetherness. **Conclusion:** This study has led to an in-depth understanding of the everyday experience of the intergenerational Singapore-Chinese families of a person with dementia, within the shared context of their family construction. This study makes an original and significant contribution to knowledge through the development of a new theoretical model on intergenerational family connections in dementia care. The findings will better inform formal and informal service providers and policy makers on how best to support and maintain the relational dynamics of intergenerational Singapore-Chinese families who provide care for the person with dementia at home.
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DEDICATION
This thesis is dedicated to the Five Intergenerational Families who took part in this study and, also, to those families caring for a family member with dementia whom I have worked with and encountered over the years. The sharing of their experiences has made this study possible and I thank them for this.

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• The 6th International Carers Conference in Gothenburg, Sweden from 3rd to 6th September 2015 and DART on 30 November 2015.
• A book publication, Social Research Methods in Dementia Studies: Inclusion and Innovation - Chapter eight: Under one roof: using photographs, genograms, ecomaps and family interviewing to document intergenerational family care in Singapore-Chinese families where one member has dementia

You continue to inspire me with your innovative ways of doing research.

Lastly, but most importantly, I would like to thank my husband Tack Wei, my pets and my mum and dad for all their help over the years; without their practical and emotional support this study could not have happened.
BACKGROUND TO THESIS

The Personal Context
The author is a nurse by training and has worked in the acute care setting before joining her current organization to fulfill her passion in teaching. She holds a Master of Science in Advanced Practice (Critical Care) from the University of Surrey, United Kingdom. She is currently an Assistant Director at the School of Health Sciences (Nursing), Nanyang Polytechnic in Singapore. Being a Singapore-Chinese, she is fully aware of the local Chinese culture and is conversant in Mandarin and the local Chinese dialects such as Hokkien, Teochew and Cantonese.

The author is a full-time caregiver for her husband who is a tetraplegic from a spinal cord injury. Her awareness journey for dementia began in the mid-1990s when a grandaunt who used to be an active and independent lady was diagnosed with dementia. By default, the unmarried eldest daughter became the primary caregiver in addition to working full-time. As her grandaunt’s behavior became increasingly difficult to manage, caring for her at home was stressful for the eldest daughter. This was in spite of weekly assistance from other family members such as the other daughter, son-in-law, daughter-in-law and grandchildren. During the week days, there were occasions in which her grandaunt would forget to turn off the gas cooker before leaving the house and she would often ‘wander off’ and was unable to find her way home. As my grandaunt’s condition worsened, she began neglecting her basic activities of daily living which, in turn, led to frequent family arguments and misunderstandings between the person with dementia and the daughter who was the primary caregiver.

Within the span of just a few years, her daughter had no choice but to place her mother in continuing care (nursing home). Whilst in the care home, my grandaunt could not remember any of her family members and the daughter used to share how ‘heart wrenching’ it felt when her mother could not even recognize her. Eventually, my grandaunt passed away in 2010, a skeletal form of her former self.

Shortly after her death, the author’s own father was admitted to the hospital for multiple cerebral infarctions. Three months prior, my father had exhibited signs and symptoms of vascular dementia. The period of hospitalization and long rehabilitation was a stressful experience for the family. Complex issues surfaced. Instead of providing support of any form, some relatives and other family members who were overseas worsened the situation by giving negative comments on care provision and distancing themselves from the situation. Some family members could cope while others could not. This brought about a host of caregiving conflicts and strains, particularly those faced by the primary caregivers - the author and her mother.

The range of work and personal experiences eventually set in motion the impetus for a funded project in collaboration with the local Alzheimer’s Disease Association in Singapore and the Centre for Enabled Living which is under the Ministry of Social and Family Development. The study continued to the next stage in which a second funding was sought and obtained from the TOTE Board SIR Fund. The aim of the second project was to provide an educational and informational portal which is web- and apps-based for family caregivers of people with dementia. The author was also a member of the advisory workgroup on recommended design and set-up of an older person and dementia friendly environment for the Dementia Resource and Training Centre at the Alzheimer’s Disease Association. She is a regular speaker at scheduled educational talks which are organized by the Alzheimer’s Disease Association for their caregivers’ support group. During scheduled activities, she particularly enjoys interacting with the family caregivers. In addition, the author is presently
the project lead for the ongoing Smart Home and Innovation Space which depicts dementia-, wheelchair- and eco-friendly and smart technology features to support people with dementia and their family caregivers living in the community. For the author, the caregiving experience has provided her with a deeper and more meaningful understanding about dementia, the person with dementia and what family caregivers go through. The whole experience has provided a sense of altruism in which the author has committed and dedicated her time and effort in providing educational and training support for family caregivers of people with dementia.

An Introduction to the Study and Study Aims
This is the first study of its kind in Singapore and the author is the first nurse researcher to do this work. The focus of this research is on intergenerational Singapore-Chinese families caring for a family with dementia and living together ‘under one roof’. The study addresses the exploration of caregiving experiences, the impact of caregiving, and the family systems revolving around the lives of the intergenerational Singapore-Chinese families. The author was not able to collect data from people with dementia as permission from the Alzheimer’s Disease Association would not allow this.

Organisation of Thesis
This thesis has six chapters:

Chapter one provides an overview of dementia and the typical intergenerational Singapore-Chinese families. The chapter will go on to provide an overview of dementia and the local population demographics, characteristics of the person with dementia, characteristics of the intergenerational Chinese family caregivers, their caregiving experiences, impact of the caregiving experiences and the relevance of these family caregivers to this study.

Chapter two describes the literature review on intergenerational families and caregiving in dementia, rationale for the review and objectives of the review. The method which includes eligibility criteria, information sources, search, study selection, data collection process, data items and synthesis of results is also described. The results section entails study selection, study characteristics, results of individual studies and synthesis of results. Finally, this chapter describes the discussion which includes the summary of evidence, limitations and conclusions from the literature review.

Chapter three details the methodology and methods which were deployed for this study. This includes the aims and objectives of the study, theoretical rationale and the reasons for a case study design. The methodological approach was based on the gaps which have been identified during the review of the literature. This chapter also addresses reflexivity and issues involving ‘practitioner research’. The study design will be described with an overview of the participatory approach adopted and narrative analysis used and the reason for using these two methods for presenting the everyday experience of the five intergenerational Singapore-Chinese families caring for a family member with dementia. A description of how rigour was addressed in the research process will follow. Finally, the ethical issues, sample size and issues of recruitment will be discussed.

Chapter four covers the five intergenerational Singapore-Chinese families, including a range of methods such as interviews and photographs to convey their everyday family life, and description of the author’s co-construction and evolution of the family genogram and ecomap with each family, the author’s personal encounters with each family, the author’s reflection and the intergenerational issues encountered by the families. The five case studies are briefly shared with study participants indicated with a * and the person with dementia, a #. Family 1 – *Olive, *Pete and #Angel; Family 2 – *Clive, *Joy, *Kit and #Dolly; Family
3 – *Ben, Barbara, Tim (overseas) and #Pam; Family 4 – *Ellie, Ginny, Clara and #Elaine; Family 5 – *Mindy, Max, Sandy, *Shaun and #Margaret. I have maintained anonymity as well as chosen Western names for the participants and the person with dementia to cater to the wider international audience who may possibly have difficulty following the flow of the storylines if Chinese sounding names are used.

Chapter five presents a cross-case analysis of the five case studies. Constant reading and re-reading of the five intergenerational cases resulted in the emergence of three themes that explained and explored the various dynamics in the data, namely: i) Family values, and its supporting sub-themes of culture; religion; and filial piety; second theme: ii) Family support, and its supporting sub-themes of timeliness; internal support network; and external support network; and the third theme: iii) Family bonds, and its supporting sub-themes of relational; closeness and conflict; and challenges. Data analysis also generated a meta-theme ‘Intergenerational Family Connections’ which was supported by three properties: i) Strongly held beliefs and practices; ii) Shared space; and iii) Supporting family togetherness.

Chapter six covers a review of the study’s findings on family connections, relational dynamics and how these may inform health and social care practitioners who are involved with intergenerational Singapore-Chinese families on two main areas. First, the importance of making anticipatory goals; and second, to be aware of the current and future supportive mechanisms that sustain intergenerational family connections for families living ‘under one roof” where one member has dementia. The study’s findings are taken into account within the broader context of the past and current literature and its implications for education, practice, policy and research in dementia made visible. An outline of the study limitations and methodological reflections is outlined. The chapter concludes with a summary of the recommendations for practice, research, policy and education for intergenerational families providing caregiving for a family member with dementia.

Definition of Terms and Writing Conventions Used
The following terms and conventions have been used in the thesis:

- ‘Person with dementia’; or ‘people with dementia’; or ‘family member with dementia’ will be synonymous terms used to describe the person with dementia.
- ‘Early stage dementia’; or ‘moderate stage dementia’; or ‘late stage dementia’ will be terms used to describe the stages of dementia for the person with dementia.
- ‘Family caregiver’ or ‘family carer’ will be synonymous terms used to describe intergenerational family members who provide regular care, supervision and/or support to the person with dementia. Family caregivers are mainly the spouse, children/children-in-laws and other relatives. Intergenerational family refers to several generations of family. Singapore-Chinese refers to citizens or residents of Singapore who are of Chinese ancestry. Families refers to a group of people affiliated by birth, marriage, or adoption. Members of the immediate family may include a spouse, parent, brother and sister, and son and daughter. Members of the extended family may include grandparent, aunt, uncle, cousin, nephew and niece, or sibling-in-law.
- Within the text of the thesis, numbers from one to nine are written within the text in full, with numbers 10 and above written in numerical form. Exceptions to this are descriptive statistical measures and sample measures (‘n’); when a number begins a sentence; and when numbers form part of a title, for example: Category 1; Diagram 2; Family 3; Figure 4; Table 5; and so on.
- Harvard style of referencing has been used. Where there are two authors, these are cited and where there are three or more ‘et al.’ has been used. Authors are presented in alphabetical order in the text and the bibliography. Within the bibliography each publication outlines a full author list.
• Direct quotes from the literature and data collected from participants within the present study are presented with double quotations marks and indented and italicised in the text if the quote extends beyond 40 words. Shorter quotes are embedded in the text using double quotation marks and are also italicised. Single quotation marks are used within the thesis to denote the use of phrase or colloquialisms.
• Single spacing is used for quotations, footnotes, references, preliminary pages and text within the tables.
• The names of the intergenerational family members engaged in this study are written with the person providing the main care in the first position, the other members in second, third, e.g. Clive (person providing the main care), Joy and Kit (persons providing the secondary care), whenever names appear together and, lastly, Dolly (the person with dementia).
• Throughout the thesis, the author will be referred to as ‘the author’, ‘researcher’, ‘I’, ‘me’, ‘my’ or by name depending on the context in which it is used.
CHAPTER ONE
DEMENTIA AND THE INTERGENERATIONAL SINGAPORE-CHINESE FAMILIES IN CONTEXT

1.0 Introduction
Dementia is described as a syndrome affecting memory, cognition and functional ability (World Health Organization 2012). Vascular dementia is the most common of all the dementia sub-types affecting the Singapore Chinese population (Ampil et al 2005; Sahadevan et al 2008). The prevalence of dementia in Singapore is increasing in tandem with the ageing population (Singapore Department of Statistics 2012) with one in 10 people aged 60 and above to have dementia, according to a recent nationwide study (Subramaniam et al 2015). In terms of demographic profile, the Chinese has the biggest number of older people with dementia (Singapore Department of Statistics 2012).

1.1 Overview of dementia and the local population demographic
Dementia originates from the Latin term ‘de mens’ (Gustafson 1996) which means ‘without a mind’. Rather than a disease, it is “a syndrome - usually of a chronic or progressive nature - which affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement” (World Health Organization 2012, p.7). The cognitive impairments of dementia are frequently accompanied and, sometimes heralded by, a decline in emotional control, social behaviour or motivation (World Health Organization 2012). These manifestations can affect the person’s execution of his or her activities of daily living and instrumental activities of daily living. If a family caregiver is left unsupported, the burden associated with psychological and behavioural problems, and physical demands related to the person with dementia can inadvertently lead to undesired institutionalization of the person with dementia (Kua & Tan 1997).

Dementia has several sub-types (see Figure 1). The most common is Alzheimer’s disease which accounts for 60 to 70% of cases (World Health Organization 2012). Other major sub-types include vascular dementia, dementia with Lewy bodies, fronto-temporal dementia and other types of dementia (World Health Organization 2012). In Singapore, diagnosis is confirmed using the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV) criteria (American Psychiatric Association 1994), considered the gold standard for the clinical diagnosis of dementia (Holmes et al 1999; Jobst et al 1998; Lim et al 1999a). This is further supplemented by an objective approach with cognitive tests.
Figure 1: Dementia sub-types (World Health Organization 2012)

Singapore has one of the most rapidly aging populations in the Asia-Pacific region. By 2030, it is estimated that 18.7 percent (%) of Singapore’s population of 5.1 million will be aged 65 and above (Singapore Department of Statistics 2012). Those who are over 75 years of age would have increased six-fold from 48,000 in the year 2000 to 291,000 in 2030 (United Nations 2004). This means, by 2050, Singapore’s population could be the world’s fourth oldest, with a projected median age of 54 years (United Nations 2006). With the aging population, a report by the Asia Pacific members of Alzheimer’s Disease International (Access Economics Pty Limited 2006) has predicted the prevalence of dementia in Singapore to increase from 22,000 in 2005 to 53,600 in 2020, 80,000 in 2030 and 186,900 in 2050. Correspondingly, this means that an additional 53,600 and 186,900 caregivers and/or families will be expected to shoulder the caregiving responsibilities (Seow & Yap 2011).

Based on the various screening instruments, the evidence from local epidemiological studies have confirmed the prevalence of dementia or cognitive impairment to range from 2 to 14% (Kua 1991; Kua & Ko 1995; Lim et al 2003; Chiam et al 2004) with age-related increases in prevalence of cognitive impairment from 0.8% in those aged between 60 to 64 years to 32.2% among those aged 85 years and older (Chiam et al 2004). Furthermore, the findings from locally conducted epidemiological studies on the prevalence of dementia (Kua 1991;
Kua & Ko 1995; Lim et al 2003; Chiam et al 2004) are also consistent with other populations in the world in evidence-based estimates as generated by the Delphi Consensus Study (Ferri et al 2005) and other comparison studies (Kua & Shen 1996).

Ethnic variations in dementia prevalence have also been demonstrated with higher dementia prevalence among the Malays and Indians as compared to the older Chinese population (Chiam et al 2004; Sahadevan et al 2008). Nevertheless, the prevalence of dementia in the Chinese population is considered significant. This is because, relative to the other ethnic groups, the Chinese forms the largest ethnic group in Singapore comprising 74% of the total population (Singapore Department of Statistics 2012). Locally, vascular dementia is more common in the Chinese and Malays while Alzheimer’s disease is found to be more common in Indians and Eurasians (Ampil et al 2005; Sahadevan et al 2008).

1.2 Characteristics of the person with dementia
In 1990s Singapore, the majority of the people with dementia were diagnosed with mild to moderate dementia (Kua & Tan 1997; Lim et al 1999). Currently, more are diagnosed with moderate and advanced stage dementia (Liew et al 2010; Tew et al 2010). The person with dementia is usually female (Liew et al 2010; Lim et al 1999; Tew et al 2010), aged between 60 to 99 years, residing with the main caregiver (Liew et al 2010; Tew et al 2010) and receiving assistance in activities of daily living from the family caregiver (Kua & Tan 1997; Lim et al 1999). Most have been receiving care in the home setting for more than three years (Kua & Tan 1997; Liew et al 2010; Tew et al 2010).

1.3 Characteristics of the intergenerational Chinese family caregivers
Congruent with the hierarchical order of caregiving in a typical intergenerational Chinese family, the family caregiver usually begins with: the spouse, daughter, daughter-in-law, son and other next-of-kin (Kua & Tan 1997). However, social norms are changing. The extended family - a once common sight - has begun to disintegrate (The National Family Council and the Ministry of Community Development, Youth and Sports 2009). Unlike the traditional family where multiple family caregivers are residing together, the number of potential family caregivers has shrunk from three or four generations to its current state. Developing this point further, nowadays, a typical intergenerational family comprises caregivers who are usually middle-aged and mostly children followed by spouses (Lim et al 1999; Netto et al 2009; Tew et al 2010; Yap & Seng 2009). The unmarried daughter or son is now left to care for the older parent(s) and/or person with dementia (Seow & Yap 2011). Local studies have
also observed that most family caregivers are women and daughters (Kua & Tan 1997; Lim et al 1999; Netto et al 2009; Tew et al 2010; Yap & Seng 2009). Family caregivers are also either working full-time or part-time (Netto et al 2009; Yap & Seng 2009) in addition to conducting their caregiving role. Most are equipped with secondary school, pre-university education and above (Netto et al 2009). Women’s traditional role as caregivers is undergoing transitional changes. Therefore, it has become imperative for most caregivers to seek additional help from other family members when needed (Seow & Yap 2011). However, some families are faced with challenges especially when the adult child or children has/have migrated overseas. That leaves the other healthy or frail older spouse to provide care to the person with dementia with, or without, the assistance of another person who is usually the foreign live-in maid (Thang & Mehta 2009). I will return to the discussion around the live-in maid under the next sub-heading.

1.4 Caregiving experiences and impact on the Chinese family caregivers

For family members providing care, caregiving is usually related to the betterment of pain and suffering for an ill member. To date, there is no standard definition of family caregiving. However, it is “understood to involve providing extraordinary care, often outside the bounds of what is usual in family relationships” (Yap et al 2005, p.263). The provision of care can typically stretch over extended period of time and requires dedicated investment of personal time, energy, finances, and tasks that may be unpleasant, emotionally stressful and physically exhausting (Schulz & Martire 2004). Often, family caregivers are entrusted to provide assistance with basic activities of daily living (bathing, dressing, toileting, transferring, continence care, feeding) in addition to the provision of a protective environment and emotional support. Such are the day-to-day routine of the typical family caregiver of the person with dementia for as long as the care is required and the caregiver is able to provide the continuity of care. The daily involvement in care provision can eventually lead to a host of caregiving experiences and impact on the intergenerational Chinese family caregivers (Liew et al 2009; Netto et al 2009).

There are many factors which determine the caregiving experience of the intergenerational Chinese family caregivers. The cultural and moral values from the key elements of filial piety are essentially what determine caregiving. For example, respect and love for one’s parents, not bringing any type of dishonour to one’s parents, taking good care of one’s parents and obeying one’s parents (Dai & Dimond 1998). Hsueh (2001) further conceptualized filial piety into four key elements: concern for parental health; financially
supporting parents; fulfilling the housing needs of parents; and respect for parental authority. This cultural belief is what shapes intergenerational Chinese adult children’s attitudes and behaviours toward their parents, thus ensuring the continuance of parental well-being (Sheu 1997) including in the presence of dementia. It is also this family-centred cultural construct that binds children towards sacrificing their self-interests physically, financially and socially for the benefit of their parents - or family - as a filial responsibility (Dai & Dimond 1998). This is the core foundation of the traditional mosaic of a typical intergenerational Singapore-Chinese family comprising several generations co-habiting within the same household or living in separate households (Thang & Mehta 2009). Although no local studies have explored filial piety and its impact on the caregiving experience in dementia, the basis of this argument is supported by a study on Chinese-Canadian caregivers of people with dementia (Ho et al 2003).

In Singapore, families are also likely obligated to care as a result of policies which are implemented along the lines of filial piety. An outcome of this reinforcement can be seen in the majority of one or two intergenerational Chinese households in the high rise flats in land scarce Singapore in which approximately 85% of Singaporeans are living (Thang & Mehta 2009). In these high rise flats, most older Singaporeans living with dementia are still residing at home with their family caregivers who are mainly the spouse, children (Singapore Department of Statistics 2009), children-in-law and grand-children (Tang & Mehta 2009; Yap and Seng, 2009). Additionally, the Parents’ Maintenance Act ensures continued financial support of older people (including those living with dementia) from adult children (Mehta 2006).

To manage time and competing family/work demands, a common solution is for most families to employ a live-in maid who is usually from the Philippines, Indonesia or Myanmar (Seow & Yap 2011). This is affirmed by a local study which showed that about 50% of families of people with dementia have live-in maids (Tew et al 2010; Yap & Seng 2009). In fact, typically, one in every six households would have a live-in maid (Tang & Mehta 2009). The live-in maid, who is mainly female, is regarded as an ‘extra pair of hands’ in the family caregiving setting (Tang & Mehta 2009). Apart from performing the household chores, she also attends to the physical caregiving of the person with dementia whilst the children provide financial support and make the caregiving decisions (Seow & Yap 2011). In view of the existing residential structures, the live-in maid and the person with dementia sometimes rotate and stay in the homes of different children (Seow & Yap 2011). For smaller
families, the live-in maid may be the only person staying with and caring for the person with dementia in a one or two room high rise flat (Seow & Yap 2011). Arguably, some of these live-in maids have become an important support structure for the family, but it is unknown at present whether or not families view the live-in maid as a member of the family.

1.5 Relevance of the intergenerational Chinese family caregivers to this study

Consistent with the political and social scene, it would seem that the intergenerational family caregivers are entrusted with the care of the person with dementia who is still residing at, or near, the home. It is equally important to explore the informal support of the live-in maids as they often assume the supportive role in the care of the person with dementia. Presumably, they also function as an important part of the intergenerational families’ support systems. In view of the progressive decline in memory, cognition and, eventually, functional abilities, caring for a person with dementia can be fraught with a range of positive and negative experiences. The negative experiences can lead to psychological and physical burdens, whereas the positive can lead to caregivers’ sense of satisfaction (Liew et al 2009; Netto et al 2009). Most of the intergenerational family caregivers are working individuals who have to balance their time between work and caregiving. Consequently, whether or not the caregiving role has rewarded, or overwhelmed, the intergenerational family caregivers is not the real issue as what needs to be considered is how the family unit can be better supported to still function cohesively and as a whole. However, in order to determine such an outcome, a more in-depth understanding about intergenerational Singapore-Chinese families is required. This exploration will form the substance of the next chapter.

1.6 Summary

The prevalence of dementia in Singapore is predicted to increase from 22,000 in 2005 to 53,600 in 2020, 80,000 in 2030 and 186,900 in 2050 (Access Economics Pty Limited 2006). Furthermore, a recent study on the prevalence and risk factors of dementia in the Singapore resident population has been established to be one in 10 of individuals aged 60 years and above (Subramaniam et al 2015). Thus, the impact on the intergenerational Singapore-Chinese families is significant as the Chinese forms the largest ethnic group (Singapore Department of Statistics 2012). Most people with dementia are still cared for at home by their families (Kua & Tan 1997; Liew et al 2010; Tew et al 2010). These economically viable family caregivers are either working full-time or part-time (Netto et al 2009; Yap & Seng 2009) which necessitates the employment of live-in maids to provide caregiving support (Tew et al 2010; Yap & Seng 2009). Caregiving can lead to a host of positive and negative
experiences for intergenerational family caregivers. However, at present, little is known about intergenerational Singapore-Chinese family caregivers and their family systems which inhibits, at the very least, the provision of tailor-made support. As such, the literature review in the next chapter will use a systematic approach to explore, and collate, the research evidence about intergenerational caregiving experiences in dementia care.
CHAPTER TWO
INTERGENERATIONAL FAMILIES AND CAREGIVING IN DEMENTIA: A LITERATURE REVIEW USING SYSTEMATIC METHODS

2.0 Introduction
Whilst caring is undertaken in a family system there are, currently, gaps in the literature about understanding the intergenerational experience of caregiving at home for a person with dementia. From a Singapore-Chinese context this is a concern as the Chinese population is the most prevalent cultural group in Singapore and the population most likely to involve intergenerational family members caring at home - and under one roof - for a person with dementia. Therefore, to shed further light on this phenomenon, this chapter will start by outlining the rationale for the literature review before outlining its inclusion/exclusion criteria. For the review, an intergenerational family is defined as having two or more family members who may, or may not, be residing together but who are caring for a person with dementia. The chapter then highlights the narrative synthesis of the 19 studies that were located following a systematic process and presents a critical appraisal about the merits, and otherwise, of each of the reported studies. The chapter ends by presenting the gaps in the literature that became the theoretical framework that facilitated the research design and questions, as explored in the remaining chapters of this PhD study.

2.1 Rationale for the review
This literature review aims to:

- Systematically seek, explore and collate information from the available global scientific literature on caregiving experiences of intergenerational family caregivers of the person with dementia;
- Identify gaps in the available evidence and evaluate the implications of these identified gaps; and
- Document the caregiving experiences of intergenerational family caregivers of the person with dementia.

The literature review was guided by the 27-item checklist (see Appendix 1) of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement (Liberati et al 2009). As the nature of this review is focused on social experiences, some of the items in the PRISMA checklist, which are more suited to clinical trials, are not strictly adhered to.
2.2 Objectives of the review
The systematic review questions are based on PICo (P = population; I = phenomena of interest; Co = Context) (Centre for Reviews and Dissemination 2009) and, in the context of this review, the systematic review questions are:

- What are the caregiving experiences of intergenerational family caregivers of the person with dementia?
- What is the impact of caregiving on intergenerational family caregivers of the person with dementia?

2.3 Methods
2.3.1 Eligibility Criteria
Inclusion and exclusion criteria were developed to facilitate a more focused and systematic literature search. Studies were selected based on criteria relating to participant characteristics, caregiving experiences of intergenerational family caregivers or impact of caregiving on intergenerational family caregivers of the person with dementia, language and duration. These are detailed below.

Inclusion criteria:
- Studies that included at least two or more generations of family caregivers of people with dementia.
- Studies that included two generations of family caregivers and where the caregivers could be from one family unit or different family units, but where the goal was to support one identified person with dementia.
- Only articles published in the English language [as there is not a budget for translation costs associated with this study].
- Articles published from 1997 to present [early 2017]. Whilst acknowledging that this is an arbitrary cut-off year, it was important to make the search manageable and therefore a 20-year boundary was set for this task.

Exclusion criteria:
- Studies that were not focused on the intergenerational family, as defined by the review parameters.
- Studies on intergenerational caregivers of people with dementia which do not depict caregiving experiences and impact of caregiving.
• Intergenerational studies where the family care of the person with dementia was not the focus.

2.3.2 Information Sources
Studies were searched via the American Bibliography of Slavic and East European Studies (ABSEES; 43 results), Applied Social Sciences Index And Abstracts (ASSIA; 2 results), British Nursing Index (BNI; 2 results), Cumulative Index to Nursing and Allied Health Literature (CINAHL; 2 results), EBSCO host Research Databases (3,510 results), Evidence Based Medicine Reviews (707 results), Excerpta Medica Database (EMBASE; 707 results), the Medical Literature Analysis and Retrieval System Online (Medline; 707 results), National Research Register (0 result), Psychological Information Database (PsychInfo; 8 results), PubMed (24 results), System for Information on Grey Literature in Europe (SIGLE; 0 result), The Cochrane Library (0 result), Web of Knowledge (24 results), the Sage Journals – Dementia (17 results), China Academic Journals (0 result), and peer-reviewed journals such as Aging and Society (1 results), Alzheimer's and Dementia (0 result), American Journal of Alzheimer's Disease and other Dementias (29 results), International Journal of Alzheimer's Disease (0 result), JSTOR (1 result), and the Gerontologist (17 results) followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe articles. A second search using all identified keywords and index terms was undertaken and yielded 7 articles from other sources. Thirdly, the reference list of all identified articles was searched for additional studies (2 articles). The last search was run on the 31st July 2017.

2.3.3 Search
The following search terms or keywords as seen in Table 1 were used to search all databases, peer reviewed journals, other sources and end reference list. Boolean searches were performed for all databases.

Table 1: The search terms or keywords used in the PICo search

<table>
<thead>
<tr>
<th>P = Population</th>
<th>I = Phenomenon of Interest</th>
<th>Co = Context</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intergenerational Multigenerational Family caregiver Caregiver Carer</td>
<td>Care, Caring, Caregiving</td>
<td>Dementia, Alzheimer’s disease</td>
</tr>
</tbody>
</table>
2.3.4 Study Selection

Study selection began with an initial literature search using the search terms or keywords as seen in Table 1. A total of 5,810 search results were yielded from the initial screening after duplicates were removed. Of these, 5,803 records were from databases and 7 records were from other sources (see Appendix 2 for details of search strategy and outcome). After screening by title, abstract and duplicates, 27 records were identified and screened according to the eligibility criteria as mentioned in the previous section, 2.3.1. Appendix 3 provides an example of a summary on the number of abstracts retrieved from the American Bibliography of Slavic and East European Studies through a search which was performed on 31st July 2017.

Further screening was undertaken, leaving 19 full text articles that were eligible for inclusion in the literature review. The 19 full text articles were made up of 17 published and electronically indexed peer-reviewed papers and 2 end references from the 17 papers. All the 19 full text articles were subsequently included following a quality appraisal. An overview of the aforementioned literature search and retrieval process is as presented in Figure 2.

Figure 2: Overview of the literature search and retrieval process (adapted from Liberati et al 2009)
2.3.5 Data collection process

Data from the 19 articles were extracted. Data extraction was done in accordance with the specific domains in the utilized appraisal checklists - the PRISMA Statement (Liberati et al 2009), Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) (von Elm et al 2007) and Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al 2007). The following data were extracted from the included qualitative studies - study design, which included theoretical framework, participant selection, setting, data collection, analysis and findings. For the quantitative studies and review, the following data were extracted - abstract, methods, results, discussion, funding. Additionally, the following data were extracted from all the included studies - author, year, title, journal, country and objectives. Details of the extracted data are in Appendix 4.

The PRISMA Statement (Liberati et al 2009), STROBE (von Elm et al 2007) and COREQ (Tong et al 2007) checklists were more objective with straightforward appraisal criteria. As such, the eligibility of the 19 articles was appraised using the PRISMA Statement (Liberati et al 2009), STROBE (von Elm et al 2007) and COREQ (Tong et al 2007) checklists. Details of the PRISMA Statement (Liberati et al 2009), STROBE (von Elm et al, 2007) and COREQ (Tong et al 2007) checklists and appraisal of the 19 articles are in Appendix 5.

2.3.6 Data items

The author further extracted information for the synthesis from each included study on the i) objectives; ii) characteristics of participants (including gender, relation to care recipient, age, generation, marital status, ethnicity and culture, educational status, employment/financial status, role); iii) Care recipients’ gender, age, living arrangement and care duration; iv) type of care provided; and v) caregiving experiences and impact of caregiving.

2.3.7 Synthesis of results

The aim of the synthesis was to observe for differences, similarities and draw conclusions across studies and to explore reasons for the differences and similarities, if possible. Given that most of the included studies were qualitative studies, quantitative studies and reviews, it was necessary to use a mainly narrative approach to perform the synthesis. Furthermore, the study designs were variable and the number of included studies and reviews was relatively small at 19. Two methods for the synthesis of results or findings - textual narrative and thematic - were utilized. For the textual narrative approach, a commentary reporting in
Appendix 7 on study and participants’ characteristics, context, quality and findings, scope, differences and similarities among studies were used to draw conclusions across the studies, as proposed by Lucas et al (2007). For the thematic approach, data, in particular findings from the selected studies, were grouped into the themes using colour mapping (Lucas et al 2007).

**Textual Narrative Synthesis**

Extracted findings from each study were interrogated using the following questions developed from the aims of the review:

1) What are the characteristics of the intergenerational family caregivers?
2) What care do the intergenerational family caregivers provide for the person with dementia?
3) What are the caregiving experiences of the intergenerational family caregivers?
4) What are the impacts related to caregiving experiences of the intergenerational family caregivers?

Data from the selected articles (for example, participants’ characteristics, the nature of care provided, verbatim quotations, score from gain or burden scales related to caregiving experiences, and impacts) and the author’s interpretations, were recorded separately (see Appendix 7). This allowed retention of the richness - or 'thickness' - of the contributing data as proposed by Lucas et al (2007). Study characteristics were summarised (see Appendix 7) and quality appraisal, using the three checklists, was also applied. As such, the 19 studies, and reviews meeting the inclusion criteria, underwent data synthesis.

**2.4 Results**

2.4.1 Study selection

Appendix 6 is a summary and textual description of the 19 selected studies and reviews which met the eligible inclusion criteria for review (see Figure 2). The studies were categorized according to qualitative and quantitative studies and reviews. Figure 2 depicts the search and retrieval process which has been explained in section 2.3.4 earlier on. The flow chart in Figure 2 also includes the final phase of the selection process which presents the eventual selection of the 19 studies.

As anticipated, due to the dearth of studies on intergenerational family caregivers of people with dementia, only five studies could be located that explored at least two or more
generations of family caregivers from a family unit. The five studies are described according to their study design, country of origin and participant characteristic as follows.

Qualitative studies:
- Boughtwood et al (2011) from Australia on Arabic, Chinese, Italian and Spanish caregivers (spouses, adult children, spouses of the adult children and grandchildren);
- Roach et al (2013) from the United Kingdom on White-British families (wives, husbands, daughter, brother and uncle);
- Szinovacz (2003) from the United States on African-American and Caucasian White caregivers (daughters, daughters in-law, husband, sons, sons in-law, granddaughters, grandsons. Two adolescents were from the same family); and
- Ward-Griffin et al (2007) from Canada (although intergenerational, the study is limited by the original study’s criteria to only mothers and daughters as participants).

Quantitative studies:
- Hamill (2012) from the United States on Mexican-American and Caucasian-White families (daughter, daughter-in-law, son, son-in-law, granddaughters and grandson);

The rest of the 12 studies and two reviews were chosen because they were able to meet the other inclusion criteria of two or more generations of family caregivers not having to be from one family unit. The 12 studies and two reviews are described according to their study design, country of origin and participant characteristic as follows.

Qualitative studies:
- Beach (1997) from the United States on Caucasian, African American, Native American and Pacific Islander adolescent caregivers (children, niece, nephew and grandchildren);
- Chan et al (2010) from Hong Kong on Chinese caregivers (spouses and children);
- Ho et al (2003) from Canada on Chinese-Canadian caregivers (wives, daughters and daughters in-law);
- Innes et al (2011) from Malta on family caregivers (husbands, wives, daughters, son and daughters in-law); and
- Netto et al (2009) from Singapore on family caregivers (daughters, sons, wife, niece and adopted family member).
Quantitative studies:
• Fisher and Lieberman (1999) from the United States on European American and ethnic minority caregivers (spouses and children);
• Kua and Tan (1997) from Singapore on Chinese family caregivers (wives, husbands, daughters, daughters in-law and sons);
• Lieberman and Fisher (1999) from the United States on people with dementia and their families (spouses, children and non-relative);
• Liew et al (2010) from Singapore on family caregivers (husbands, wives, son, daughters, sons in-law, daughters in-law, grandsons, granddaughters and non-relative);
• Lim et al (1999) from Singapore on family caregivers (sons, daughters, husbands, wives, daughters in-law, granddaughters, sisters, and friends);
• Lin et al (2012) from Taiwan on family caregivers (spouses, adult children, daughters in-law, other relatives and live-in maids); and

Reviews:
• Sun et al (2012) from the United States on publications related to Chinese American family caregivers published in peer-reviewed journals between 1990 and early 2011; and

Therefore, the 12 studies and two reviews are from different family units; however, they still represent two or more generations of family caregivers and therefore meet the study inclusion criteria for the literature review. In addition, all of the 19 included studies were able to depict the caregiving experiences, and impact of caregiving, on intergenerational family caregivers.

2.4.2 Study characteristics and results of individual studies
As suggested by Popay et al (2006), a preliminary synthesis should begin earlier on in the review with the textual description (see Appendix 6) of the 19 studies and reviews.
2.4.3 Synthesis of results

Studies and reviews were categorized according to three themes: (i) Culture; (ii) Support network; and (iii) Togetherness. The categorization of studies was done following the guidance recommendation by Popay et al (2006). Categories were derived by grouping, clustering and transforming data to a common numeric and tabulating the data variables from the included studies in order to identify patterns, such as similarities and differences, and by drawing conclusions from the observation. This was done inductively and without a priori themes to guide data extraction. Colour coding was utilized to aid visualization. Appendix 7 provides an outline about how the synthesis was conducted.

(i) Culture

Sun et al (2012) in their review noted that from a cultural perspective, dementia, as a stigmatized ‘mental illness’, can be a serious stressor for family caregivers. As a diagnosis dementia can also become a source of shame in Chinese American families and can be borne out of concern about how others in the community will react to the diagnosis. Fundamentally, caregivers may not disclose, or share, negative emotions and experiences openly, or with others whom they consider as outsiders, leading to caregivers coping with their own distress spiritually and through values of filial piety. The family centred cultural construct of filial piety forms the core foundation of the traditional mosaic of a typical intergenerational Singapore-Chinese family. Family caregivers in this situation experience more strain when support from informal networks, such as families, relatives, friends, or neighbours sever contact in order to avoid stigmatization by association. According to a Maltese study, the sheer lack of understanding and informal support from families, relatives, friends or neighbours from the social stigma can lead to isolation (Innes et al 2011). In this instance, stress can be amplified when social networks diminish (Sun et al 2012). However, in other caregiving cultures in the United States, having friends at the house (where the caregiver of person with dementia lives) engenders the selection of empathetic peers who are more objective about caregiving challenges. This is reported in an American study involving Caucasian White, African American, Native American and Pacific Islander spouses, children, nieces/nephews, and grandchildren of people with dementia (see: Beach 1997).

Currently, the above findings are inconclusive and may not help in fully answering the review question especially with regard to intergenerational care within a family unit. For example, only seven out of 25 of Sun et al’s (2012) reviewed studies are on Chinese
caregivers. In addition, the caregivers from these seven studies are American Chinese and would, in all likelihood, be Westernized and assimilated into the Western culture. The context/environment in which caregiving is provided is also different. Moreover, the participants may not be intergenerational family members from the same family unit. The other two studies (Beach 1997; Innes et al 2011) comprise non-Chinese participants and were intergenerational caregivers from different family units.

Institutionalization of a family member with dementia usually does not augur well with Chinese cultural values. However, 12 Chinese-Canadian caregivers comprising wives (n=2), daughters (n=8) and daughters-in-law (n=2) in a qualitative study (Ho et al 2003), who were opposed to the idea of institutionalizing their family members with dementia as recommended by healthcare professionals, had all made applications to nursing homes despite conflicts with their traditional cultural and personal values. Six were ready to institutionalize their relatives with dementia upon care home availability. Interestingly, these caregivers were also concerned about Western influence on their Chinese traditional values, particularly on intergenerational caregiving and the contribution from a younger generation. Arguably, and in accordance with Wang’s (2012) review, the influence of Western culture, and the acculturation of younger family members to this culture, can lead to language barriers and differences in opinions and beliefs amongst family members from non-Western backgrounds. This concern was highlighted by family caregivers in Ho et al’s (2003) study, especially that their children no longer retained traditional values. In view of this positioning, children were not expected to be obliged to provide the expected filial care and responsibility. In addition, some of the family caregivers in Ho et al’s (2003) study went on to emphasise the importance of family education in maintaining traditionalism. However, Ho et al’s (2003) study failed to shine a spotlight on filial care and responsibility in specific cultures and how this value, if present, influenced the different members of the intergenerational family.

In some cultures, caregiving provision for the person with dementia is drawn along gender lines. For instance, in a Maltese study by Innes et al (2011) involving husbands (n=2), wives (n=2), daughters (n=8), son (n=1), daughters-in-law (n=3), the findings revealed that daughters and daughters-in-law were expected to provide physical care whilst the men took control of the decision-making. Developing this point further, a daughter caring for her mother in the study shared that she was told by her brothers of her obligation - as a daughter - to assume the caregiving role. Moreover, the study appears to suggest that Maltese men
continue to maintain previous interests and are able to rationalise limitations in their caregiving role with the need to maintain active social lives (Innes et al 2011). A similar gender-based divide in care provision was shared in an Australian study by Boughtwood et al (2011) that comprised Arabic (n=19), Chinese (n=37), Italian (n=40) and Spanish (n=25) caregivers. Here, female caregivers in these cultures often failed to question, or reflect upon, the consequences of caring for themselves or the implications it may have on their future life choices. Instead, the female participants felt it was their responsibility to perform certain caring tasks that, they believed, was inappropriate for male family members to do. This cultural role expectation may permeate to the next generation of family caregivers as demonstrated in Boughtwood et al’s study (2011) by the female grandchildren’s willingness to assist older female family members in performing intimate caring tasks when compared to the males in the study sample.

Arguably, the caregiving role is generally assigned to female family members resulting from the higher levels of concern that is shown for the person with dementia. For example, Chan et al (2010) identified higher levels of concern accorded to person with dementia by female family caregivers in comparison to male counterparts in their Hong Kong study involving Chinese participants who were main caregivers. The study found that female compared with male caregivers had higher expectations of themselves to be competent, thus making them significantly more stressed than male caregivers (Chan et al 2010). It is not apparent if the gender expectation is identical across different cultures, particularly the Chinese culture, and, if so, how this applies to the intergenerational members of a family unit. The one study on this topic area conducted by Chan et al (2010) only highlighted female caregivers were more empathetic, and serious, about their caregiving role.

Spousal obligation is based on the notions of individual responsibility and in accordance with cultural values. The previous relationship between the caregiver and person with dementia, spousal devotion and responsibility, and the need to change and re-adapt personal lifestyles to suit the new situation, seemed to resonate across a number of studies (see: Boughtwood et al 2011; Ho et al 2003; Innes et al 2011). For some participants, the deep sense of spousal devotion and responsibility is deeply rooted within the cultural tradition (Ho et al 2003). However, such individual devotion and responsibility has also transgressed usual cultural norms. For instance, in Boughtwood et al’s (2011) study, some Italian and Spanish-speaking caregivers, particularly male spouses, mentioned they were doing new tasks which were normally not expected of them.
Finally, the caregiving experience can become stressful when other support systems enter the home bearing a different set of cultural values. This occurs when other support systems, such as the live-in maid, entered the lives of family carers who employed that person (Lin et al 2012). A cross-sectional study in Taiwan involving spouses (n=112), adult children (n=306), daughters-in-law (n=41) other relatives (n=30) and their live-in maids from Indonesia (n=42) found that the live-in maid was more individualistic than family-centred as the role was perceived as a working obligation (Lin et al 2012). To explain this finding further, this is because caregiving is seen as a task rather than as love. Therefore, the live-in maid enters the family home with a degree of emotional detachment as they attempt to acclimatise into the domestic caregiving situation. If left unaddressed, this can become a source of burden for the family caregiver and the live-in maid (Lin et al 2012). Again, this finding is inconclusive as only one study has highlighted this particular aspect. Furthermore, the input and involvement of intergenerational members from each family unit is not reported.

(ii) Support Network

Generally, family caregivers seek respite from caregiving through informal and formal support systems. The reason for this is that the stresses from caregiving have been shown to be either mediated by, or influenced by, these systems. According to a Canadian study, informal support is usually provided by family and friends; specifically, with friends and family providing social and emotional support respectively (Ho et al 2003). Chinese family caregivers tend to depend more upon family support and less upon services for people with dementia as seen in Kua and Tan’s (1997) quantitative study conducted in Singapore. Help and support from adult family members and siblings have also been shown to bring about positive caregiving experiences (Wang 2012) and this ‘total’ family help, or support, is determined by several factors. For example, Lieberman and Fisher (1999) found that total family help is determined by the family caregiver’s educational status and person with dementia’s ‘troubling’ behaviours. Moreover, the greater the family's positive conflict resolution skills and the more focused their decision-making style, the more help other family members provided (Lieberman & Fisher 1999). However, caregivers’ strain becomes inevitable when the family is unable to resolve conflicts (Ho et al 2003).

In dementia care, significant burden can be experienced when the sole responsibility falls upon the primary caregiver and there is lack of support from extended family members (Wang 2012). Sometimes the lack of support is simply due to geographical barriers, such as families in developed countries being geographically dispersed and not readily available to
caregivers, or family members who have migrated to other countries (Wang 2012). In addition, functional deficits increase with illness progression and care can become both labour-intensive and time-consuming, leading to the caregivers increased feelings of burden (Chan et al 2010). However, the literature suggests that caregivers of people with severe dementia tend to accept their role better and experience less personal burden (Chan et al 2010; Liew et al 2010; Tew et al 2010) especially when family support increases and fewer complaints from others about the caregivers, or the person with dementia, are received (Chan et al 2010).

Furthermore, families providing high levels of help to one another are less likely to institutionalize the family member with dementia compared to families who reported providing low levels of family help (Lieberman & Fisher 1999). Moreover, the stronger the family's negative feelings towards one another, the greater the probability that the family institutionalize the family member with dementia (Lieberman & Fisher 1999). Intensified conflict, distress, and frustration amongst family members - over time - are commonly cited reasons for institutionalization together with on-going, and emerging, challenging family interactions and difficulties when attempting to coordinate the care of the family member with dementia. As a consequence, families who are ‘divided’ and ‘in conflict’ are seen to place the person with dementia into care more frequently than families who have more positive emotional ties (Lieberman & Fisher 1999).

Indeed, building on the preceding finding, in Fisher and Lieberman’s (1999) quantitative, longitudinal study involving 164 mostly European and ethnic minority family caregivers comprising spouses (n=92) and adult children (n=40) from different family units, the authors found that recommendations for institutionalization were usually based on the degree of the person with dementia’s functional deficit and the amount of care to be performed by family members. On the other hand, the Chinese family caregivers in Ho et al’s (2003) study felt that institutionalization contradicts their traditional Chinese culture or their personal family values. Moreover, the caregivers from Ho et al’s (2003) study, who had expressed negative feelings, perceived that residents of nursing homes were treated ‘badly’ and felt that the family’s act of institutionalizing a family member with dementia would be labelled negatively within their culture (Ho et al 2003).

In contrast, the findings from a quantitative cross-sectional study by Tew et al (2010) - conducted in Singapore - that involved 252 Chinese and 14 non-Chinese caregiver
participants suggested a preference from these caregivers (85.7%) to continue to look after the person with dementia at home. Nonetheless, four factors were associated with the choice of nursing home: caregiver is working; no live-in maid; lower caregiver gain; and behavioural problems in the person with dementia. A few studies have researched the predictors of institutionalization, namely caregivers’ characteristics, the person with dementia’s characteristics and living arrangements (Ho et al 2003; Lieberman & Fisher 1999; Lim et al 1999). High levels of behaviours that challenge in the person with dementia, and lack of support systems, are usually the cited reasons for considering institutionalization (Chan et al 2010; Fisher & Lieberman 1999; Ho et al 2003; Kua & Tan 1997; Lieberman & Fisher 1999; Liew et al 2010; Lim et al 1999; Tew et al 2010). Institutionalization of the person with dementia seems to be a common and consistent finding across numerous studies.

However, the actual intergenerational support network from within each family unit cannot be wholly determined in the studies. The gap still exists on an in-depth understanding about factors that lead to the institutionalization of the person with dementia in relation to the support network of intergenerational members within one family unit. For instance, there are already limitations to Tew et al’s (2010) study which may impact on the findings of this synthesis. Firstly, it is not possible to determine if the caregiver’s preference on whether to care for their relative with dementia at home, as opposed to institutionalization at the point of study, would translate into the eventual outcome. Secondly, the external validity and generalizability of the result may be limited due to the sample characteristics, that is, the self-selected population of caregivers who are educated and able to complete the questionnaires independently. There is also a likelihood that respondents were motivated caregivers who had been bringing the person with dementia for regular doctors’ appointment in the dementia clinic, or they were active participants of the local Alzheimer’s Disease Association who had received education and support as part of their regular attendance. As such, the proportion of caregivers who preferred in-home care may have been inflated and may not be representative of the views of other members of the family unit.

The live-in maid is becoming a common source of informal support in the Chinese community in Southeast Asia. They are usually hired by the family caregiver with whom the person with dementia resides and when the caregiver needs to work. Tew et al (2010) found that most of the Chinese and non-Chinese main caregivers in their cross-sectional study from Singapore lived with the person with dementia and a significant number of these caregivers were working and receiving assistance in their caregiving role from a live-in maid. Lin et
al’s (2012) cross-sectional study, conducted in Taiwan, suggested that families who employ live-in maids cope better and indicated less psychological burden even when the person with dementia was exhibiting behaviours that challenge compared to those caregivers without live-in maids. However, there are limitations to this study. Firstly, the reliability and validity of the questionnaires have been confirmed in Taiwan for the family caregivers, but not for the Indonesian version which was used for the live-in maids. Secondly, the reported symptoms of the person with dementia were based on the caregivers’ reports. In this case, the caregivers’ ratings of the symptoms may also be subjective as these may be affected to some extent by their emotional state.

In the reviewed studies, formal social support or services, such as government-supported home-care programmes, informational support, formal emotional support from professional counselling and support groups and hired professional helpers, are channels from which family caregivers have sought assistance (Chan et al 2010; Ho et al 2003; Innes et al 2011; Liew et al 2010; Tew et al 2010). According to Chan et al (2010), perceptions about the usefulness of social services differ across the trajectory of dementia. The caregivers in that study comprised wives (n=5), husbands (n=5), daughters (n=16) and a son (n=1) of people with mild dementia and the sample indicated a preference for mutual support groups to assist them in coping with distress (Chan et al 2010). Day care facilities were preferred to other support services, such as home care and respite services, as these services allow family caregivers to ‘take a breather’ when the family member with dementia is attended to (Chan et al 2010).

On the other hand, caregivers of people with late-stage dementia generally benefited from community-based services, but most caregivers regarded residential services as the best long-term care arrangement (Chan et al 2010). Information leaflets, audio visual materials, and problem-oriented skills training programmes, and an accessible ‘resource person’, were regarded as practical and helpful for obtaining information and advice about specific aspects of caregiving (Chan et al 2010). Similarly, Liew et al (2010) and Tew et al (2010) found that the use of active management and participation in caregiver educational and support group programmes were positively evaluated by family caregivers (Liew et al 2010; Tew et al 2010). Increased caregiver gain was also positively correlated with a sense of caregiver competence, encouragement and active management caregiving strategies (Liew et al 2010; Tew et al 2010). In comparison, limited availability of suitable social support, or services
Innes et al. (2011), and criticism as a caregiving strategy (Liew et al. 2010), were identified as stressors to caregivers.

Family experience in dementia requires further understanding as suggested by Roach et al. (2013) who observed that biography and family storylines were important to determine for intergenerational families of younger people with dementia. In their longitudinal case study with five intergenerational families, it was seen that different family storyline types were used, these being: agreeing, colluding, conflicting, fabricating and protecting. These five storyline types were used at different points and at different times in the dementia care trajectory. The authors observed that families who adopted a mainly ‘agreeing’ storyline are more likely to seek alternatives in positively overcoming challenges in their everyday lives in contrast to families who adopted mainly ‘conflicting’ and ‘colluding’ storylines. The latter families were more likely to require help to understand family positions and promote change. Therefore, Roach et al. (2013) suggest that the identification of the most dominant and frequently occurring storylines used by families may help to further understand family experience in dementia and assist in planning supportive services.

(iii) Togetherness
Caring for a person with dementia has brought about positive changes in family relationships and family bonding as noted in several studies (see for example: Beach 1997; Hamill 2012; Netto 2009; Roach et al. 2013; Szinovacz 2003; Ward-Griffin et al. 2007). Caregivers reported having a closer relationship with the person with dementia due to more frequent contact and close attention (Netto et al. 2009; Roach et al. 2013). Additionally, positive outcomes in the relationship with other members of the family have also been seen to happen. As an illustration, Beach (1997) reported that sibling activity and sharing increased as a result of coping with the person with dementia’s more challenging behaviours. In addition, distant sibling relationships have also undergone positive changes (Beach 1997) with the family becoming closer, bonded and united in the goal of providing ‘good care’ for their relative with dementia (Netto et al. 2009). Ward-Griffin et al. (2007), in studying the mother-daughter relationship have termed the nature of such a close and positive relationship as ‘co-operative and cohesive’ and described such positive relationships as based on reciprocity, cooperativeness, flexibility, attentiveness, positive team work and mutual emotional bond/attachment. It is this deep sense of shared relational experience in caregiving where bonding develops which brings the intergenerational family closer together.
Moreover, Beach (1997) in her qualitative study on 20 Caucasian, African American, Native American and Pacific Islander adolescent caregivers [comprising children (n=4), nieces/nephews (n=4) and grandchildren (n=12)] also noted improvement in the relationship between the parent and adolescent as shared by the adolescent participants. However, it should be acknowledged that data were gathered from narratives and retrospectively reported by adolescents without input from other intergenerational family members. Therefore, their perceptions on the relational outcomes from caregiving may not be similarly perceived by other family members. Significant mother and adolescent bonding may possibly result from the greater sense of intimacy within the mother-adolescent relationship (Beach 1997; Szinovacz 2003).

The literature also reveals that a greater sense of intimacy between the adolescent and parent caregiver is determined by several factors. For instance, a qualitative study by Szinovacz (2003) from the United States on African-American and Caucasian White caregivers [comprising daughters/daughters-in-law (n=13), husband (n=1), son/sons-in-law (n=1), granddaughters (n=13) and grandsons (n=4)] found that adolescent caregivers were more empathetic and respectful of the caregiving parent when they genuinely understood the stress their parents were undergoing. The study also reported that joint involvement in caregiving enhances adolescent–parent bonds. Positive reinforcement accorded to the adolescents by the mothers, and their feeling of being more trusted to perform important caregiving tasks, further reinforced this relationship (Szinovacz 2003). In fact, the adolescents in Szinovacz’s (2003) study shared the need to offer help and reassurance whenever they perceived their mothers as experiencing emotional burden. On the one hand, the adolescents in the study expressed a genuine desire to spend time with their mothers (Szinovacz 2003). On the other hand, the adolescents lamented restrictions on their own - and the family unit’s - activities due to the care situation. They also complained about ‘spill over’ of caregiver stress on other family relationships and about the parent-caregivers’ focus of attention to the family member with dementia (Szinovacz 2003). These negative features strongly influenced the adolescents’ adaptation to the care situation (Szinovacz 2003).

In contrast to the previous studies involving adolescents, a cross-sectional study by Hamill (2012) on daughter/daughters-in-law (n=29), son/son-in-laws (n=24), adolescent granddaughters (n=21) and grandsons (n=8), found that parents’ influence on their children’s involvement in caregiving was not determined by the degree of affection which their children have for them but, instead, on the affection for grandparents living with dementia.
Grandschildren provided more help when parents provided more care and when grandchildren had greater affection for grandparents. Adolescent grandchildren exhibited lower levels of social responsibility and more negative attitudes toward the provision of long-term care when fathers experienced higher subjective burden.

Consequently, caregiving can lead to deterioration in family relationships and poor bonding in some intergenerational families resulting in unfavourable consequences, such as institutionalization of the care recipient and burden of the caregiver as presented in the previous identified theme. Interestingly, prior relational conflict between the caregiver and care recipient has a part to play. Kua and Tan (1997) found that daughters-in-law who had previous relationship conflict with their mothers-in-law complained more about the burden of care. Ward-Griffin et al (2007) negatively describes the nature of such relationship as the ‘custodial mother-daughter relationship’ and ‘combative mother-daughter relationship’. In the custodial mother-daughter relationship, the caregiver continues to provide care as part of her duty and familial caregiving expectations. However, there is an absence of emotional attachment. Over time, increasing interpersonal conflict and emotional distress becomes unavoidable. In the case of the combative mother-daughter relationship, the relationship is emotionally charged and commonly shaped by their previous relationship. Historical conflict, tension and hostility in the mother-daughter relationship may lead to elder neglect and/or abuse of the person with dementia.

Strained relationships with other family members have also been reported (Chan et al 2010; Szinovacz 2003) leading to institutionalization of the person with dementia over time (Lieberman & Fisher 1999). In studies which include adolescents, the worsening grandparent-grandchildren relationship and parent-child relationship are related to deterioration in communication, affection and decrease in shared leisure activities (Szinovacz 2003). Although caregivers seem to be aware that their behaviours toward the adolescents are affected by their caregiving responsibilities, they do not realize that these behavioural changes also have a profound impact on adolescents’ perceptions of the entire relationship (Szinovacz 2003). What is significant in Szinovacz’s (2003) study is the impact of the adult caregiver’s stress - and family tensions - resulting from the care situation impinging upon how adolescents adapt to the care situation and correlating these to a worsening parent-child relationship. Finally, adolescents’ distress can play out in the form of highly problematic individuals and futures, a situation that is worrying to say the least (Szinovacz 2003).
2.5 Discussion

2.5.1 Summary of evidence and limitations

The approach taken in the synthesis has led to some limitations related to the potential for bias. For instance, the selection and arrangement of the family caregivers and person with dementia’s characteristics and the selected studies’ findings with regard to the phenomena of interest (caregiving experiences and impact of caregiving experiences) included in the data extraction and synthesis table was, to some extent, subjective. Correspondingly, the most relevant themes emerging from the textual descriptions were identified due to their perceived importance at least partly subjectively. As suggested by Popay et al (2006), this is precisely the reason why conclusions need to be ‘down weighted’ as these are based on the lone reviewer’s identification through extensive examination of primary studies. In the case of this particular synthesis, qualitative and quantitative studies and reviews were included. This resulted in methodological heterogeneity thus, necessitating the use of the tools and techniques described in Popay et al’s (2006) guidance. In view of the variances in study designs, several techniques were considered appropriate: groupings and clusters; tabulation; transforming data into a common rubric; vote counting as a descriptive tool; and translating data (thematic analysis). These were utilized to identify similarities and differences across the different studies with the aim of drawing conclusions.

Heterogeneity related to sample size of the included studies is another limitation which may likely affect external validity. Nevertheless, the justification for qualitative studies with regard to the small sample size is their focus on the number of participants needed to reach data saturation rather than on a large sample size, as required in quantitative studies. In other words, sampling for qualitative studies is performed until no new information is obtained and saturation is achieved (Polit & Beck 2004). Typically, the number of participants needed to reach saturation depends on a number of factors (Morse et al 2002). For example, saturation can be achieved with a relatively small sample when the ‘right’ participants are recruited and able to reflect and communicate about their experiences effectively (Polit & Beck 2004). The eight quantitative studies, however, were varied in terms of sample sizes from 29 to 489 participants and the narrative review by Sun et al (2012) also had heterogeneity in sample sizes across their included studies. Concerningly, the narrative review by Wang (2012) failed to report the sample sizes of included studies.

Heterogeneity related to study design across the qualitative and quantitative studies was another limitation, but one which could not be avoided. In this review, the qualitative studies
were usually conducted via face-to-face or focus group interviews and participant observation, except for one which included the use of families’ own biography and shared photographs (Roach et al 2013). There was a mixture of quantitative studies including mixed method design, longitudinal designs, cross-sectional studies and quantitative surveys. Nevertheless, the reviews also presented a similar heterogenous mix of studies. Moreover, in line with the inclusion criteria of selecting only articles published in the English language, articles written in other languages were not reviewed. This may have contributed to the inevitable exclusion of relevant articles on caregiving experiences and impact of caregiving on intergenerational family caregivers of people with dementia. This is particularly salient for literature in the Chinese language.

Some of the data variables appertaining to the characteristics of caregivers and the person with dementia, and the conduct of the studies, were unclear or not provided in the 19 selected articles. This difficulty was encountered during data extraction and synthesis. The narrative and thematic synthesis in this review has attempted to combine data across the 19 studies and systemic reviews. The main limitation of the narrative and thematic synthesis, as with any overview, is in the varied characteristics and culture of the participants. Moreover, the experiences of the people with dementia, caregiving experiences and the impact of caregiving experiences, as determined by the type and levels of support, may not have been the same across the 19 studies and included systematic reviews.

Furthermore, only five studies were actually based on at least two or more generations of intergenerational family caregivers from a family unit, with the rest selected because they met the inclusion criteria of two or more generations of family caregivers not having to be from one family unit. None of the five studies were exclusively focused on intergenerational Chinese family caregivers, except for Boughtwood et al (2011), which included some 37 out of 121 participants. Of the studies included in this chapter that met the study inclusion criteria, only six involved Chinese and/or mostly Chinese participants. The review also noted a dearth of studies on intergenerational caregiving involving adolescents and men.

The themes from the current literature in the intergenerational family experience of dementia that emerged as a result of this review were: i) culture; ii) support network; and iii) togetherness. The only published accounts included in this review of the caregiving experiences of intergenerational caregivers of people with dementia over a longitudinal period - and representing the various members from a family unit - came from the United
Kingdom, with no existing primary academic research published on the subjective, everyday experience of Chinese intergenerational families of people with dementia, including in Singapore. The evidence base exploring the experiences of intergenerational families of people with dementia remains in need of development and this population continues to be under-represented in the literature. A large chronological gap also exists in the literature with regards to research on caregiving experience in dementia, with few studies published in Singapore in the early 1990’s and a steady stream since this time (to 2017). This gap also indicates a lack of emphasis placed on research with intergenerational Chinese families within the literature and the increased attention it should receive. Virtually all published research in Singapore on caregiving in dementia are written on the main caregiver and the collective intergenerational members comprising the entire family unit are overlooked within dementia research, policy and care provision. It was apparent from this review that the main family caregiver’s experiences has consistently been reported in the literature separately from the experiences of the intergenerational family members of people with dementia as a family unit, continuing a tradition within both dementia care provision and research where each intergenerational member of families of people with dementia are viewed as separate and sometimes competing entities. Furthermore, there were virtually no studies where an inclusive family-centred study design had been used when working with the intergenerational families of people with dementia. The current study therefore aims to present a new creative lens through which the construction of the experience of Singapore-Chinese intergenerational families is given an added dimension through a family and domestic (home) perspective that, at present, is lacking from the literature.

2.5.2 Conclusions

Intergenerational family caregivers in the review are usually those most involved with the care of the person with dementia. None of the studies on Chinese family caregivers has included the entire family unit and studied how the various members of each family unit play a part in caring, at home, for the person with dementia. The specific role of the participating and non-participating family members is generally not well described in the literature. However, even if described, they are usually retrospective accounts from the key participating family member. At this juncture, no conclusion can be made about the actual caregiving experiences and impact of caregiving on intergenerational families as an entire family unit. This will form the substance of my research question, aims and objectives as outlined in the next chapter, including the research design to help address these concerns.
2.6 Summary

Although family caregiving of people with dementia has been receiving some focus in Singapore since the 1990s, studying of intergenerational Singapore-Chinese families caring for a family member with dementia ‘under one roof’ has not been explored. So far, the Singapore studies which were conducted from the mid-1990s to 2010 (Kua & Tan 1997; Lim et al 1999; Yap & Seng 2009; Netto et al 2009; Liew et al 2010; Tew et al 2010) are quantitative in nature with only a recent one which adopted a qualitative approach. The topics of coverage are also limited to stress, burden and gains of caregiving, profile of the primary family caregivers, and common factors leading to the institutionalization of the person with dementia. As a result, this has not facilitated the local and international understanding of the complex caregiving experiences of the intergenerational Singapore-Chinese family caregivers and their family units at home. More recently, family caregivers have been receiving attention from policymakers, who fear that the impact of caregiving will lead to families not wanting to care for the older person with dementia. However, it is not clear how intergenerational family members fit into this caregiving scenario in terms of their experiences as caregivers and how caregiving impacts upon the family unit.

A review of the selected 19 studies and narrative reviews from electronic databases and peer reviewed journals using a systematic approach has identified a lack of studies on the entire family system and how the various members of the family unit play a part in caring for the person with dementia. It further reinforces the fact that there are currently no available published studies on the intergenerational Chinese families which look at the immediate and extended family to better understand the caregiving experiences and impact of caregiving on these intergenerational families. The existing overview remains fragmented with general assumptions because of the existing gaps and insufficient evidence-base about the caregiving experience of a typical intergenerational Chinese family. This review, therefore, indicates that the study of intergenerational Singapore-Chinese families caring for a family member with dementia ‘under one roof’ presents as an area worthy of further research attention. It also suggests a variety of methodological tools to focus on the naturalistic everyday caregiving experience of intergenerational Singapore-Chinese families providing care for a family member ‘under one roof’.
CHAPTER THREE
METHODS OF STUDY

3.0 Introduction
Chapter three details the methodology and methods which were deployed for this study. This starts with outlining the aims and objectives of the study, theoretical rationale and the reasons for undertaking a longitudinal case study design. The methodological approach was based on the gaps which have been identified during the review of the literature. This chapter will also address reflexivity and issues involving ‘practitioner research’. The study design will then be described with an overview of the participatory approach adopted and narrative analysis used and the reason for using these two methods for presenting the everyday experience of the five intergenerational Singapore-Chinese families caring for a family member with dementia. A description of how rigour was addressed in the research process will follow. Finally, the ethical issues, sample size and issues of recruitment will be discussed.

3.1 Aims and Objectives of the Study
The main research question is: How do intergenerational Singapore-Chinese families care for a family member with dementia ‘under one roof’? To answer this research question, the primary aim of this study was to explore the meaning, construction and place of ‘under one roof’ in the lives of intergenerational Singapore-Chinese families and their family member with dementia living at home in Singapore. The primary aim of this longitudinal, narrative case study was supported by four objectives:

- To work collaboratively to understand how intergenerational Singapore-Chinese families care for a family member with dementia ‘under one roof’.
- To map how intergenerational Singapore-Chinese families care for a family member with dementia ‘under one roof’ using a variety of approaches to document their everyday activities.
- To identify the main factors that impact upon how intergenerational Singapore-Chinese families caring for a family member with dementia living ‘under one roof’ negotiate with, and assign meanings to their everyday life.
- To develop creative methods of working with intergenerational Singapore-Chinese families caring for a family member with dementia ‘under one roof’ and maintaining researcher reflexivity during all research encounters.
The aim and objectives of the study were met by conducting a participatory, narrative, longitudinal case study with five intergenerational Singapore-Chinese families caring for a family member with dementia. In-depth interviews with the recruited families were undertaken while co-constructing family biographies with each intergenerational family during repeated visits for a duration of between six to 15 months. The co-construction of these biographies was instrumental in fully involving, and engaging, the families in the presentation of their narrative story. The family biographies largely took the form of textual and non-textual data generated from the 23-item structured questionnaire, genograms, ecomaps, drawings, audio recordings and digital photographs of the home environment, items and activities. Digital photographs were also provided by some of the intergenerational families. Narrative analysis was used to analyse this qualitative data and to develop the theory in understanding the intergenerational Singapore-Chinese families’ experience of caring for a family member with dementia. The data from the 23-item structured questionnaire assisted in providing the demographic information about the intergenerational families. This was cross referenced with the information provided by the intergenerational families during the audio-recorded interviews and when co-constructing the genograms and ecomaps with participants. The detailed rationale of the choice of these methods and how they fit the design of this study is described in the next section.

For this PhD study, multiple case study design was chosen in accordance with the processes outlined in Figure 3 as the methodology has the ability to explore complex social units using multiple sources of evidence co-constructed with the participants and in accordance with their needs, value-system and biographical situation (Yin 2009). As will be seen in the study, the participating intergenerational families comprised multiple variables of importance in aiding the understanding of the phenomenon - that is caring ‘under one roof’ for the person with dementia in the home by intergenerational family members. As the case study was anchored in real-life situations, each event is able to provide a rich and holistic account of the phenomenon under study (Yin 2009) and offer insights and illuminate meanings in the actual context of intergenerational care for a family member living with dementia in the home.

3.2 Theoretical Rationale for the Study
There is no Singapore-Chinese intergenerational studies in dementia care; the intergenerational Singapore-Chinese families being no exception in this case. As presented
Figure 3: The multiple case study design (adapted from Yin 2009, p. 57)
in the systematic review of the literature in chapter 2, those published or available studies in the literature have not been able to offer in-depth information on how all members of the intergenerational Singapore-Chinese families residing together (if at all) care for a family member with dementia and how this knowledge can be effectively translated to practice. This study represents an original and novel contribution to the literature on intergenerational Chinese family care in dementia and the first time such a longitudinal qualitative study in family care and dementia has been undertaken in Singapore. Digital photographs, ecomaps, genograms, drawings and transcript data were used in the study design which included intergenerational family members residing together as part of a family unit. In addition, most Western models on family systems and caregiving construct the meaning and composition of the family unit in a different way. For instance, Rolland’s (2012) system-based, biopsychosocial model broadly defined the ‘family’ as all persons involved in the family unit and caregiving but did not clearly include members outside the immediate family.

3.3 Researcher Reflexivity
An important and ongoing issue throughout this project was my role as both a cultural insider and also as a ‘nurse practitioner-researcher’, that is, a nurse doing research into an area which was relevant to my own practice (Reed & Proctor 1995). Whilst the word constraints of this thesis prevent a discussion about the advantages and challenges faced at all stages of the research process, there are specific issues worth highlighting. As this research study involved the exploration of intergenerational caregiving in a real world setting, I drew on my nurse practitioner experience as well as the research methods in the decisions I made whilst at the person’s home and in documenting what I was seeing. My choice of a case study design with a flexible and exploratory approach was influenced by my academic and clinical experience and, also, after discussion with my research supervisors. The researcher in me fully understood the legitimate need to adhere to the original research protocol while the nurse practitioner in me empathised with the needs of the participants at times.

An important aim of this PhD study was to make recommendations for education, practice, policy and research. As I have outlined in the introduction to this thesis, I had worked with intergenerational families and their family member with dementia during the course of my nursing career and through my own personal experience. Hence, I was aware of the experiences faced by family caregivers, but not in the depth I later acquired after completing the study. Moreover, there were also certain pertinent issues with respect to methods worth noting. My experience as a nurse practitioner was relevant to the narrative approach to the
study; for example, the sensitising experience served as a means in facilitating the intergenerational participants’ stories about their everyday lives and this is appropriate in thematic narrative analysis (Riessman 2008). My own experience also enabled me to develop rapport with my participants, an important aspect of rigour in qualitative research (Davies & Dodd 2002). However, most importantly, I had to be mindful not to make hasty assumptions or selection of certain shared storylines or narrative accounts.

Indeed, as highlighted by Reed and Procter (1995), it is inevitable for nurse practitioner-researchers to be faced with specific challenges. Therefore, they should acknowledge the tensions between roles and the need to reconcile these as much as possible, rather than attempt to ignore or bury such issues (Reed & Procter 1995). A number of these tensions were encountered during this project. As I was conducting my interviews, the participants often regarded me as a nurse, rather than as a researcher, and I had to be mindful of my role perception and positioning. Admittedly, I felt conflicted at times. For example, I was often asked to provide advice or confirmation about prescribed medication or medical diagnosis related matters. I could only listen and advise the participants to refer to the attending physicians who were overseeing their family member with dementia, consciously aware of my research role in this given context. There were also instances when my experience as a nurse practitioner came to the fore, for instance in: recognising and ensuring appropriate management for fall prevention; highlighting issues of risk to the main family caregiver and advising common home safety implementation which could be done. The regular and planned supervision was helpful for me in teasing out thesis areas and in reflecting upon my roles.

3.4 Study Design

Contact with each of the recruited intergenerational families was delivered over differing periods, with all sessions delivered in the home of the intergenerational families as co-arranged with them, with the exception of one particular family caregiver who chose to have some of the interviews conducted at her workplace. Contact was undertaken over a longitudinal period, ranging from six to 15 months.

3.4.1 Participatory Approach in the Study

I adopted a participatory approach in this study as it favoured the involvement and collaboration with the intergenerational family participants in the knowledge-production process (Bergold 2007; Bergold & Thomas 2012) such as the contribution of digital
photographs, drawings and co-construction of the family genograms and ecomaps. The fact that the intergenerational family participants identified their homes as the interview site also meant that I was able to observe the caregiving activities in the most naturalistic of environments. My repeated visits over time were also advantageous in facilitating my continuous observation and mapping of the observed patterns. Furthermore, according to Bergold and Thomas (2012), this approach also provided a deeper insight into the contextual and structured meaning and dynamics inherent in the phenomena of interest; in this case, intergenerational caregiving to a person with dementia where all participating members lived ‘under one roof’.

The participation of the intergenerational family members was relevant as the fundamental guiding principle for this research approach, representing an attractive and fruitful knowledge-generating option when researching the social world in the sense of habitualized practice (Bergold 2007), that is, the everyday lives of intergenerational families caring for a family member with dementia in this study. At the same time, due to the collaborative nature of the participatory approach, developing and building participants’ trust was important. Rath (2012) asserts that trust develops and builds on long-term, honest relationships that are characterized by closeness, empathy, and emotional involvement. However, throughout this PhD study, I have found that the degree of trust which was developed from the rapport building varied between intergenerational family members and across families. Some were faster to ‘warm up’ whilst others took longer. This differing set of responses to the same research question and design is presented further in chapter 4.

Moreover, the participatory approach which I undertook also required the observation of specific culturally appropriate sensitivities peculiar to individuals of Chinese ethnicity. This is an important consideration when working with participants from this particular ethnic background, especially when the research setting is located in the private spaces of their homes. Dong et al (2010) emphasised this important point when conducting their community-based participatory research on Chinese participants. According to these authors, it is important for the researcher to be ‘personally familiar’ to research participants. Being ethnically Chinese and familiar with the local language (Chinese) and dialects (Hokkien, Hakka and Cantonese) was an added advantage – and arguably a necessary entry criteria to undertake the research. As will be shared in the later chapters, mindful of the customary and common practices, I would usually remove my shoes before entering the intergenerational families’ homes and bring along small token gifts; example, a packet of
grapes, oranges and such. Reciprocally, the families would offer refreshments when I visited. When I managed to pay my last respect at the funeral of one of the family members with dementia during the course of my research, I made the typical and very Chinese monetary contributions known as ‘baijin’ - or ‘white gold’ - to the family as expected and anticipated, a practice to help deflect funeral costs.

In relation to the contribution and co-construction of information, and following the study protocol, all intergenerational family participants were informed and their permission sought as to whether or not they were willing to share digital photographs which they had taken and believed relevant to this study. Some participants were more forthcoming and eager to share their stories through digital photographs whilst others were more hesitant. Photography and drawings have gained much value in eliciting health-related stories (Frith & Harcourt 2007; Guillernin 2004; Radley & Taylor 2003a, 2003b; Rich et al 2002; Smith et al 2006) and, as anticipated in this study, photography provided a useful resource for exploring the intergenerational families’ stories of caring for their family member with dementia. At the same time, I also sought permission from the participants to take digital photographs of items, the environment or activities in and outside their homes. Prior to utilizing these digital photographs, I made it a point to seek further permission from the participants.

I decided on the concurrent and comparative use of genograms and ecomaps (see Figure 4 in page 53) for my study as they would serve as valuable research tools, in combination, to provide a graphic portrayal of the composition and structure of the intergenerational families and their personal and social family relationships. Although the development and utilization of genograms and ecomaps have mostly been in clinical practice with families and rarely in research, as research tools they would provide visual data that facilitated my understanding of the intergenerational family’s experiences. As noted, genograms and ecomaps have appeared in the family nursing literature since the introduction of the Calgary Family Assessment Model in 1984 (Wright & Leahey 1984). Thus far, there is emerging, although scant, evidence in the English language literature on the combined use of the genogram and ecomap in family caregiving researches (Duarte et al 2016; Koo & Pusey 2018; Rempel et al 2007). In their study, Rempel et al (2007) have argued for the increased utilization of the genogram and ecomap as a data generation method in their study of male family caregivers’ experiences. The co-construction activities depicted the caregivers’ descriptions of their family structure and social networks, including supportive and non-supportive relationships.
that incorporated health-related resources. In fact, the interactive use of genograms and ecomaps in Rempel et al’s (2007) study had facilitated their increased understanding of the family’s social networks as a context for caregiving; promoted a relational process between them and the caregiver; and uncovered findings such as unrealized potential in the caregiver’s social network that may not have been revealed if not for the combined use of the genogram or ecomap.

For this present study, co-construction of the family genograms and ecomaps with the intergenerational members of the five recruited families was not a one-off event. In essence, the co-construction of these diagrams underwent changes across the period of time I spent with the intergenerational families, with the inclusion and reveal of more information from the participants as time passed. The interactive use of genograms and ecomaps in this study involved co-constructing and analysing these diagrams concurrently and comparatively in conjunction with the in-depth interviews with the intergenerational families. The outcomes of this process included the generation of more useful questions during both the data generation and data analysis phases of this research. The concurrent and comparative use of the genograms and ecomaps enabled the identification of new information such as the presence of caregiver support within the participant’s network of kin/external family and support services. This was made possible after describing what the symbols for the figures meant and explaining what the genogram and ecomap were all about to the participating intergenerational families. I also made it a point to show participants the different versions following the co-construction.

Figure 4 is an example of the genogram and ecomap adapted from Rempel et al (2007) which was used and co-constructed in this study. The genogram provided a graphical representation of the members of the intergenerational family and their relationships with each other while the ecomap provided a graphical representation of interconnections and relationships of the family within the larger social matrix or system (Bronfenbrenner 1979), including informal (example, friends, extended family members, live-in maid) and formal (example, community services) supports. It enabled illustration of how the intergenerational families existed within the context of their relationships with other individuals and institutions which the intergenerational families have contact with. I found the genogram and, especially, the ecomap to be useful tools in establishing rapport with the families (Cox 2003), learn more about their perceptions and meanings attached to caregiving (Hartman 1986), and organize
Figure 4: Example of a genogram and ecomap

19 June 2016

Healthcare
- TSSH - CR's regular follow-up (since 2011)
- Polyclinic Dental Care

Extended Family
- Cousins are in Penang, Malaysia

Neighbors
- Not helpful

CG1’s Work
- Admin staff at Tou Chi Foundation till Sep 2015
- Unemployed since then
- Ex colleague (HCD, Social Service Dept) of 16 yrs from Tou Chi. Providing advice about employment
- Senior Accounts Assistant in a Finance Dept since Feb 2016

CG2’s Work
- Retired
- 84, VD 2008, Early 3SS 2007. H/O HTN, Stroke, T/L PO, post-op
- 1yr HTN, stroke
- 1yr on Aspirin
- Ex-colleague of CG1
- Senior accountant at Tou Chi
- Died of a liver 27 yrs ago, HTN, stroke

Support from Municipal
- CG1 sought M/F’s help when brothers refused to foot the bill (late 2000s)

Family Tribunal Court
- Court ordered mediation or meeting for maintenance
- CG1’s family to pay for maid & others (late 2000s)

Religion
- Buddhist

Chinese Physician
- CG1 consults TCM for minor ailments

Recreation / Resource
- Library

Finance
- Rental from 3-room HDB
- Own Videography business – 1 to 2 projects per yr
- Own Videography business – 1 to 2 projects per yr

Day Care
- Kwong Wei Shui Day Care
- Rehab Centre before the maid (2011/2012)

Social Support
- CHAS
- SSGD
- IDAC insurance

Social Support
- VWO
- ADA support services

Domestic Worker
- Maid
- 38 yr old lady from Myanmar since 2013
- Paid by the eldest brother
- Lived in Foreign

Legend:
- Very close / Strong
- Estranged / Cut off
- Poor conflictual
- Distant / tenuous
- Energy flows
- Past situation

Nursing Home
- CR was admitted to Tei Pei Old People’s Home X8/12 in 2012 when PBI needed to undergo a gynaec surgery

Family Tribunal
- Court ordered mediation or meeting for maintenance
- CG1’s family to pay for maid & others (late 2000s)
To illustrate the use of the genogram and ecomap, I present the example of Family 2 (Clive – son-in-law; Joy – youngest daughter; Kit – grandson; and Dolly – the person with dementia). During my first interview with Clive (the main caregiver), in April 2015, the process began with co-producing a genogram and ecomap together. The first task was actually to appraise Clive about what a genogram and ecomap actually looked like and what forms they could take and, perhaps more importantly, why it was a necessary task to start. To help guide this process, I used an anonymous and illustrative example of a completed genogram and ecomap that was included in the study ethics approval forms (see Appendix 8) to demonstrate their typical flow and context.

Specifically, I included demographic information in the genogram such as age, death, living arrangements, occupation, educational level and timeline of critical events to augment my understanding of the family’s caregiving context in preparation for subsequent interviews and, also to use the pictorial nature of the enhanced genogram to prompt Clive to further describe their caregiving context. Clive was quick to catch on with what was being asked of him and enthusiastically shared some of the main elements of his family genogram and ecomap with me. The initial sketching of the genogram and ecomap were therefore done on my mobile tablet with me later refining the contents with reference to my research notes and audio-taped interview transcripts. On the 12th July 2015, I showed Clive the updated version of the genogram and ecomap to seek his clarification, input and confirmation that this illustration was moving in the right direction. This working diagram is as later shared in chapter 4.

Similarly, when I interviewed Kit and Joy on the 12th July 2015, it was clear that they preferred to visualise and document their genogram and ecomap using ‘pen and paper’. Keeping flexible and sensitive to their needs was key in helping to co-produce and diagram together. Similar to the previous situation, Kit and Joy required some help to initially understand what a genogram and ecomap looked like. Therefore, instead of an anonymous genogram and ecomap being shared, Clive gave permission for his own genogram and ecomap to be used for this purpose. I used the genograms and ecomaps at the beginning of each interview to frame the time that was spent together and to give an opportunity to re-check the authenticity and representativeness of the diagrams as family relationships.
naturally move and change over time. Indeed, the final version of the family genogram and ecomap (a synthesis of all the ecomaps produced over the time together) was eventually agreed by Clive, Joy and Kit on the last interview and it is these final versions that are shared in chapter 4 respectively.

Developing a number of iterations of the genogram and ecomap with Clive, Joy and Kit opened up conversational pathways as to why caring was structured in the family in the way that it was and how events have unfolded to allow this to happen. As can be seen in the final ecomap, Dolly, Joy, Kit and Clive were ‘safe’ within an inner circle in the ecomap with strong lines linking the immediate family together. As part of this safe space, and in developing the ecomap, Clive shared more openly about why he ended up staying at home to provide the care for Dolly. The genogram and ecomap also facilitated a discussion on Family 2’s conflict with Joy’s extended family, particularly her eldest brother and how the family has decided to cut off this source of support which without the aid of these tools would not have been obviously revealed. For example, during the last few visits, only did Clive and Joy slowly reveal the non-supportive nature of their extended family. Somehow, the relational process of jointly diagramming the family structure and support network led to conversation about Family 2’s extended family and descriptions of experiences of supportive and non-supportive interactions.

3.4.2 Practical Aspects in Audio Recording and Transcribing
As suggested by Hydén (2013), this study used audio recording of narratives as this allowed for analysis of the transcribed audio texts. I, therefore, used a voice data recorder – the Sony Walkman NWZ-B142F - placed on the table next to the participant in the home or hand held to facilitate audio recordings participants were comfortable to share during the scheduled interviews. Participants were asked to describe their caregiving experience and encouraged to tell their everyday stories. Their narrative accounts were typically started by the questions in the interview guide (see Appendix 8). Participants were asked to share about topics which they felt were important to them and wished to share. Typically, most of the interviews were conducted either at the dining or living room area of the families’ homes, with the exception of one family where the interview was conducted at the participant’s workplace on most occasions. These locations were determined by the participants. This process was repeated at every interview sessions, ranging from 40 minutes to 4 hours 25 minutes per visit. Where possible, I also audio recorded participants’ conversations with me, including when we co-
constructed the genograms and ecomaps together. This process allowed me to add on information which might be inadvertently missed out during the co-construction process.

As recommended by Smith et al (2008), to avoid problems of interpretation and ensure accurate meaning is captured during data collection, interviews conducted in the local language (or dialect) for participants who indicated their preference in being interviewed in Chinese (Mandarin). This was done for two participants (Olive from Family 1 and Clive from Family 2) and the rest were still conducted in English. Only then can original words, phrases and concepts be securely embedded in the actual context and the risk of misinterpretation and loss of participants' intended meaning be minimised (Smith et al 2008). Smith et al (2008) further suggested for interviews to be conducted by fluent native speakers who are effectively bilingual and to audio record the interviews with participants’ permission. As I was fluent in both English and Chinese, conducting the interviews on my own and audio recording the conversations did not pose any challenges. Following this process, the audio recordings (English and Chinese) were played on a number of occasions and transcribed accordingly. Recordings in the Chinese language were transcribed verbatim in Chinese characters first as recommended by Smith et al (2008) and translated to English thereafter. As I was the only lone researcher, Smith et al’s (2008) suggestion for two Mandarin speaking researchers to check a sub-sample of transcripts against the original audio recordings to ensure local meanings were captured as far as possible was carried out. I obtained assistance from a workplace colleague to do so.

I will now describe narrative analysis, the second method used to capture the shared everyday caregiving experience of each case study and outline why this was added to the research methods to build a picture of the mixed methods in this study.

3.4.3 Narrative Analysis

Narrative analysis relates to a cluster of methods used to study and interpret texts that have stories in common (Riessman 2008). Williams and Keady (2008) put forward this straightforward definition of the approach:

“Narrative research and analysis is about asking for people’s stories, listening and making sense of them and establishing how individual stories are part of a wider ‘storied’ narrative of people’s lives” (p.331).
In narrative research approaches such as what was used in this study, this information was used to make sense of the interrelationship between identity, self and the social world (Williams & Keady 2008), seeking to understand “the changing experiences and outlooks of individuals in their daily lives” (Roberts 2002, p.1). Accordingly, narrative inquiry “is grounded in the study of the particular” (Radley & Chamberlain 2001, p.331) and, hence, facilitates exploration of in-depth caregiving experiences within case study research (Yin 2009). This is important in intergenerational family study such as this where the aim is to focus on individual experiences within the context of intergenerational family relationships. Charon (2008) goes on to explain that narrative knowledge “provides one person with a rich, resonant grasp of another’s situation as it unfolds in time” (p.9) and this level of detail is important in facilitating an in-depth understanding about the intergenerational families providing care for a family member with dementia, as revealed in this study. In order to achieve this level of investigation, Atkinson (2002) outlines three stages in the process of interviewing individuals about their life story or everyday experience:

1) Preparing for the interview and understanding how a life story can be beneficial.
2) Guiding the person through the telling of his or her life story during the interview process.
3) Transcribing and interpreting the material or obtained data.

In this PhD study, narrative analysis began from the rapport building phase and continued up until the end of the study. Due to constraints of space in this thesis, in each intergenerational family case study, a narrative summary is provided with further details outlined with respect to the study. I now turn to the issue of understanding why narrative analysis was beneficial for this study and used alongside the other data.

3.4.4 Practical Aspects to Narrative Analysis
It was crucial to consider how the intergenerational families caring for a family member with dementia ‘under one roof’ could be supported to narrate about their everyday experience with caregiving. The aim was to carry out audiotaped qualitative interviews with the family caregiver either situated alone or together with other intergenerational family member(s). As such, a degree of flexibility was necessary during the interview situation especially for family caregivers who wanted to be interviewed alone as space constraint within the residential apartments (which most of the intergenerational families were residing in) meant that conversations could be overheard during the interview. Also, families determined the space in the home where the interviews ought to be conducted which further constrained the
researcher’s ability to control the research environment; however, this was a small price to pay for the richness of the data that emerged from such encounters. Such issues were documented by the researcher and discussed with her supervision team as there was no obvious ‘easy solution’ to such naturally occurring situations, only lessons that future researchers could learn from.

In the context of an interview, questions were used to prompt participants about their caregiving experiences and the impact of caregiving. The list of potential questions is included in Appendix 8. Nevertheless, as experienced during the interviews, the intergenerational family participants would usually take the lead in narrating what they wanted to share about their caregiving experience, rather than be imposed by a structure - or series - of questions however well-meaning their formulation. Where necessary, interviews used drawings, genograms, ecomaps and digital photographs from inside and around the house to help support the intergenerational families to tell their story. As the author is fluent in the Chinese language, interviews were also conducted in Chinese as it was the language of choice for some of the adult caregivers who were better able to express themselves in Chinese.

Field notes were made following each interview visit of the intergenerational families. These would document my reflections and further observations and impressions about what was shared by the intergenerational families. This process was useful, not only in obtaining information, but also to observe how the intergenerational families of people with dementia provided care and how the experience has been like for them. Audio recordings were transcribed by the researcher, and translated to English if the interview was conducted in Chinese.

For this study, intergenerational family participants were also asked to provide digital photographs which were related to their everyday experiences and interactions. They were given the freedom to select and photograph activities and items in the home environment which were deemed as important to them (Frith & Harcourt 2007). Participants were asked to describe the photographs and share what these photographs meant to them (Frith & Harcourt 2007). Once consent had been obtained, participants were then asked to email these digital photographs with description to the author. The author also took digital photographs of items and activities in and around the home environment so as to add further authenticity to the narrated data (Riessman 2008).
3.4.5 Quantitative Measure

The following measure was also used: A 23-item researcher-developed structured questionnaire. A 23-item researcher-developed structured questionnaire in English and Chinese (see Appendices 9 & 10) on family caregiver and the person with dementia’s characteristics were utilised. This was also used for the purpose of corroborating the obtained quantitative data with the qualitative data from the in-depth interviews and vice versa. The format of the structured questionnaire was in hard copy. Quantitative data from the 23-item questionnaire was entered into the Statistical Package for the Social Sciences Software version 24.0. This was then imported into NUD.IST Vivo to explore for relationships between the coded qualitative data and the participants’ characteristics. Andrew et al (2008) have found this to be a beneficial data analysis approach to facilitate the synthesis of mixed methods data.

3.5 Managing and Analysing the Data

A most challenging aspects of this study has been to manage the voluminous amount and variety of data gathered. As posited by Yin (2009), using multiple sources of evidence is the first principle of data collection when employing case study design. This study had multiple sources of evidence as outlined below:

- Audio recordings of biographical interviews and associated transcripts.
- Structured questionnaire.
- Field notes containing observations and reflections.
- Digital photographs and associated transcripts.
- Drawings and associated transcripts.
- Genogram.
- Ecomap.

Yin (2009) recommends creating a case study data base to manage data of this amount. Therefore, I have created case files to keep soft and hardcopy records of each intergenerational family/case, both in my designated computer and hardcopy folder. For example, the quantitative questionnaires were completed on paper and filed in case files. Transcripts and field notes were entered into NUD.IST Vivo 10 to facilitate analysis. There were two types of analysis which occurred, that is, within case narrative analysis and cross-case thematic narrative analysis.

3.5.1 Within-case Narrative Analysis

NUD.IST Vivo 10 was used to analyse transcripts of audio data to identify recurring and outstanding features. Initial broad descriptive codes were employed in this instance. Audio
data were used alongside the other data (questionnaire, field notes, transcripts accompanying the drawings, digital photographs, genograms and ecomaps) to ensure data were viewed accurately. The steps in this study followed the approach described by Hutchby and Wooffitt (2008) to study recurring patterns in the data:

1) Highlight and make a collection of examples of a particular pattern within the data.
2) Analyse and describe one particular occurrence in detail.
3) Return to the data to see if other instances of the pattern can be analysed and described in this way (Hutchby & Wooffitt 2008).

In view of the voluminous amount and multiple data sources, NUD.IST Vivo 10 was found to be an efficient way to manage this large data set. Moreover, locating all the evidences in one single location was helpful in maintaining Yin’s (2009) third principle of collecting evidence in case study research, that is, maintain a chain of evidence. This principle facilitates clear cross referencing of evidences within the case study and into the case study report. Descriptive narrative codes were kept separate from thematic narrative codes. Codes were diligently compared across to explore and identify recurring themes and linkages in the different data strands. In order to facilitate the efficient cross referencing, I generated sub-headings for the presentation of each individual case. I first began with a title name which was most suitable to capture the essence of each family; for example, ‘Intergenerational Family 1 – Main Family Storyline: Finding Reconciliation’. I then provided - a pencil sketch by way of a brief introduction and overview of the family including the number of research contacts and duration, and my encounters and rapport with the family; a description and presentation of the co-construction and evolution of the genogram and ecomap with the family; my personal encounters with the family including the significant quotes and digital photographs from the participating members of each family; my reflection as a researcher and nurse practitioner; the intergenerational issues within each family as shared; and a summary of each family at the end. This was done to harmonise the presentation of each case study, yet allowing a uniform and transferable platform for cross-case analysis, as explained in the next heading.

3.5.2 Cross-Case Thematic Narrative Analysis

Data across the five intergenerational families were compared and examined to uncover recurring themes. These themes were compiled and tabled accordingly. This is a method as recommended by Yin (2009), in order to display the data from individual cases “according to some uniform framework” (p.156) when performing cross-case synthesis in works
involve the use of case studies. Transcripts of interviews, field notes, digital photographs, genograms and ecomaps were read and analysed in relation to individual members of each intergenerational family, followed by the family unit itself. Once analysis of a family unit was completed, work began on the next case. Basically, each process began with repeated reading of interview transcripts, listening to the audio recorded interviews and viewing of any visual data such as digital photographs, genograms, ecomaps and drawings that illustrate the participant’s life story (Keady et al 2009). Following this process, narratives were further broken down into stories to create a sense of the whole; an analytical approach as recommended by Reissman (2008).

In an everyday research context, this meant that I explored transcripts line by line and coded the line with reference to a particular sequence within the text. Chosen sequences could refer to a significant storyline, event, experience or issue. I also shared sections of interviews with my research supervisors who read them separately. This enabled codes to be compared and discussed during regular skype supervision sessions. This process uncovered recurring themes within the data. Again, coding and emergent themes were discussed, refined and explored during skype supervision sessions to help gain an authentic representation of the case study data and present a meaningful story that formed the theatrical frame of the study.

3.6 Rigour
Several sources on narrative analysis (Creswell 2007; Creswell 2012; Riessman 2008) and important texts and debates in the field of qualitative work (Davies & Dodd 2002; Lincoln & Guba 1985; Morse et al 2002; Seale & Silverman 1997) were consulted when considering issues of rigour. The difficulty in clearly defining this area arose from the lack of a standard method in narrative inquiry (Reissman, 2008). Therefore, for the purpose of ensuring rigour for this study/thesis, the following principles were employed:

- **Language and rigour with data collected in Chinese (Mandarin)** – I adhered to the suggestion by Smith et al (2008) for the researcher to be effectively bilingual and fluent in the local language (Mandarin and dialect). This was to ensure that the “original words, phrases and concepts are securely embedded in context and the risk of misinterpretation and loss of participants' intended meaning is minimised” (p. 3). In this study, I conducted the qualitative interviews in Chinese (Mandarin) for intergenerational family participants who were Chinese speaking. In this instance, all related audio recordings were transcribed verbatim in Chinese characters and
translated to English. Following that, all the transcripts were checked against the original audio recordings to ensure local meanings were captured as far as possible.

- **Explicitly aiming for recurring themes in the audio data** - During the course of the literature review, it was apparent that some authors chose to present only certain extracts without consideration for potential criticisms that there might be bias in selecting the data which was presented. I attempted to avoid this by providing a mix of data sources (textual and non-textual data) such as questionnaire data, audio recordings, drawings, digital photographs, genograms, ecomaps with corresponding transcripts in my attempt to capture textual and visual representations of the caregiving experience ‘under one roof’, explicitly aiming for recurring patterns during analysis.

- **Viewing transcripts as working documents not as perfect records of audio data** – Silverman (2006) asserts that there is no such thing as a perfect transcript and the level of detail was pretty much dependent on the research problem on hand. This awareness guided my examination of the transcribed texts from the audio recordings where I would regularly and repeatedly listen to the original recordings whilst engaging in analysis; for example, playing the original recordings, while engaging in further analysis of the transcript via my desktop computer. With this emphasis, I wanted to ensure that the data was the original recordings of narratives from the audio recordings and avoid mistakenly assuming that the issues have derived from the transcript.

- **Using supervision to further explore and discuss data** - Regular supervision sessions via Skype facilitated the viewing and discussion of the textual and visual data such as transcripts, digital photographs, drawings, genograms and ecomaps together to compare and refine observations. These sessions are important in enhancing the rigour in narrative analysis. To strengthen the narrative analysis, my research supervisors also read through sections of interview transcripts. During Skype supervisions, we compared observations and discussed ideas. We also met together via Skype as a supervision team to explore my cross-analysis of data.

- **Audit trail** - I kept field notes of each encounter with the intergenerational families, typing or transferring these into my laptop computer following my visit, usually within 24 hours. These included an events log of what I did with the intergenerational families during each visit, my observations and my own field reflections of each family/case. In addition, I kept a reflective journal detailing my personal thoughts, issues and decisions with regard to the general research process. I created a folder of
all email conversations with my research supervisors about the research and methods as these consisted of on-line systems of supervision and reflection. According to Reissman (2008), these on-line systems aim to strengthen issues of persuasiveness.

- **Prolonged contact** - I was involved and engaged with the intergenerational families from six to 15 months, and together, with the collection of a variety of evidences, this meant that I was somehow deeply immersed and intimate with their lives. This contributed to the credibility of my findings (Lincoln & Guba 1985). Where possible, I also consulted with the intergenerational families when engaging in analysis including: clarifying the transcripts; showing the digital photographs, drawings, genograms and ecomaps, and discussing information that were evident; providing written summaries of research findings and asking for feedback; and discussing potential questions evolving from the analysis over the telephone, short message service or WhatsApp after formal contact had ended. The design of the project also meant that analysis was on-going rather than being left until all data was collected. In this way I could discuss ideas and issues with participants as they emerged or use learning from one family/case to inform the next.

- **Audio recording and use of NUD.IST Vivo** - all interviews were audio recorded and transcribed in full (Jefferson 2005). All data was entered into NUD.IST Vivo 10 to ensure thorough and systematic analysis (Seale & Silverman 1997).

### 3.7 Strengths and Limitations

The strength and limitations of the mixed methods approach as presented will be returned to in the discussion chapter. As outlined and illustrated, the different methods can be used to complement and inform one another. Clearly, narrative analysis required for the various forms of data is time consuming. Hence, the likelihood of inadequate time being given to this method cannot be denied. The study employed a variety of data and their presentation in terms of adequate detail was a challenge. The details to be reflected were done in close consultation with my research supervisors and decisions were made within the research process and the format of this thesis.

### 3.8 Ethical Approval

Ethical approval for this study was sought and given from both the University of Manchester, United Kingdom and Nanyang Polytechnic, Singapore prior data collection as the author is a part-time PhD student at the University of Manchester in the United Kingdom whilst
simultaneously based in Singapore. Approvals were granted by the University of Manchester Research Ethics Committee in August 2014 [ref: 14207; see Appendix 11] and Nanyang Polytechnic Institutional Review Board in December 2014 [ref: SHS-2014-011; see Appendix 12], following submission of the required documentation (see Appendices 13 to 22) and the research protocol (see Appendix 23). It is worth noting that approval from the Institutional Review Board in Singapore took a little longer than expected to finalise and approve. This was because the present study was one of the first longitudinal qualitative studies ever conducted in Singapore, and the first to recruit an entire family unit as a point of social research connection. Hence, the Institutional Review Board in Singapore had to ensure that an appropriate risk management procedure was in place.

3.9 Sample Size and Issues of Recruitment

The following inclusion and exclusion criteria were used. Participants were recruited based on:

Inclusion criteria
1) Immediate family who may include the spouse, children, children in-law, step children, step children in-law, sibling, nephew, niece, grandchildren or others who are related by blood, marriage or adoption.
2) Must be an intergenerational Singapore-Chinese family.
3) At least two intergenerational family caregivers residing with a person with dementia in a single household/family unit.
4) Literate in English, Mandarin or dialects and able to complete survey questionnaire or be interviewed.
5) Aged 12 years and above.
6) Must be providing care or assistance to a person with dementia. Providing care to the person with dementia could mean attending but not exhaustive to the activities of daily living (bathing, dressing, toileting, transferring, continence care, feeding) and/or instrumental activities of daily living (using the telephone, shopping, preparing food, housekeeping, doing laundry, using transportation, handling medications, handling finances) needs (Katz et al 1970; Lawton & Brody 1969).

Exclusion criteria
1) Not an intergenerational Singapore-Chinese family.
2) Less than two intergenerational family caregivers residing with a person with dementia in a single household.

3) Not literate in English, Mandarin or dialects and unable to complete survey questionnaire or be interviewed.

4) Aged less than 12 years.

5) Not providing care or assistance or participating in care decision to a person with dementia.

6) A person with dementia.

I was not able to recruit people with dementia in this study at the insistence of the Alzheimer’s Disease Association (Singapore) and, therefore, the design did not include the person with dementia. Some of this fear about inclusion, such as the potential for doing emotional harm to the person with dementia is reminiscent of the psychosocial research scene in the United Kingdom that routinely excluded people with dementia in the 1980s and most of the 1990s (Keady et al 2007). However, the families in this PhD study took an initiative by subtly including the person with dementia so that their presence – if not their words – was made visible in the recorded actions.

The recruitment of the family participants was expected to be challenging for a variety of reasons including the longitudinal nature of the study, number of expected interviews, type of data collected (especially digital photographs) and the number of intergenerational family members to be recruited from each intergenerational family. The recruitment process is outlined in Appendix 23. I delivered presentations about the research to the staff and two groups of family caregivers (English and Chinese speaking) at the Alzheimer’s Disease Association (Singapore) during their caregivers’ support group sessions on 21st March 2015. The purpose of this was to ensure that participants were aware of the inclusion/exclusion criteria and objectives of the research project. Staff members at the Alzheimer’s Disease Association (Singapore) were then asked to inform the researcher once potential family caregivers expressed their interest in participating in the study. As expected, recruitment was challenging for the reasons outlined above.

However, a total of nine reply slips from family members from the English and Chinese language caregivers’ support group sessions were returned with nine families consenting to take part in the study - one of whom was put on reserve (Family 4); two failed to meet the inclusion criteria for the study; and one could not participate as the family was caught in an
unforeseen crisis situation almost immediately after the recruitment process. Although the response rate met the targeted number of families to be recruited, the researcher had to undergo a second round of recruitment in February 2016 – Family 5 was recruited at this time. This was because two intergenerational families - who had participated from October and December 2015 respectively - could no longer proceed with the study and were withdrawn: one at their own request and one through a reported incident which breached the risk analysis as part of the research protocol. No further details on these participating families are therefore included in the thesis. In this instance, their data were not used in the analysis. The final number included in the PhD is five intergenerational families and is reflective of the in-depth qualitative analysis involved in the interview process in case study research (Roberts 2002; Keady et al 2009). The number was manageable for a PhD study and enabled within and between cross-case analysis as part of a case study design (Yin 2009).

3.10 Summary
This chapter presented an overview of the methodologies and methods used, including the practical and ethical challenges in ensuring approval via the University of Manchester Research Ethics Committee and Nanyang Polytechnic Institutional Review Board. Although the study managed to recruit five intergenerational families, recruitment was challenging. On the practical front, carrying out each aspect of the research design was time consuming, especially when carried out by a lone researcher. Besides, there was also concurrent work in developing the data pertaining to the life story resources from the families. Although the mixed methods approach was a creative and novel approach, and also, the first of its kind in Singapore, it was not without challenges. This was coupled with the fact that there was no previous research in the field to guide the current study. Furthermore, the methods in this study have not been used either in research or practice. This meant that a step by step method was unavailable as guidance. Research and practice decisions had to be considered carefully, drawing on research knowledge, clinical knowledge and exploring issues in consultation with my research supervisors. The five intergenerational families in this study will be presented in chapter 4 in a sequential order in which they were recruited. I have created pseudonyms for the families and altered other contextual details in order to maintain confidentiality of these intergenerational families.
CHAPTER FOUR
FINDINGS: THE CO-CONSTRUCTION OF FAMILY BIOGRAPHIES

4.0 Introduction
The chapter begins with a description of the recruitment process and the study sample before proceeding to a case study presentation of each of the five intergenerational families who comprised the study sample. By presenting each family's work as a separate case, this chapter describes the separate co-construction of each family biography, although a similar structure has been adopted in each case study with the importance of family storylines, as well as the dominant family storylines, emphasised. This chapter is concluded with a summarised reflection of all family biographies.

4.1 Sample
A total of five intergenerational families providing care for a family member with dementia were recruited from the recruitment site, that is, the Alzheimer’s Disease Association for the main caregiver and the families’ home for the secondary caregiver(s). A summary of recruited participants is presented in Table 2. As described in chapter three, project recruitment was facilitated by the staff from the Alzheimer’s Disease Association with project briefing done by the researcher. The potential participants were presumably all those main family caregivers who were attending the English and Chinese language sessions during the scheduled Caregivers’ Support Group at the Alzheimer’s Disease Association. As the schedule of the Caregivers’ Support Group sessions was determined by the Alzheimer’s Disease Association, it was not possible to maintain a presence in every session and brief potential participants. In total, 60 recruitment packs were provided to the staff in charge of the Caregivers’ Support Group at the Alzheimer’s Disease Association.

Table 2: Participant Demographics

<table>
<thead>
<tr>
<th>Family</th>
<th>Participants</th>
<th>Sex</th>
<th>Age (in years)</th>
<th>Relationship to the Person with dementia</th>
<th>Person with dementia</th>
<th>Diagnosis</th>
<th>Age at Diagnosis (in years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Olive</td>
<td>F</td>
<td>48</td>
<td>Youngest daughter</td>
<td>Angel</td>
<td>Vascular Dementia</td>
<td>77</td>
</tr>
<tr>
<td>1</td>
<td>Pete</td>
<td>M</td>
<td>50</td>
<td>Youngest son</td>
<td>Angel</td>
<td>Vascular Dementia</td>
<td>77</td>
</tr>
<tr>
<td>2</td>
<td>Clive</td>
<td>M</td>
<td>53</td>
<td>Son-in-law</td>
<td>Dolly</td>
<td>Vascular Dementia</td>
<td>84</td>
</tr>
<tr>
<td>2</td>
<td>Joy</td>
<td>F</td>
<td>53</td>
<td>Youngest daughter</td>
<td>Dolly</td>
<td>Vascular Dementia</td>
<td>84</td>
</tr>
</tbody>
</table>
4.1.1 Sample Characteristics: Demographics

The mean age of participating intergenerational family members at entry into the study was 48 years (SD = 16.53), the range was 19 to 65 years. As presented in Table 2, the nine participating intergenerational family members comprised of: four daughters; two sons; one son-in-law; and two grandsons. As these relationships indicate, 44.5% of the intergenerational family members were female (n=4) and 55.5% were male (n=5). Intergenerational family members were also engaged in various forms of employment with 78% in employment, either full-time or part-time (n=7); and 22% (n=2) studying.

All intergenerational family members of the sample indicated their ethnicity as ‘Singapore-Chinese’ (n=9; 100.00%). This figure is not representative of the population of Singapore as at the time of the last national census only 74.30% of the resident population reported their ethnicity as ‘Singapore-Chinese’ (Singapore Department of Statistics 2016). This figure would also certainly be unrepresentative of all intergenerational family members of people with dementia. Further work is needed to explore caregiving experiences of other ethnic groups in dementia context to ensure service provision is reaching all those in need.

4.1.2 Presentation of Case Studies

In order to maintain consistency, the author has presented each intergenerational family’s case study in a particular and systematic structure, highlighting the storylines of the family and indicating the dominant family storyline, that is, how the intergenerational family presented themselves during the longitudinal duration of the author’s personal interactions with them. The intent of this structure is two-fold: firstly, to present the experience of the intergenerational family providing care for a family member with dementia under ‘one roof’; and secondly, to illustrate the meaning of an intergenerational family biography through a theoretical lens. As such, the case studies are organized in one chapter to purposely provide
a continuous presentation of the study findings with the individual family biographies forming distinctive parts of the chapter. In particular, it is meant to demonstrate how the five intergenerational families co-constructed their family biographies with the author in various ways using different methodological tools – digital photographs, genograms and ecomaps. This is an especially useful dimension to share from a reflexive perspective.

In view that the biographies were co-constructed together with the intergenerational family members during the longitudinal engagement, the family case studies are, therefore, written in the first person to emphasise the very personal account and deep engagement of the author in the research. Also, from a reflexive perspective, the author’s actions and motivations when working with the intergenerational families was important to reflect. Thus, each of the case studies will attempt to present this aspect.

The actual names and any identifying details of the participating intergenerational members are anonymised with the use of pseudonyms to maintain confidentiality. This was done in agreement with the participants. Themes derived from the interviews with each intergenerational family were integrated into the presentation of each case study in order to represent the research process holistically.

The five intergenerational family case studies are chronologically presented according to when each family was recruited. This is intended to provide the reader with a sense of the study’s progression. Also, the case studies are presented individually and will begin on a new page in order to preserve the identity and integrity of each intergenerational family’s co-constructed biography. Table 3 presents a summary of the total number of research contacts with the five intergenerational families. The detailed research contacts with the individual intergenerational families will be presented in their respective case studies.

Table 3: Summary of Total Research Contacts

<table>
<thead>
<tr>
<th>Family</th>
<th>Names</th>
<th>Date of Research First Contact</th>
<th>Date of Last Research Contact</th>
<th>Total Number of Research Contacts and Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Olive and Pete</td>
<td>Wednesday, 25th March 2015</td>
<td>Sunday, 19th June 2016</td>
<td>9 (19 hours 47 minutes)</td>
</tr>
<tr>
<td>2</td>
<td>Clive, Joy and Kit</td>
<td>Wednesday, 25th March 2015</td>
<td>Tuesday, 5th July 2016</td>
<td>12 (32 hours 28 minutes)</td>
</tr>
<tr>
<td>3</td>
<td>Ben</td>
<td>Saturday, 6th June 2015</td>
<td>Saturday, 11th June 2016</td>
<td>8 (12 hours 31 minutes)</td>
</tr>
<tr>
<td>4</td>
<td>Ellie</td>
<td>Monday, 25th January 2016</td>
<td>Wednesday, 20th July 2016</td>
<td>7 (7 hours 50 minutes)</td>
</tr>
</tbody>
</table>
4.2 Intergenerational Family 1 – Main Family Storyline: Finding Reconciliation

4.2.1 Introduction

Family 1 represents an intergenerational family, Olive, Pete and Angel, comprising two generations, staying ‘under one roof” with all members and a live-in foreign domestic worker (maid) contributing to the care of a person with dementia in various capacities. This was the first family whom I recruited into the study. At the time of the first visit, the intergenerational members were in conflict with one another about the care of their mother who was living with dementia. However, over time, the conflict came to a resolution and was a significant storyline of my time with this family.

4.2.2 Family 1 – Olive, Pete and Angel

Overview of Family 1: Family 1 comprised Olive (youngest and only daughter, 48 years old), Pete (second and youngest son, 50 years old) and Angel (person with dementia, 84 years old) at the point of first contact in April (involving Olive) and October 2015 (involving Pete) respectively. The family relied heavily on their live-in maid of three years from Myanmar (NOTE: See footer) for Angel’s daily activities of daily living. They were a mainly Chinese (Mandarin), English and dialect speaking (Hokkien) family with Buddhism-Taoism as the focal religion. Typical of most Singaporeans, this lower middle income family resided in a three-room Housing and Development Board (HDB) high-rise apartment on the third floor with lift landing. Photographs 1 to 3 of the outside and inside of their home were taken when I visited the family in April 2015. The family has lived in the apartment, which was bought by their late father, since the apartment block was built 30 years ago. Considered one of the pioneer blocks, home was strategically nestled on prime land in the heart of the city, that is, within ‘Little India’. Angel, widowed since her 50s, has late-moderate stage vascular dementia. She was diagnosed with early stage dementia in May 2008. She was wheelchair bound and totally dependent upon my contact with them. Angel’s other son – the eldest – was residing on the fifth floor with his own family (wife, son and a daughter) during my time with the family.

Footer: Myanmar, also known as Burma, is a sovereign state in South East Asia bordered by Bangladesh, India, China, Laos and Thailand.
This extended family used to assist in caring for Angel in the earlier days. Angel has been staying with Olive all this while. Pete only moved in with them after his divorce more than ten years ago. The family utilized and received information, support and health services from the local Alzheimer’s Disease Association, nearby polyclinic and general hospital (Tan Tock Seng Hospital) for managing Angel’s dementia and her other medical conditions.

Photograph 1: HDB apartment block which Family 1 resided in (photographed by the researcher on 12th April 2015)

Photograph 2: Lift lobby on the first floor of the apartment block leading to the third floor (photographed by the researcher on 12th April 2015)

*Overview of my encounters with Family 1:* A total of seven face-to-face interviews were conducted in their home from April 2015 to June 2016, lasting about two to three hours each in duration. In line with the study protocol, the interviews included the completion of a 23-item structured questionnaire, co-construction of the genogram and ecomap with the family (Olive and Pete), drawings, audio recordings and digital photographs of the home.
environment, items and activities. Olive also contributed digital photographs of Angel, and old family photographs which I am unable to show due to preservation of confidentiality. A summary of research contacts with all the members of Family 1 is presented in Table 4.

Photograph 3: Living room of Family 1 (photographed by the researcher on 12th April 2015)

Table 4: Research contacts with all members of Family 1

<table>
<thead>
<tr>
<th>Contact</th>
<th>Day and Date</th>
<th>Nature of Contact</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Wednesday, 25th March 2015</td>
<td>Arranged for first face-to-face contact with the family.</td>
<td>5 minutes</td>
</tr>
<tr>
<td>2</td>
<td>Thursday, 26th March 2015</td>
<td>Short Message Service (SMS) and telephone communication to arrange for the first face-to-face contact with the family.</td>
<td>5 minutes</td>
</tr>
<tr>
<td>3</td>
<td>Sunday, 5th April 2015</td>
<td>Relationship building; gathered background information about family. In-depth interview with Olive. Face-to-face personal introduction and project explanation, informed consent taking, construction of the family genogram and ecomap, completion of questionnaire. Field notes. Arranged for the next interview.</td>
<td>1600 to 1900 hours (3 hours = 180 minutes)</td>
</tr>
<tr>
<td>4</td>
<td>Sunday, 12th April 2015</td>
<td>In-depth interview with Olive. Audio recording from 1752 to 1814 hours - 22 minutes 2 seconds. Took digital photographs of the outside and inside of the apartment. Field notes.</td>
<td>1530 to 1800 hours (3.5 hours = 210 minutes)</td>
</tr>
<tr>
<td>5</td>
<td>Sunday, 4th October 2015</td>
<td>Arranged via Short Message Service (SMS) on Friday 2nd October 2015. In-depth interview with Pete. Audio recording from 1753 to 1837 hours – 50 minutes and 52 seconds. Completed the</td>
<td>1540 to 1837 hours (2 hours 57 minutes = 177 minutes)</td>
</tr>
<tr>
<td>No.</td>
<td>Date &amp; Time details</td>
<td>Details</td>
<td></td>
</tr>
<tr>
<td>-----</td>
<td>---------------------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Sunday, 6th December 2015</td>
<td>Arranged via Short Message Service (SMS) on Friday 4th December 2015. In-depth interview with Olive. Confirmed and agreed on the earlier genogram and eco-map done in April 2015. Agreed on the new one for Dec 2015. Field notes.</td>
<td>1530 to 1730 hours (2 hours = 120 minutes)</td>
</tr>
<tr>
<td>7</td>
<td>Sunday, 17th January 2016</td>
<td>Arranged via Short Message Service (SMS) on Saturday 17th January 2016. In-depth interview with Olive. Audio recording from 1615 to 1810 hours – 1 hour 49 minutes 30 seconds. Olive showed me digital photographs of her outings in October 2015 and January 2016 with Pete, Angel, and the maid. Field notes.</td>
<td>1545 to 1815 hours (2 hours 30 minutes = 150 minutes)</td>
</tr>
<tr>
<td>8</td>
<td>Sunday, 3rd April 2016</td>
<td>Arranged via Short Message Service (SMS) on Tuesday 22nd March 2016. In-depth interview with Olive. Digital photographs. Field notes.</td>
<td>1515 to 1815 hours (3 hours = 180 minutes)</td>
</tr>
<tr>
<td>9</td>
<td>Sunday, 19th June 2016</td>
<td>Arranged via Short Message Service (SMS) on Saturday 18th June 2016. In-depth interview with Olive. Audio recording from 1605 to 1711 hours – 1 hour 6 minute 42 seconds. Field notes.</td>
<td>1530 to 1800 hours (2 hours 30 minutes = 150 minutes)</td>
</tr>
</tbody>
</table>

**TOTAL** | **1,187 minutes (19 hours 47 minutes)**

**My rapport with Family 1:** Interview schedules were arranged with Olive through Short Message Service (SMS). The interviews were mainly conducted with the family in English and Mandarin on the floor at the sofa area in the living room with Diagram 1 representing the usual seating arrangement. Mindful of the customary and common practices, I would usually remove my shoes before entering the home and bring along small token gifts, example, a packet of grapes, oranges and such. Reciprocally, Olive would offer plain water or tonic drinks when I visited.

**4.2.3 Co-construction and Evolution of the Family Genogram and Ecomap**

Co-constructing a family genogram and ecomap helped to shape and ground my understanding of the family and the family systems, a method I adopted across all five cases reported in this chapter. For Family 1, the family genogram and ecomap took almost 14 months to co-construct, evolve and complete, that is, from April 2015 to June 2016. For this family, I began with the construction of individual or separate genograms and ecomaps as
based on my face-to-face interviews with each member. After which, I compared the information, integrate and synthesize accordingly after validation with the family. In total, it took about two to three rounds of validation.

Diagram 1: Seating arrangement for interviews at the sofa area for Family 1

When I first interviewed Olive face-to-face on 5\textsuperscript{th} April 2015, I informed her that I would be constructing a genogram and ecomap of the family with her. Using the interview guide, I showed her how this would normally look like. As I interviewed Olive, I co-constructed the genogram and ecomap (see Figure 5) using my mobile tablet. I further fine-tuned this upon reaching home and reflecting upon the data and interview experience (see Figure 6).

Similarly, when I interviewed Pete on the 4\textsuperscript{th} October 2015, I engaged and facilitated him in the co-construction of the family genogram and eco-map (see Figure 7). This time round, I used pen and paper. In view of the re-organization of caregiving activities and Olive’s resignation in September 2015 and new job as a Senior Accounts Assistant in February 2016, the genogram and eco-map underwent revision in October 2015 and June 2016. This was co-constructed and verified with Olive. Additional information to the ecomap related to Olive and the improvement in her relationship with her siblings was included when I interviewed her on the 19\textsuperscript{th} June 2016. Olive and I agreed on the final shape and content of the genogram and ecomap, as shared in Figure 8. This concluded the final version of the genogram and ecomap for Family 1 (see Figure 8).

The intergenerational structure of this nuclear family throughout my interactions with them from April 2015 to June 2016 as illustrated in Figures 6 and 8 are coded where CG1 and CG2 indicate the case study participants (CG1 = Olive; CG2 = Pete) and CR indicates the
4.2.4 My Personal Encounters with the Family

The daily intergenerational routine and care organization: When I first visited the family, the apartment looked chaotic, for example, the living room was cluttered with plastic bags and items strewn everywhere - on the floor, coffee table and sofa (see Photograph 3). However, the domestic environment looked more neat and organized when I visited from January 2016 onwards, a parallel with the family’s adjustment patterns and overall well-being over the time of my visits.

According to Olive and Pete, Angel (the family matriarch) started showing tell-tale signs of the onset of dementia in September 2007, such as constantly losing her things and getting lost, but was only formally diagnosed in May 2008. The formal diagnosis was after Olive’s insistence on bringing her to see the physician. Olive mentioned that her brothers “could not be bothered” and felt that it was “a waste of money on something that was irreversible”. It was obvious that she was still angry with them when disclosing this piece of information.

As Olive was working at the time as a full-time administrator, she had arranged for Angel to attend a local day care facility for older people. However, the ‘going home’ timing for Angel’s day care was simply ill-fitted to Olive’s work schedule as she had to work until late at night. Hence, Olive depended heavily on her eldest brother and his family to care for Angel until she came home from work. It seemed that this caring action was done by her eldest brother and his family grudgingly, as revealed below:

“They rely fully on my niece to fetch her, bring her up. Later, at night, my eldest brother’s wife was also working full-time, nobody would be cooking for her. Got to wait for my brother to buy dinner home. By then, it was 7 or 8 o’clock. At that time, my mother ended up eating cold food. Sometimes, when my brother returned from work, he would vent his frustrations on her when he was unhappy at the workplace.”

(fourth interview with Olive)

Olive also shared how she had “no choice” and was “forced to make a difficult decision” to admit Angel for a period of 8 months in a nursing home in 2012. Olive was totally unable to care for her beloved mother then because of her own poor health. She was undergoing and recuperating from a major surgery then. While relating the entire experience, she was sobbing and shared how it really “broke her heart”. She had continued to try enlisting both brothers’ help but they continued to disregard her requests. This reached the tipping point for Olive. Seemingly left with no other choice, Olive brought the matter to the Family
Tribunal Court which operationalised the Parents’ Maintenance Act, requiring her brothers to contribute financially to Angel’s care as per their affordable means. At the same time, Olive brought in a mediator. At the time, her brothers were furious at this course of action especially in involving “outsiders” in family matters, as Olive shared at the time of our second interview together:

“My second brother was dead set against going to the tribunal court for a face-to-face session. Actually, my two brothers and I were required to go down to the tribunal court for an interview but the two of them refused. Only an email reply was sent. I got so angry. I had no choice. I invited my volunteer ‘brother’ to come to my home to discuss with my two brothers. Actually, my eldest brother loved to ‘save face’. He said that this was our ‘family affair’. Don’t let an outsider interfere. Because he didn’t take any action, I had no choice. Very angry! On the verge of exploding with anger!” (second interview with Olive)

Eventually, Olive’s brothers were obligated to contribute financially to Angel’s care. This first step had paved the way for the family to hire a live-in maid to ease Olive’s caregiving role in performing Angel’s activities of daily living. Olive’s eldest brother has been paying for the live-in maid’s monthly salary as stipulated by the Parent’s Maintenance Act. Somehow, Pete took on the role of doing the marketing and groceries using the rentals from his own apartment whilst overseeing the care of Angel through the live-in maid. Olive would take charge of the utility bills and Angel’s nutritional needs as Pete revealed:

“As far as my brother is concerned, he is the sponsor. Ya, just the salary. Therefore, all the grocery, I am taking care. Because I myself have one property in Tampines. So, I rented out my whole unit. I collect the rental from there. My sister pays the electricity bills, town council and she also needs to buy something else. Some of the nutritious meals for my mom.” (first interview with Pete)

During my year-long visits with the family, I could see that there were signs of reconciliation and healing. It was heartening to see that the siblings were able to progressively come to terms and make amends, especially in light of the earlier conflicts which had happened. For example, during one of my earlier visits in April 2015, Olive volunteered to show me some digital photographs of Angel on her mobile tablet. While doing so, she openly shared that the tablet was a birthday present from Pete, which was a huge step forward in one way but was still met by Olive with a degree of suspicion:

“My brother bought a tablet for storing her digital photos. Yes. He bought this for me during my birthday. "I buy this for you!" I was thinking, "Why are you so nice? Giving this to me!" Last time our brother-sister relationship was such that we
From this birthday present which coincided with the start of my contact with this family, the reconciliatory efforts progressed to family outings. As usual, Olive would proudly take out her tablet and show me digital photographs of her outings with Pete and Angel. The brother and sister had even rented a car together for one of the outings. These were typically trips ‘down memory lane’ and places of interest: a living reminiscence perhaps. Examples of such living reminiscences to which they brought Angel included Amoy Street, the famous Thian Hock Keng Temple, Singapore Botanical Garden and Marina Bay Sands. Amoy Street was where the family grew up. During my visits it became apparent that Pete had come to terms and accepted his mother’s diagnosis and I could sense Olive’s delight as she smilingly shared about the family outings. During my visits, I was also able to observe Pete’s obvious display of acceptance. He would usually kiss Angel on the cheek and hug her affectionately before going out and after returning home. Previously, this was never the case, as Olive confirmed during the fourth interview: “Now he is more able to think and help out. Sometimes when he comes home, he does activities with ‘ma ma’, gives her a touch, kisses her. Last time he doesn’t even touch her at all.”

Not only was the reconciliation taking place between Olive and Pete, it has somehow included Olive’s eldest brother and his family. This was evidently so when Olive informed me that she, Pete, her eldest brother and his family have assembled together at Olive’s apartment to celebrate Angel’s 86th birthday in May 2016. She showed me digital photographs of them posing with Angel and her birthday cake. The digital photographs bore no traces of any past or present conflicts. Unfortunately, I am unable to share any photographs to depict the family get-together as it would involve revealing the faces of non-research participants – Olive’s eldest brother and his family, the live-in maid and Angel. However, the internal descriptive narrative of the photographs was one of a connected and happy intergenerational family together with their own extended family. According to Olive, “this was a first”. I could hear a sense of achievement and contentment in Olive’s voice as she shared this development. Nevertheless, I could also tell that she wished very much for her eldest brother and his family to visit more often:

“The other time, I told you that on my mother’s 86th birthday, my eldest brother said, ‘Why don’t we buy a birthday cake for mother?’ One week before the birthday, on Sunday, he invited his wife and two children down to sing happy birthday song for.
mother and just eat the cake. Otherwise, my brother has never observed my mother’s birthdays. All along, he has never observed.” (6th interview with Olive)

To complement the narratives and my observation, the positive changes in the siblings’ relationship can also be visually seen and compared by making reference to the two ecomaps which were done in April 2015 (see Figure 6) and June 2016 (see Figure 8) in which the prior relationship as indicated by an irregular line (conflictual) is now replaced with two parallel lines indicating a close relationship. For the family genogram, arrows are used in Figure 8 to obviously indicate the effort and investment made by the two brothers towards their mother, where this was previously absent in Figure 6.

Role of the live-in maid: Since 2012, Olive, in particular, and Pete have co-managed Angel’s care with their live-in maid. Olive described the maid’s role as one of ‘utmost importance’ as she was dependent on her for Angel’s activities of daily living and daily feedback on Angel’s condition. The live-in maid has been caring for Angel long enough to understand and was familiar with her condition and behaviour. In fact, during my usual interviews with the family, she would be the one attending to Angel’s activities of daily living and providing all the specific details about Angel to Olive. Without her input, there was no way for Olive to know Angel’s condition in detail:

“On another aspect, the helper also gives me feedback because I will ask her. If she doesn’t tell me, I would not know what my mother’s condition is, why, when she loses her ability to walk. If I don’t ask, I will not know her condition is deteriorating now.” (sixth interview with Olive)

and

“So, the maid told me when 'ah mah' is in a good mood, she will quickly let her drink, let her eat something [Olive gleefully described Angel's mood]. That time, it is very easy to feed her. When her mood is disturbed, it's not that easy to feed her. She will eat and throw at the same time.” (fourth interview with Olive)

Olive was appreciative of her live-in maid and acknowledged the challenging role she had to play and the sacrifices made. It was not simply pertaining to activities of daily living alone but to be alert to Angel’s every move:

“So her role is to make sure my mother takes her three meals, cleanliness and hygiene and later at night whether she is sleeping soundly, making sure she is really sleeping. Then, she can go to sleep. So, she has to stay up quite often. So, it is quite
taxing for her in this aspect. Her role is to be very alert of my mother’s movement.”
(sixth interview with Olive)

Even though the live-in maid’s role was difficult and challenging, she was described to have shown genuine concern for Angel such as covering her ears when there was thunder and putting a blanket and pillow for her at night:

“She has taken care of her very well and that’s why she... there was once when she told me that during the daytime just before it was about to rain, there was thunder. After seeing the thunder and lightning, she was worried that my mother would be afraid. So, she helped her to cover her ears. [Laugh] [She] hugged her, thinking she would be afraid. But at night, if my mother went to sleep, she would get up to cover her with the blanket and place her pillow properly for her.” (sixth interview with Olive)

In order to illustrate the relative importance of the live-in maid and the strength of the relationship she had with the family (see ecomaps in Figures 6 and 8) as shared by Olive and through my field observation, I have used triple parallel lines to indicate a very strong and important relationship and bi-directional arrows to illustrate the reciprocal efforts put in by the family and live-in maid to ensure this relationship works. Nevertheless, as seen in the data and through our time together, there were inevitable conflicts which arose between the family and the live-in maid. The conflicts arose over, for example, cultural differences. Olive actually confessed the difficulty in acculturating her ‘as part of the family’ as below:

“But sometimes, she is very understanding and sometimes when she gets as angry as a bull, we don’t have any solution. So it’s also hard to treat her as a member of the family because the people from this country, their culture is very different from the Chinese culture. They will be quite stubborn. So if there are some things that can be communicated, that’s good. If it can’t be communicated, they are stubborn and it’s difficult to complete things.” (sixth interview with Olive)

4.2.5 Researcher Reflection

Forming a Genuine Relationship with the Family: Initially, I was unsure what to expect. I recalled an overwhelming sense of sadness, a sinking feeling in my heart, upon my first encounter with the family and on seeing their living condition. Olive looked worn out and in need of help. My heart went all out for her but I was mindful not to create a situation of overdependence and ‘crutch mentality’. Olive was forthcoming and eager to share everything from the beginning which facilitated the rapport and relationship building. On the other hand, Pete was more cautious. I did not have a chance to get to know him better from just one interview. He was one of those individuals who required a longer time to build
rapport and would only share detailed family matters with someone close which he informed me during that one time interview. Otherwise, he did not share much.

*As a Researcher:* Olive was very eager to share her many grievances about her conflicts with her brothers, the current support and health care services. I could tell that she was hoping for me to share these through my research and bring about changes. At the outset, I highlighted that I would be sharing the caregiving experience of the family, telling their stories but I might not be able to share everything that was said. I did not wish to mislead and disappoint her.

During the earlier days of my interviews with Olive, she would send me Short Message Service (SMS) to ask if I would be visiting them. Somehow, it felt as if she was expecting a weekly Sunday visit then. So as not to disappoint her and to set the correct expectation, I had to maintain a professional stance as a researcher. I was aware that the interviews would end eventually and did not wish to create a vulnerable situation in which Olive became dependent on my regular visits or presence.

*As a Nurse/Resource Person:* Periodically, Olive would consult me about medical related matters and Angel’s prescribed medication. During one of the interviews, she shared that Angel has cataract problem and asked me for advice on whether she should go for surgery or not. There were also days which Olive would just ventilate her frustrations as a caregiver and her past and present plight. I just sat and listened quietly because I could sense that was what she needed – a listening ear.

4.2.6 Intergenerational Issues

*Conflicts with siblings/extended family:* From the beginning stage of Angel’s dementia until the earlier part of my research encounter with the family, Olive’s relation with her siblings was strained. At one time, she was even accused by her eldest brother of attempting to grab the one and only possession left behind by their late father – the three-room HDB apartment - for herself. She reckoned, this was one of the reasons why her eldest brother was reluctant to help initially: “Eldest brother accused me of seizing the current apartment which my late father had bought” (researcher’s field note on first interview).

It continued until when the house ownership was transferred to her. Olive’s eldest brother was unhappy over it. Traditionally, it was an expectation that the family property would be
automatically given to the first-born son. This was not the case for this family. To make matters worse, houses are expensive in land scarce Singapore and the family apartment was sitting on prime site. Thus, I understood why Olive’s eldest brother was unhappy over the matter. Accordingly, on our third interview together, Olive felt confident enough to share the following: "My eldest brother always felt that the fengshui of this house is good."

A further point of contention with Olive was the fact that Angel had always shown favouritism towards Pete and, yet, it was Olive who ended up caring the most for her; in fact, solo at the beginning. Pete had also confessed to me that he was Angel’s favourite son. This was the reason why Olive felt angry with Pete for not showing his concern for Angel during the earlier days of her dementia:

"I told ‘ma ma’. You are biased. I am the one taking care of you but you favour second brother more. My brothers don’t care! I was the one who insisted on bringing ma ma to see the doctor when she kept losing her way and ended up at the police station." (researcher’s field note on first interview)

Nevertheless, in spite of the issues and conflicts, I could tell that Olive was regretful and almost forgiving towards her brothers. There was even a tinge of regret when she related the following information during the second interview which explained her brothers’ own personal predicaments. Olive’s eldest brother was facing marital problems of his own when Angel started having dementia: “Because in his own home, he and his wife had frequent quarrels. I didn’t even know. I was so busy looking after my ma ma. Therefore, if your home has any problems, I wouldn’t have any inkling.” Pete, on the other hand, was still bitter about his own divorce and had not come to terms yet when Angel started having dementia: “He feels that many people owes him for his sorry state. Therefore, he doesn’t bother about anything. He is in his own world. He doesn’t feel like facing his own mom to deal with her.”

4.2.7 Case Summary
Family 1 comprised Olive (youngest daughter), Pete (youngest son) and Angel (person with dementia). The family relied heavily on their live-in maid for Angel’s daily activities of daily living. They were a mainly Chinese, English and dialect speaking family with Buddhism-Taoism as the focal religion. This lower middle income family resided in a three-room HDB high-rise apartment. Angel has late-moderate stage vascular dementia. She was diagnosed with early stage dementia in May 2008. She was wheelchair bound and totally dependent. Angel’s other son – the eldest – was residing on the fifth floor with his own family (wife, son and daughter). This extended family used to assist in caring for Angel in earlier days.
Family 1 utilized and received information, support and health services from the local Alzheimer’s Disease Association, nearby polyclinic and acute general hospital for managing Angel’s dementia and her other medical conditions.

From the beginning stage of Angel’s dementia until the earlier part of my research encounter with the family, Olive’s relation with her siblings was strained. At one time, she was even accused by her eldest brother of attempting to grab the one and only possession left behind by their late father - the three-room HDB apartment - for herself. She believed that this was one of the reasons why her eldest brother was reluctant to help initially. This situation continued until the house ownership was transferred into Olive’s name. This was a source of family conflict. A further point of contention with Olive was the fact that Angel had always shown favouritism towards Pete and, yet, it was Olive who ended up caring the most for her. This was the reason why Olive felt angry with Pete for not showing his concern for Angel during the earlier days of her dementia. Nevertheless, in spite of the issues and conflicts, Olive was regretful and forgiving towards her brothers as they were also faced with their own fair share of problems. Olive’s eldest brother was facing marital problems of his own when Angel started having dementia. Pete, on the other hand, was still bitter about his own divorce and had not come to terms with this life stressor when Angel was undergoing her transition into living with dementia.

On the 19th June 2016, I informed Olive that I had completed all my interviews with her and exited the family and data collection. My average monthly to three monthly interactions with this family for a period of about 14 months had presented a consistent picture of an intergenerational family that was progressing towards conflict resolution and reconciliation over time. The previously emotionally distant and siblings at odds with one another were starting to come to terms with their mother’s dementia and learning to express their appreciation and support for each other. The learning point from Family 1 highlights that a lack of understanding about dementia and what this means and earlier unresolved intergenerational conflicts may negatively impact relational dynamics and how intergenerational members connect with one another and provide timely support for their family member with dementia.
Figure 5: Version 1: Genogram and Ecomap with Olive on 5th April 2015
Figure 6: Version 2 Genogram and ecomap of Family 1 (co-constructed with the family in April 2015)
Figure 7: Version 1: Ecomap with Pete on 4th October 2015
Figure 8: Final Genogram and Ecomap of Family 1 (co-constructed with the family from October 2015 to June 2016)
4.3 Intergenerational Family 2 – Main Family Storyline: Kindred Spirits

4.3.1 Introduction
Family 2, recruited at around the same time as Family 1, represents an intergenerational family, Clive, Joy, Kit and Dolly, comprising 3 generations, staying ‘under one roof’ with all members contributing to the care of a person with dementia in various capacities. It was also a family whom I felt most familiar with and one where I experienced first-hand, the provision of organized, person-centred caregiving by a family and sacrifices for a loved one living with dementia - An intergenerational family whose members performed meaningful things together. Regardless of the circumstances and challenges, the intergenerational members were akin to kindred spirits – one could feel a sense of togetherness, solidarity, camaraderie, mutual respect and warmth. Unlike Family 1, this family preferred not to employ a live-in maid to assist with the provision of care for their family member with dementia. They would rather withhold that for as long as possible.

4.3.2 Family 2 – Clive, Joy, Kit and Dolly

Overview of Family 2: Family 2 comprised Clive (son-in-law, 53 years old), Joy (youngest daughter, 53 years old), Kit (grandson, 19 years old) and Dolly (person with dementia, 88 years old) at the point of first contact in April (involving Clive) and July 2015 (involving Joy and Kit) respectively. They were a mainly Chinese (Mandarin) and dialect speaking (Hokkien and Hainanese) family with Taoism-Buddhism as the focal religion. Typical of most Singaporeans, this middle income family resided in a five-room HDB high-rise apartment on the twelfth floor with lift landing. Photographs 4 to 6 of the outside and inside of their home were taken during one of my visits in July 2015. The family has lived here for about 13 years but would be shifting to their new home near the sea towards the end of 2016. Clive explained that the new home would be more accessible and friendly towards older people with better amenities in preparation for Dolly’s later stage of dementia. Both the old and new residences were located on the north-eastern part of Singapore. Dolly, widowed since her 70s, has early stage vascular dementia which was diagnosed in January 2011. Her family has kept her diagnosis from her. Dolly’s two other children - an older son and daughter - have migrated overseas with their families. She has been staying with Clive, Joy and Kit for 20 years. The family utilized and received information, support and health services from the local Alzheimer’s Disease Association, nearby polyclinic and general hospital (Changi General Hospital) for managing Dolly’s dementia and her other medical conditions.
Photograph 4: HDB apartment block which Family 2 resided in

Photograph 5: Lift lobby on the second floor of the apartment block leading to the twelfth floor

Photograph 6: Living room and dining area of Family 2 - on the right and left accordingly
Overview of my encounters with Family 2: A total of 11 face-to-face interviews were conducted in their home from April 2015 to July 2016, lasting 120 to 265 minutes in duration. The interviews included the completion of a 23-item structured questionnaire, co-construction of the genogram and ecomap with the family (Clive, Joy and Kit), drawings, audio recordings and digital photographs of the home environment, items and activities. The family also contributed digital photographs of activities which they did together. A summary of research contacts with all the members of Family 2 is presented in Table 5.

Table 5: Research contacts with all members of Family 2

<table>
<thead>
<tr>
<th>Contact</th>
<th>Day and Date</th>
<th>Nature of Contact</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Wednesday, 25th March 2015</td>
<td>Clive called to indicate his interest to participate in the study. Provided a quick brief to clarify. Followed by Short Message Service (SMS) to arrange for first face-to-face contact with the family.</td>
<td>5 minutes</td>
</tr>
<tr>
<td>2</td>
<td>Wednesday, 8th April 2015</td>
<td>Relationship building; gathered background information about family. In-depth interview conducted in Chinese (Mandarin) with Clive. Face-to-face personal introduction and project explanation, get-to-know-you session, informed consent taking, construction of the family genogram and ecomap, completion of questionnaire. Field notes.</td>
<td>1600 to 1900 hours (3 hours = 180 minutes)</td>
</tr>
<tr>
<td>3</td>
<td>Friday, 26th June 2015</td>
<td>Arranged via SMS on Thursday 18th June 2015. In-depth interview with Clive. Chatted with Clive and Dolly. Took digital photographs of the outside and inside of the apartment and activities and items in the home. Field notes.</td>
<td>1500 to 1900 hours (4 hours = 120 minutes)</td>
</tr>
<tr>
<td>4</td>
<td>Friday, 3rd July 2015</td>
<td>Arranged via Short Message Service (SMS) on Monday 29th June 2015. In-depth interview with Clive. Audio recording from 1736 to 1856 hour – 1 hour 19 minutes 54 seconds. Took 55 digital photographs of the outside and inside of the apartment and items inside. Field notes.</td>
<td>1528 to 1915 hours (3 hours 47 minutes = 227 minutes)</td>
</tr>
<tr>
<td>5</td>
<td>Sunday, 12th July 2015</td>
<td>Arranged via Short Message Service (SMS) on Friday 10th July 2015. In-depth interview with Joy and Kit. Face-to-face personal introduction and project explanation, informed consent, assent consent, family genogram, ecomap and questionnaire. Interview with Kit in English; Audio recording from 1108 to 1115 hours - 7 minutes 37 seconds. Interview with Joy in English and Mandarin - Audio recording</td>
<td>1100 to 1300 hours (2 hours = 120 minutes)</td>
</tr>
<tr>
<td>#</td>
<td>Date of Interview</td>
<td>Details of Interview</td>
<td>Duration (in minutes)</td>
</tr>
<tr>
<td>----</td>
<td>-------------------</td>
<td>----------------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>6</td>
<td>Wednesday, 9th December 2015</td>
<td>Arranged via Short Message Service (SMS) on Monday 30th November 2015. In-depth interview with Clive. Audio recording from 1218 to 1320hr – 1 hour 2 minutes 18 seconds. Took digital photographs. Field notes. Verification of genogram and ecomap and drawing a new one.</td>
<td>265 minutes</td>
</tr>
<tr>
<td>7</td>
<td>Wednesday, 20th January 2016</td>
<td>Arranged via Short Message Service (SMS) on Monday 18th January 2016. In-depth interview with Clive. Audio recording from 1146 to 1201 hour - 45 minutes 50 seconds. Took digital photographs. Clive showed me videos of their activities. Field notes.</td>
<td>180 minutes</td>
</tr>
<tr>
<td>8</td>
<td>Sunday, 14th February 2016</td>
<td>Arranged via Short Message Service (SMS) on Friday 12th February 2016. Chinese New Year (7th day of Lunar New Year) visit. Field notes.</td>
<td>125 minutes</td>
</tr>
<tr>
<td>9</td>
<td>Thursday, 24th March 2016</td>
<td>Arranged via Short Message Service (SMS) on Tuesday 22nd March 2016. In-depth interview with Clive. Audio recording from 1049 to 1200 hour - 1 hour 11 minutes 23 seconds. Took digital photographs. Field notes. Clive showed me most recent digital photographs of activities and places which they have been.</td>
<td>178 minutes</td>
</tr>
<tr>
<td>10</td>
<td>Sunday, 15th May 2016</td>
<td>Arranged via Short Message Service (SMS) on Thursday 12th May 2016. In-depth interview with Joy. Audio recording from 1553 to 1641 hour - 47 minutes 12 seconds. Field notes.</td>
<td>160 minutes</td>
</tr>
<tr>
<td>11</td>
<td>Tuesday, 14th June 2016</td>
<td>Following the distressed call from Clive on Friday 10th June 2016. Hospital visit where Dolly was admitted. Field notes.</td>
<td>178 minutes</td>
</tr>
<tr>
<td>12</td>
<td>Tuesday, 5th July 2016</td>
<td>Short Message Service (SMS) from Clive on Saturday 2nd July 2016. Went for a stroll with Clive and Dolly. Took digital photographs. In-depth interview with Kit. Audio recording from 1609 to 1701 hour - 51 minutes 48 seconds. Chatted with Clive. Showed me recently taken videos and digital photographs of Dolly after her hospitalization. Field notes.</td>
<td>210 minutes</td>
</tr>
</tbody>
</table>

**TOTAL** | 1,948 minutes (34 hours 51 minutes) |

My rapport with Family 2: Interview schedules were arranged with Clive through Short Message Service (SMS). The interviews were mainly conducted with the family in
English and Mandarin at the dining area with Diagram 2 representing the usual seating arrangement. Specifically, Dolly’s chair which is demarcated in red in Diagram 2 had a soft red coloured cushion which Clive explained was for preventing pressure sores. Mindful of the customary and common practices, I would usually remove my shoes before entering the home and bring along small token gifts, example a packet of grapes, oranges and such. Reciprocally, the family would offer refreshments (usually prepared by Dolly) when I visited them, including invitations for dinner. It became a norm for Clive and Dolly to extend the invitation. I had to politely decline each time, explaining that my loved ones were waiting for me. Clive was adapt at making everyone feel at ease by jokingly saying that I would stay if Dolly cooked delicious food. Dolly hugely reminded me of my late grandmother. I could not resist giving her bear hugs after interviews.

Diagram 2: Seating arrangement for interviews at the dining area for Family 2

4.3.3 Co-construction and Evolution of the Family Genogram and Ecomap
The family genogram and ecomap took almost 15 months, that is, from April 2015 to July 2016 to co-construct and evolve. For this family, I began with the construction of individual or separate genograms and ecomaps as based on my face-to-face interviews with each member. After which, I compared the information, integrate and synthesize accordingly after validation with the family. In total, it took about two to three rounds of validation.

When I first interviewed Clive face-to-face on 8th April 2015, I informed him that I would be constructing a genogram and ecomap of the family with him. Using the interview guide, I showed him how this would normally look like. As I interviewed Clive, I co-constructed the genogram and ecomap (see Figure 9) using my mobile tablet. I further fine-tuned this upon reaching home.

Similarly, when I interviewed Kit and Joy on the 12th July 2015, I engaged and facilitated
them in the co-construction of the family genogram and eco-map (see Figures 10 and 11). This time round, I used pen and paper. For Kit, I only did the ecomap (see Figure 11) but not the genogram. I showed him the one I did with Clive and sought his agreement. In view of the re-organization of caregiving activities and Clive’s new job as a security guard, the genogram and eco-map underwent revision on 9th December 2015. This was co-constructed and verified with Clive. I also re-verified with Joy when I interviewed her on 15th May 2016. Additional information to the ecomap related to Kit was included when I interviewed him on the 5th July 2016. On the 5th July 2016, I showed Clive the fine-tuned version (see Figures 12 and 13) to seek clarification and confirmation. This concluded the final version of the genogram and ecomap for Family 2.

The intergenerational structure of this nuclear family throughout my interactions with them from April 2015 to July 2016 as illustrated in Figures 12 and 13 are coded where CG1 and CG2 indicate the case study participants (CG1 = Clive; CG2 = Joy and Kit) and CR indicates the person with dementia (Dolly).

4.3.4 My Personal Encounters with the Family

The daily intergenerational routine and care organization: Since Dolly’s diagnosis of vascular dementia in 2011, Clive has given up his food stall business to stay at home to care for her whilst Joy continued working full-time as a Human Resource administrative executive in a private multi-national Information Technology (IT) company. In late 2015, they tried operating a food stall again but gave up after a few weeks as Dolly could not adapt to the change. Clive decided to become a security guard to assist in their livelihood. Meanwhile, Kit, the only son of Clive and Joy, was undergoing his compulsory two and a half years of National Service and would only be home for the weekends. He would be commencing his degree in accounting course in one of the local universities under a scholarship scheme in August 2016. Clive elaborated on why he ended up staying at home to provide the care for Dolly:

“My wife and I have discussed. It’s better for her to work while I stay at home to look after mama. She works in Human Resource and the salary pays well. We are comfortable financially. Lucky, we don’t have to worry about our son. He knows how to focus on his study. And, he is on government scholarship.” (researcher’s field note of first interview with Clive)

He shared their experience as an intergenerational family in making sense of things, accepting Dolly’s condition, harnessing the support from available services/agencies and
organizing their routine since Dolly’s diagnosis. They have continued utilizing the services and learning to cope with Dolly’s condition from Changi General Hospital (the general hospital nearest to them) and the local Alzheimer’s Disease Association:

“In relation to that, we did not know what to do. I discussed with my wife. I have encountered this before. But, let me try. Buying at 11 o’clock and buying again at 2 o’clock meant there was a problem. Thereafter, we informed my wife’s brother and sister. The end result was, we were the ones who brought her for tests and the diagnosis was confirmed at Changi General Hospital. This was when we first accepted this condition. We started off with ADA, communicated with the ADA caregivers and have been attending their monthly sessions till now. We have never stopped going for the past 4 years. We have been attending all the sessions. They have been teaching us different strategies. Changi also offers management strategies which Ms Kuo has shared with us. At ADA, we learnt about Chinese remedies – what medicine can and cannot be eaten. We learnt about music and medical therapies. Whatever, we learnt, we tried our best to put them to good use in our everyday life. We incorporate these into her daily routine and organize accordingly.” (third interview with Clive)

Similarly, Joy also shared about what they have learnt from the Alzheimer’s Disease Association and how this has facilitated confidence in them. She described the customization of routines and the significance to the family:

“After visiting the hospital and they said this, my husband find out more about the activities or the agency to look for. So, when we look for all these...ADA, we find out more activities from there also. So, from there, we learn more and more how to manage and take care and make my mom feel more comfortable. Like she is a normal person. Have more confidence. Supermarket...maybe choosing the vegetables. Let her choose. From there, we are more careful and know how to make her more confident. And even make myself more confident as well. So, from what my husband has customized, we realized that the daily routine is very good for her and she has more confidence. Even, when we go shopping, we make her feel secure. Because I think he is trying to keep her occupied. I think that maybe through some walking or exercise, circulation is improved. Then, we unconsciously, we do it daily until weekend. I also join them. So, we attended some seminar. There was a lady from UK who also mentioned that daily routine is very important.” (first interview with Joy)

Additionally, Dolly has a host of medical conditions and was on a cocktail of medication with follow-up at the nearby Polyclinic and Changi General Hospital. Medication became an issue when Dolly started having dementia. But, the family’s resourcefulness, kindred spirit and camaraderie promptly resolved the issue:

“Later on, few months later, for a short duration, we discovered a possible medication compliance issue. We were able to quickly resolve this issue related to organization of medication. We were able to resolve this within 1 month! Within 1
month. Really within 1 month [Laughs]. Within the first month, we managed. We tried a few methods. I was unsure if she took. Thereafter, I thought of a solution of using the sauce cup. Therefore, my wife and I went to buy a packet worth of 100 cups to organize. We realized this method of organizing is not bad. Completely no more worries on this.” (third interview with Clive)

I asked Clive why he thought of using this method. He reasoned that it just came naturally and implied that the actions resulted from genuine intent from the heart. The sincerity could be heard in his voice as he earnestly shared this:

“You asked me why? I also don't know [Laughs]. Just thought about it! Just like what we have given her personally, the memory blocks. The building blocks! Ms Kuo was 'surprised' why I knew how to do it this way! For the arranging of alphabets, I took that out automatically. When I bought this file, I thought about it. So, if you ask me how I thought about using these things, it's very natural! If you have the heart to think about it, everything will be natural! It's very natural. You think of looking after her, you will naturally think about what should be done.” (third interview with Clive)

Dolly was always seated with us during the most part of the interviews, with Clive purposefully encouraging her to share about her younger days in Hainan, China - life in the farm and during the Japanese occupation. His modus operandi was asking Dolly leading questions for her to share stories with me. It gave me a glimpse of why Clive was so full of respect and admiration for Dolly. Both of them were noticeably enjoying the interactions which were always lively and filled with jokes, reflective of a very close kinship. It was difficult to exclude Dolly. I just played along.

I also managed to observe how Clive engaged Dolly in performing the household routines and activities. Example, Clive had gently reminded Dolly that it was time to feed the family's 12 year-old pet ‘tortoise’ which Clive claimed, has a strong bond and affiliation with Dolly. The pet ‘tortoise’ has been described as being “able to recognize her”. He also engaged Dolly to take down the laundry and fold them while the interview was ongoing. The act was rather subtle which made it an automatic action on her part. Towards evening, Clive would excuse himself intermittently to prepare dinner with Dolly in the kitchen. The camaraderie was obvious. I could see that he was also watching her discreetly from the dining area after he left her to continue with the preparation. Since the kitchen was in clear view from where we were seated, he would provide instructions from the dining area. I could hear the active discussion on what menu to prepare for dinner.

It was obvious that Clive was committed in ensuring that whatever they do as a family would
benefit Dolly’s overall health and well-being. He wanted to ensure that her pre-morbid conditions and her dementia were well managed or maintained for as long as possible by continuously engaging her in daily routine activities which were familiar to her:

“In my opinion, when dementia happens in the family, we still managed to resolve the medication problem within the month. When it comes to physical health, for the brain we have no solution for that but we are able to manage the physical health. The daily exercise has helped her overall physique a great deal. We can’t do anything to change the state of the brain but we can do something for the body’s health. My wife and I are both unanimously agreeable on this. [Laughs]. Basically, we make it a point to ensure that what we do relates to her well-being. The daily morning activities are meant in helping her brain. Also, the simple hand and leg exercises. After breakfast, we go for a 1 hour walk, go NTUC to buy groceries/necessities. You can see in the pictures. Haven't changed for many years [Laughs]. Haven't changed for many years. Go RC, chit chat with the elderly. Different places. Sometimes, we go to the nearby garden, basketball court, school to see the students playing happily. We go until the end, look at the tall trees, see the wind blow at the trees until they look as if they are about to topple [Laughs]. ” (third interview with Clive)

As part of the daily one hour walk, Clive would explore nature with Dolly to engage her mind (see Photographs 7 and 8). He described some of the typical things they did together:

“Along the way, we look at the houses, birds' nest. The one you saw just now. We look at it slowly. We look at fruit trees. There was one time, we even saw a squirrel. We will go examine. Sometimes when we walk past and smell the aroma of curry, I will ask her, "Ma ma, what do you smell?" I ask her to take note of everything around her. This is based on what we have learnt. We are not sure if it works or not but want to do, must do.” (third interview with Clive)

The family has continued to do the grocery shopping with Dolly (see Photographs 10 to 12) and supervised the payment at the cash register from afar (see Photograph 9). Clive shared that by doing so, she would feel useful and independent. They have ingeniously articulated and re-customized some of Dolly’s habitual routine whilst still providing her with satisfaction and joy:

“It's mom's routine. Last time, she didn't buy Toto. She bought 4D. We have been staying together, around the birth of my son until now, for 20 years. Her usual is going to NTUC to buy. We let her continue her routine. How she lives now is what she used to do last time. She goes NTUC to buy things, queue, we still let her continue. Her habit of buying 4D, we also let her continue. Then, we realized, when she buys 4D, her writing is a bit [Laughs]. Not as fast as last time. Therefore, recently she also doesn't know what number to buy. So, decided to buy Toto. Toto can win more money. At night can sleep much better [Laughs]. Now, she is used to this routine, she goes and buy. Buy $1, $2, $3 Toto. Therefore, downstairs, the two to three ladies selling Toto at NTUC also recognize her and talk to her. Greetings. Considered not bad. Downstairs. "Aunty, coming to draw salary again! Any
“winnings?” [in Hokkien] [Laughs. After she hears that, she is very happy! Give her a life with long journey. Do those things which she likes to do.” (third interview with Clive)

Photograph 7: Dolly examining a bird’s nest during her morning walk (from Clive who took this in April 2015)

Photograph 8: Dolly examining the papaya tree with fruits during her morning walk (from Clive who took this in April 2015)

Photograph 9: Dolly making payment at the cash register (from Clive who took this in March 2013)

Photograph 10: Dolly buying groceries at NTUC (from Clive who took this in March 2013)
Undoubtedly, intergenerational bonding was consciously enabled through the family doing routine things together as depicted in the various family digital photographs which I was privileged to view and receive. For instance, Joy and Kit’s weekends would be spent accompanying Dolly for activities (see Photographs 13 to 16). Clive would be the one taking photographs of them:

“Those photos you saw are the ones showing her accompanying her mom for walks, different cafes, to our son’s army camp [Laughing]. She accompanies mom to go for different activities. When she has time, she will accompany mom. Sometimes, she takes off to bring mom for RC organized activities.” (third interview with Clive)

and,

“Kit comes back from school, back from NS [National Service]. All these, like his NS orientation, family members go, we also include my mom. Then, the graduation or whatever. Then, also the camp, the English language one, we also just include her. Even go up the bus, we slowly, slowly include her. Make her feel like she is one of the members. Then, happy for the grandchild. Then, like put on the hat, then, we ask my mom to put on for him [Kit]. Then, we take photo.” (first interview with Joy)
Photograph 13: Going for walks (from Clive who took them in June 2015)

From left to right - Joy and Dolly

Photograph 14: Going out for a meal at a cafe (from Clive who took them in March 2013)

Clockwise from the left - Kit, Joy and Dolly

Photograph 15: Accompanying Kit to the army camp for his National Service enlistment (from Clive who took them in March 2013)

Clockwise from the left - Joy, Dolly and Kit

Photograph 16: Accompanying Dolly for an activity organized by the Residents’ Community Centre (RC) (from Clive who took them in May 2015)

Dolly, dressed in blue cardigan

Apart from the convincing digital photographs showing the family togetherness, I felt that it was important to depict this conclusively in the ecomap as well (see Figure 13 - Ecomap).
The very close bond and strong relationship between Clive, Joy, Kit and Dolly was presented in the form of triple parallel lines and bi-directional arrows to indicate reciprocal efforts from all.

Creating meaningful memories: Clive was also taking photographs of my interviews with his family across time. At the beginning, he ushered Dolly and I to the sofa area and took photographs of us posing together. He reasoned that this was helpful for Dolly to remember me when I visited them next. Thus far, for Dolly, he has been photographing the candid moments to monitor for any changes across time (see Photographs 10 to 12). I took the opportunity to ask Clive why he has been taking photographs. His intent was to compare if there were any observed differences of Dolly across the years.

Clive was innovative and creative in his caregiving roles, harnessing his artistic skills to create meaningful paintings. Table 6 is a compilation of his elaborate and laborious artworks. He had taken great effort (see Figure 13 of the ecomap, under recreation, where I have used triple parallel lines and bi-directional arrows to indicate its significant importance and positive effects on the family) to paint them for an intended purpose - symbolic in nature and strategically hung on the wall at different rooms of the house to create a familiar environment in preparation for Dolly when they move house at the end of 2016: “Because when we were at ADA, we saw that some, towards the end, could not even recognise themselves. Therefore, paint big, big paintings for her to remember. Drawing big paintings became a natural progression. Exactly like this. [Laughs]” (fourth interview with Clive).

Clive was of the opinion that Kit has his own life to lead (as depicted in the ecomap in Figure 13, under Kit’s friends and recreation). Therefore, he did not wish to impose any caregiving responsibilities on him. Most of the time, Kit was the one who voluntarily helped in his limited role. This was what he modestly shared on his contributions towards Dolly’s care:

“Usually, I will be busy with school. So, I help my father print the music notes and things to draw. Then, help convert the songs online to his phone to play the songs. Just helping my father. For the pictures, he will search online from Google. Then, I help him to print it out. Then, the music notes, it's like, use the Microsoft, then, draw the circles, add the numbers, the colours, the print out.” (first interview with Kit)

Although Kit’s contributions were somewhat limited, a sense of solidarity and camaraderie could be felt through Kit’s sharing of his contributions during the second interview: “Maybe, like, lighten his workload. Because, I am better at these things. So, I just do for him.”
In addition, Clive has actively co-created Dolly’s story telling of her past with her through drawings (see Table 7). I have also used the ecomap in Figure 13 to illustrate the relative importance of this to the family. Again, by using triple parallel lines and bi-directional arrows to depict its significant importance and the reciprocal effort. Clive would do the sketches and, she, the colouring.

Close kinship and reciprocal love: There was a sense of close kinship and genuine feelings and acts of reciprocal love the family showered on one another. In fact, caring for Dolly has brought the family closer together:

“I realized that... After I realized my mom has dementia, then, when helping her to cope with the daily routine and have more confidence in her daily routine, it also
helped me to realize that health is also very important. And, through exercise and communication with the family members, it helped us to become closer with the family members.” (first interview with Joy)

Table 7: Examples of Clive’s co-created drawings with Dolly

<table>
<thead>
<tr>
<th>Drawing 1: Rice field, water buffalo, geese and frogs</th>
<th>Drawing 2: Mother hen protecting her chicks from the eagle</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Drawing 1" /></td>
<td><img src="image2.png" alt="Drawing 2" /></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Drawing 3: Fences to ward off wild boar</th>
<th>Drawing 4: Sweet dumpling</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image3.png" alt="Drawing 3" /></td>
<td><img src="image4.png" alt="Drawing 4" /></td>
</tr>
</tbody>
</table>

The family members’ acts of concern were like a contagion which culminated in another member wanting to do the same. This was what I gathered from Kit when he disclosed the following information:

“They are quite nice and patient. But sometimes, no time. So, I do what I can. Like they will arrange the medicine into the cups by servings. Then, take time every morning, do some exercises or do some brain puzzles. This kind of things. So, like that would be quite nice and needs a lot of patience to do so. If there's a need, I'll do it.” (first and second interview with Kit)

Somehow, Dolly’s own acts of concern for the family has played a major role in creating the close kinship and reciprocal acts. Clive looked and sounded genuinely touched as he narrated about what Dolly did:
“She asked, "Have you eaten?" This is our life. Life's touching moments. You will be touched. She was having rigors and still asked me if I had eaten! We went to eat first. When she was admitted for surgery .... How to say? During the referral, we also went with her. Wherever we go, we always prepare clothes for the cold for her. Myself, I don't feel the cold but my hands and legs feel cold. Maybe the body is not so healthy. She touches my hands, "Wah, you are very cold. Do you want to wear another piece?" She cares for me. Like, when I had to get the security license. I went to Katong. You saw the picture at the MRT. It was raining heavily. We only had one umbrella. When we were going home, we sat outside because it was cold inside. She saw that my shirt was wet and asked if I was cold. She cares very much for us..... In the morning, she is very concerned about us. In the morning when I return home tired [Security guard], she saw me eating. After that, she will tell me, "You haven't eaten? Hurry up, go and eat." She knows I need to go and sleep in a short while. Then, I said, "I bring you for a walk. Very hot. I bring you for a walk. She said, "You go and sleep first. My walk is not necessary." Her telling me all these has 2 aspects. Another aspect is, she cares about me. Looking at her thinking, she is satisfied of the entire care process. Her entire thinking is full of satisfaction. Her thinking represents that her 'brain' is still very good.” (fourth interview with Clive)

Another example was when Dolly insisted on addressing the spiritual elements before Kit’s overseas trip to ensure his safe journey:

“"You said going overseas need to go pray to the God [in Hokkien]. Actually we went to pray the day before. Later when we returned, she said grandson is going overseas. She wants to bring him to pray. So, we brought her to pray [in Mandarin] [Laughs]. Ma ma and I, the whole family went out to buy the luggage bag for my son. Went together.” (six interview with Clive)

My engagements with Kit and information about him from Clive and Joy have revealed that he was not a person of many words. But, he shared a close kinship with Clive, Joy and Dolly as conveyed through this slice of information:

“Like quite close with my parents also. Like, enjoy spending time together. But won't like always tell them about everyday life. All these. Because guys are like this. Like close but we [Kit and Dolly] don't interact a lot nowadays. Because also quite busy in the army. Only weekends, then, come back. Normally, I'll be in my room. Then, my parents will bring her out for walks. But she [Dolly] has never forgotten me [Smiling]. Because she sees me for twenty years already.” (second interview with Kit)

Though, Kit was not involved in providing physical care, he has a unique emotional bond with Dolly. This was evident from photographs of them together (the researcher is unable to provide the photographs which could demonstrate the obvious bond between Kit and Dolly due to confidential issue. Clive was protective of Kit’s identity being accidentally revealed through the research). As shared by Clive, this was demonstrated through his gestures of
concern such as putting on the cardigan for Dolly and asking about her. Clive took the opportunity to show me a digital photograph of Kit putting on a cardigan for Dolly during the sixth interview: “Do you see my son helping ma ma wear a cardigan? We didn't ask him to help. He himself helped.”

Clive further explained why the bond between Kit and Dolly was so. He went on to cite several more examples of what Kit had done for Dolly and his acts of concern:

“Because at home, he regards Po Po [Maternal grandmother] as a very important member. In fact, he has very little interactions with his "Ah Ma" [Paternal grandmother]. He has more interactions with Po Po. When he was very young, she really looked after him. Childcare, taking bus, looking after him. Therefore, his meals, everything was cared for by Po Po. The relationship is very good. But, my son, in reality, is not a very expressive person. Therefore, when mom was hospitalized, a few years ago, when he returned home, the first thing he did was look around. When he realized something was amiss, he asked me. When he is worried, he does not openly express his emotions but when he takes notice and asks, we know he is worried. He is very attentive. He will...after returning home from secondary school, ask, "Is Po Po at home?" He will show concern. When Po Po was having fever and rushing to go to the hospital, it so happened to be just before his book-in [National Service book-in]. Therefore, he happened to see Po Po in that state, having fever and having chills. She was having high fever and having very bad chills. First time we saw her having chills like this. He was looking for her. Actually, he has already changed to his uniform for book-in [To camp], he went to look for a thick sweater to cover her. We told him to go back [To camp]. That time was 11+ when he agreed to go back by taxi. While in the taxi, he called to find out whether Po Po has gone back. He was very concerned about Po Po! Very concerned. He did not openly express but from this incident, you could see that he was very concerned about his Po Po.” (third interview with Clive)

4.3.5 Researcher Reflection

Forming a Genuine Relationship with the Family: Prior to engaging the family, I had this in mind. “Treat others as how you would like others to treat you. Be myself, be personable and friendly with the family as much as possible. No false pretences.” In terms of two-way communication, I tried my best to answer questions which were asked. In turn, I also listened attentively to what each member said and asked sensible questions about the family to indicate my interest and sensitivity. Eventhough the visits were for the purpose of conducting interviews, I constantly reminded myself that the family’s well-being and interest should be at the foremost. An example, was to fit my interview time to suit their convenience - Making them feel important that their time was more precious than mine. Usually, I would let the family talk and have their air time.
Observing them as individuals and their interactions with each other provided an inkling of how I ought to fashion my relationship with them. I also had to be mindful of the personality of the different family members. Clive was cheery, laughed and joked a lot. He felt easy to talk to. But, I could see from the onset that Clive was protective over the family and acted as the gatekeeper. During the 12th July 2015 visit, Clive was initially nearby and within earshot during the interview. When I was interviewing Joy, I could sense that Clive was nearby, at times interjecting into the conversation, when Joy was sharing her caregiving experience. Subsequently, Clive, Dolly and Kit were in the bedroom. Later Clive came out, contributed to the interview and started preparing lunch for the family. The kitchen was openly facing the dining area. Therefore, whatever that was said could be overheard. Joy was timid but cheery. I noticed that she would look towards Clive for reassurance. During my interviews with her, she was always giggly. Maybe even nervous. I reminded myself not to overpower the conversation. Kit was soft spoken, quiet and shy. He required warming up and gentle probing. He was mostly monosyllabic during the first interview on the 12th July 2015. He only became more conversational and at ease during the second interview on the 5th July 2016.

As a Researcher - Observer-as-participant: The fact that I have identified myself and my purpose in being there and having some interaction but not extensive participation with the family activities might have altered the family’s behaviour from what it would have been normally. Clive would usually ask me what I wish to know and see during my visits. At times, he would play out the activities for my sake.

As a Nurse/Resource Person: Clive and his family knew of my background as a nurse. Sometimes, Clive would seek my opinion and share with me about certain medically-related concerns, Dolly’s prescribed medication and the strategies which they have employed to manage Dolly’s dementia.

As a Friend/Confidante: Sometimes, I felt like ‘Sponge Bob’. Example, Clive would ‘ventilate’ and share information about his frustrations with his workplace colleagues and Joy’s eldest brother when I least expected it and it was not part of the data which he was keen to share or was required. This was made as per field note on the 5th July 2016:

“After Kit’s interview, I chatted with Clive to do some catching up on how things have been. He shared about his workplace and the challenges related to the different types of idiosyncratic behaviours of his colleagues. Clive confessed that he has not
been painting since the last one he did for his son. Apparently, being a security guard has tired him out. Clive showed me the email exchanges between his wife and her brother. His aim in sharing this was to provide more clarity of the conflict and misunderstanding between his wife and her eldest and only brother. “If you see my brother in-law in person, you would not believe he is the one who wrote those emails.” The entire email threads were forwarded to my email. Clive told me he has asked Kit to help him craft the emails in English to his brother in law. He has involved his son as he wanted to expose him to the truth about the situation.” (researcher’s field note during second interview with Kit)

There was also an occasion when Dolly suffered a fall with laceration over the forehead and another where she was hospitalized. Clive and Joy consulted me and asked if facial swelling and bruising were normal and expected since she was on Aspirin. I explained to them that it was partly so and gave them some advice, just in case. Another occasion was when, Clive called me one evening and sought my opinion on a decision to be made. The pattern was rather peculiar as Clive has never done that before. It was difficult. I was personally concerned that I might give the wrong advice but at the same time, I felt the genuine distress in his voice. I really wanted to help. Dolly reminded me of my own grandmother who had passed away many years ago:

“Received 2 missed calls from Clive on the evening of Friday, 10th June 2016. Messaged him immediately to ask him if he was looking for me. Clive called back. Sounded choked over the phone. Informed me that Dolly was in critical condition in the intensive care unit and might require urgent surgery. Asked me for my opinion on whether they should proceed with the surgery. I felt conflicted between my roles - as a friend of the family, a professional/clinician and researcher. He reassured me that they would not blame me for any negative outcomes.” (researcher’s note on Friday, 10th June 2016)

4.3.6 Intergenerational Issues

Conflicts with siblings/extended family: The family’s connection with their extended family (Joy’s eldest brother and her other relatives) has been wrought with conflicts and negativities; thus, Clive has decided to minimize contact with them to prevent the negative impact on his family. The provision of this valuable piece of information was facilitated by the ecomap with Clive eventually sharing how contacts with Joy’s eldest brother have been purposely kept to a minimal to avoid more negative outcomes that would create added stress to the family:

“In the beginning, relatives from my wife's side used to keep in contact. But ever since, we realized that someone amongst them has been sowing discord, we seldom keep in contact. Because, when it first started in 2011. Actually, before that, I seldom kept in contact with my wife's side of the family. It's only when it happened. That's
when I brought mom to keep in touch with them. Thereafter, I realized, it wasn't a big help. When the "problem" came [negativities from wife’s side of the family], the degree of contact became lesser. It's not due to unhappiness but more of not wanting the "negative" things to influence, influence my mom and family because I still need to care for her and my son, hope that the journey and livelihood is more of a peaceful one. Positive things!” (third interview with Clive)

During my interview with Joy, she attempted to elaborate on how the situation was further worsened by relatives’ gossip and interferences:

"Sister? Nothing, much. She, only like after the children have grown up or graduated, then, she comes once a year like my brother. Like that! Until the relative. Sometimes the relative goes to Hong Kong. Then, asked her. Are you coming here already? Sometimes, through asking, they become defensive. They would say, “Whatever”. Then, that relative will come back to us. They would say, you whatever. We would say otherwise! Then, they go and tell them. Then, the more they tell, the worse the situation becomes!” (first interview with Joy)

And, according to Joy, her relatives would question her eldest brother and instigate things, causing more conflicts between the siblings:

“Then, the relative will say, "Ah, very nice!" But we didn't say anything. Just outing only. But don't know why one of the relatives during gathering, when my brother was in Singapore, then, she suddenly go and tell him, "You see, they take good care of her. We never complained about him. Something like, "I want to talk to my mom and greet her Happy New Year, you all didn't let her!" We said, "You want to talk, you can just let us know. You can just email or what." Then, we said, “He didn't talk to mom”. Then, he would call every week. Like, do in order for people to see. Then, I said, he knows my mom is like that, he doesn't even send Chinese New Year card to my mom! Then, you keep telling everybody, the relatives like, he miss the mom and said we don't let him talk to the mom. Where got? Right? I said, you want to talk, you want the third party to know, right? Then, email us or cc the third party that you want to talk. We don't let you talk, then, you have proof! Don't even email, everything. Then, keep telling people. Very fed-up! [in Mandarin] Chinese New Year card also didn't send. Keep telling people that he missed her. Hypocrite! Last time, also didn't care. Didn't care [Expressed in Hokkien]!”(second interview with Joy)

As such, contacts with Dolly’s two older children have been minimized since her dementia was diagnosed. Clive has shared that contacts with them have been purposely kept to a minimal to avoid more negative outcomes that would create added stress to the family. He had shared constantly that they would like to lead a simple and uncomplicated life as it is more manageable that way. After all, their extended family was not chipping in to help nor rendering the expected support since Dolly’s dementia:
“When we discovered there was a problem, we immediately informed the son and the daughter in Hong Kong. He is in Canada. The son is in Canada. He wasn’t of much help. In the end, it’s still us who provided the help. Even when he returned, he did not bring her to see the doctor. In the end, we decided that it’s best we bring her to see the doctor. So, we brought her to see the doctor. At Changi, we brought her to see the outpatient.” (third interview with Clive)

The estranged and distant nature of Joy’s other siblings’ relationship with the family was demonstrated (see genogram in Figure 12) using a dotted line to represent a distant or tenuous relationship, such as Joy’s relationship with her eldest sister. Estranged or cut off relationship is depicted by hash marks drawn through the line. An estranged or cut relationship is depicted between the family and Joy’s eldest brother.

4.3.7 Case Summary
Family 2 comprised Clive (son-in-law), Joy (youngest daughter), Kit (grandson) and Dolly (person with dementia). They were a mainly Chinese and dialect speaking family with Taoism-Buddhism as the focal religion. This middle income family resided in a five-room HDB high-rise apartment. The family would be shifting to their new home near the sea towards the end of 2016. Clive explained that the new home would be more accessible and dementia-friendly in preparation for Dolly’s later stage of her condition. Dolly has early stage vascular dementia which was diagnosed in January 2011. Her family has kept her diagnosis from her. Dolly’s two other children - an older son and daughter - had migrated overseas with their families. The family utilized and received information, support and health services from the local Alzheimer’s Disease Association, nearby polyclinic and general hospital for managing Dolly’s dementia and her other medical conditions.

The family’s connection with their extended family (Joy’s eldest brother and her other relatives) has been wrought with conflicts and negativities; thus, Clive has decided to minimize contact with them to prevent the negative impact on his family. Contacts with Joy’s eldest brother have been purposely kept to a minimum in order to avoid more negative outcomes that would create added stress to the family. The situation was further worsened by relatives’ ‘gossip’ and ‘interferences’. Joy’s relatives would question her eldest brother and instigate things, causing more conflicts between the siblings. As such, contacts with Dolly’s two older children have been minimized since her dementia was diagnosed.

On the 5th July 2016 I informed Clive that I had completed my research time with the family. My monthly to three monthly interactions with this family for a period of about 15 months
had presented a consistent picture of an intergenerational family whose members showed genuine concerns for each other. These could be observed through the small little things which were done and the thoughtfulness behind them. Small acts of kindness went a long way with the family and in their everyday life. The learning point from Family 2 highlights that extended intergenerational family members with negative intentions can create additional stress to the intergenerational family. Additionally, an intergenerational family with positive and cohesive relational dynamics connects effectively with one another and is able to provide timely support for their family member with dementia.
Figure 9: Version 1: Genogram and Ecomap with Clive on 8th April 2015

[Hand-drawn diagram with annotations]

Social Welfare
- ADA - monthly talk
- Shandy Reunion

Recreation
- Local parks x 6
- Daily walks x 1 km

Community Centre (CC)
- RC activities - for elderly
- Walk x 1 km to CC
- 6K Wed & Fri
- 6K walks organized by CC
- DIY - buy items for lunch craft

Social Support
- Hairdresser 8888 Co-
  - Twice yearly
  - Chinese Temple 8888 Rd
  - 3 monthly visits

Family
- PWD's little hubby's cousin's wife
  - Monthly meet-up
  - Sister of PWD
  - 1 to 3 weekly meet-up

HIV care
- CGH - mind ex
  - Pilot study

Stopped in May 2015 for Fris 2015

Mee Tua Shop
Figure 10: Version 1: Genogram and Ecomap with Joy on 12th July 2015
Figure 11: Version 1: Ecomap with Kit on 12th July 2015
Figure 12: Final Genogram of Family 2 (co-constructed with the family from April 2015 to July 2016)
Figure 13: Final Ecomap of Family 2 (co-constructed with the family from April 2015 to July 2016)
4.4 Intergenerational Family 3 – Main Family Storyline: Overcoming Crisis

4.4.1 Introduction

Family 3 represents an intergenerational family, Ben, Barbara, Tim (overseas) and Pam, comprising three generations, staying ‘under one roof’ with the only son, daughter-in-law, only grandson and live-in foreign domestic workers (maids) contributing to the care of a person with dementia in various capacities. The key intergenerational members comprised the husband and wife team. The husband being the only son of the person with dementia – trying his best to manage the crisis situation with the following in mind, that is, ensuring optimal care for his mother who has dementia and appeasing the other members of the household.

4.4.2 Family 3 – Ben, Barbara, Tim (overseas) and Pam

Overview of Family 3: At the point of first contact in June 2015, Family 3 comprised Ben (only son, 65 years old), Barbara (daughter-in-law, 65 years old), Tim (only grandson, 32 years old) and Pam (person with dementia, 88 years old). Tim was away, studying and working in the United Kingdom for the past 10 years and only returned each Christmas. The family relied heavily on their two live-in foreign domestic workers (maids) from the Philippines (NOTE: see footer) for Pam’s daily activities of daily living. They were a mainly English speaking ‘Peranakan’ family with Christianity as the focal religion. This upper middle income family resided in a double storey semi-detached house, located at a quiet cul-de-sac in the central part of Singapore. Photographs 17 to 18 of the outside of their home were taken when I visited them in June 2015. The family has lived here since the late 1990s. Pam, widowed when she was 60 years old, has late-stage dementia from Alzheimer’s disease and was diagnosed with early stage dementia in 2002. She was already wheelchair bound and totally dependent during my contact with the family. She has been staying with the family for 34 years and was a typical ‘Peranakan Matriarch’ running the household. The family received night respite service, information, support and health services from the ‘Dusk to Dawn Service’ in St Joseph’s Home, Khoo Teck Puat Hospital and the local Alzheimer’s Disease Association for managing Pam’s dementia and her other medical conditions. Sadly, Pam passed away peacefully at home on the 6th April 2016; despite an offer to withdraw the family from the study following their bereavement, they were all keen for their story to remain as part of the research reporting process.

Footer: The Philippines is a sovereign island country in Southeast Asia situated in the western Pacific Ocean and surrounded by the South China Sea on the west, the Philippine Sea on the east and the Celebes Sea on the southwest whilst sharing maritime borders with Taiwan to the north, Palau to the east and Malaysia and Indonesia to the south.
Overview of my encounters with Family 3: A total of six face-to-face interviews were conducted in their home from June 2015 to June 2016, lasting about two hours each in duration. The interviews included the completion of a 23-item structured questionnaire, co-construction of the genogram and ecomap with Ben, drawings, audio recordings and digital photographs of the home environment and items. Ben also contributed digital photographs of him doing activities with Pam and the therapist. A summary of research contacts with Family 3 is presented in Table 8.
<table>
<thead>
<tr>
<th>Contact</th>
<th>Day and Date</th>
<th>Nature of Contact</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Saturday, 6th June 2015</td>
<td>Ben called me in June 2015 to indicate his interest to participate in the study. I sent him a Short Message Service (SMS) on 5th June 2015 arrange for the first face-to-face interview. In-depth interview with Ben in English. Face-to-face personal introduction and project explanation, informed consent taking, construction of the family genogram and ecomap, completion of questionnaire. Narrative account - no audio recording yet. Field notes.</td>
<td>1505 to 1650 hours (1 hour 45 minutes = 105 minutes)</td>
</tr>
<tr>
<td>2</td>
<td>Saturday, 13th June 2015</td>
<td>Confirmed via Short Message Service (SMS) on Wednesday, 8th April 2015. In-depth interview with Ben. Audio recording – 2 hours 2 minutes 26 seconds. Took photographs of Pam’s room, adjoining bathroom-toilet, kitchen and the items within. Ben showed videos of Pam’s activities at ‘Dusk to Dawn’ and songs which he downloaded for them from Youtube. Field notes.</td>
<td>1516 to 1728 hours (2 hours 12 minutes = 132 minutes)</td>
</tr>
<tr>
<td>3</td>
<td>Saturday, 23rd January 2016</td>
<td>In-depth interview with Ben. Audio recording from 1637 to 1717 hour – 39 minutes 4 seconds. Field notes.</td>
<td>1530 to 1730 hours (2 hours = 120 minutes)</td>
</tr>
<tr>
<td>4</td>
<td>Monday, 4th April 2016</td>
<td>Ben sent a Short Message Service (SMS), informing that Pam was unwell. Postponed the interview for the coming Saturday, 9th April 2016. Sent him my get well wishes.</td>
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</tr>
<tr>
<td>5</td>
<td>Thursday, 7th April 2016</td>
<td>Ben sent a Short Message Service (SMS), informing that Pam had passed away on the 6th April 2016. Sent him my condolences. The wake/virgil service and funeral was at night on Thursday 7th April 2016 and on the morning of Friday 8th April 2016 respectively.</td>
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<tr>
<td>6</td>
<td>Saturday, 30th April 2016</td>
<td>Received a Short Message Service (SMS) from Ben on Tuesday 6th April 2016 indicating that he was available for interview on Saturday. In-depth interview with Ben. Audio recording from 1516 to 1617 hour – 1 hour 52 seconds. Field notes.</td>
<td>1508hr to 1700hr hours (1 hour 52 minutes = 112 minutes)</td>
</tr>
<tr>
<td>7</td>
<td>Saturday, 14th May 2016</td>
<td>In-depth interview with Ben. Audio recording from 1552 to 1650 hour – 56 minutes 45 seconds. Ben referred me to several online and legitimate sources for digital photographs. Field notes.</td>
<td>1533 to 1725 hours (1 hour 52 minutes = 112 minutes)</td>
</tr>
<tr>
<td>8</td>
<td>Saturday, 11th June 2016</td>
<td>In-depth interview with Ben. Audio recording from 1625 to 1638 hour - 12 minutes 43 seconds). Confirmed and agreed on the earlier genogram and ecomap done in June 2015.</td>
<td>1505 to 1755hr hours (2 hours 50 = 170 minutes)</td>
</tr>
</tbody>
</table>
My rapport with Family 3: Interview schedules were arranged and confirmed with Ben during the interviews and through Short Message Service (SMS). The interviews were mainly conducted with Ben in English at the sofa area in the living room with Diagram 3 representing the usual seating arrangement. Mindful of the customary and common practices, I would usually remove my shoes before entering the home and bring along small token gifts, example a packet of grapes, kiwis and such. Reciprocally, Ben would get his live-in maids to prepare cold honey drinks with chia seeds when I visited.

4.4.3 Co-construction and Evolution of the Family Genogram and Ecomap
The family genogram and ecomap took about 12 months, that is, from June 2015 to June 2016, to co-construct and evolve. For this family, I began with the construction of the genogram and ecomap as based on my face-to-face interviews with Ben. In total, it took about two to three rounds of validation.

When I first interviewed Ben face-to-face on 6th June 2015, I informed him that I would be constructing a genogram and ecomap of the family with him. Using the interview guide, I showed him how this would normally look like. As I interviewed Ben, I co-constructed the genogram and ecomap (see Figure 14) with him using my mobile tablet and converted this to Figures 15 and 16 which I verified with him during the third interview. It was then that he updated the following - his son was getting married, changes pertaining to his live-in maid arrangement and his own health. Thus, I had to revise the genogram and ecomap to the final version (see Figures 17 and 18) which also reflected Pam’s passing. On the 11th June 2016 which was the last interview, I showed Ben Figures 17 and 18 to seek clarification and make final confirmation. Generally, the genogram and ecomap have evolved through my engagements with Ben and his family. In some ways, this graphical representation provided a visual guide in helping me to connect with Ben and his family, and clarify the relationship within the family and their support systems.

The intergenerational structure of this nuclear family throughout my interactions with them from June 2015 to June 2016 as illustrated in Figures 15 to 18 are coded where CG1 indicate
the case study participant (CG1 = Ben), CG2 indicates the other family caregiver (Barbara) and CR indicates the person with dementia (Pam).

Diagram 3: Seating arrangement for interviews at the sofa area for Family 3 (demarcated with dotted red borders)

4.4.4 My Personal Encounters with the Family

*The daily intergenerational routine and care organization:* According to Ben, the family crisis began about 15 years ago when the once stoic, fierce and idiosyncratic Peranakan matriarch (Pam) began sitting for hours at a time at the main entrance of the house, hurling baseless (but nonetheless real for Pam) accusations at Barbara and the live-in maid and scolding them incessantly on a daily basis. For example, she accused Barbara of taking and using her jewellery. Ben was caught in the middle of this escalating situation having to defend his wife whilst reasoning with his mother as this extract from our conversation during the second interview illustrates: “Take my jewellery. Used. Used. I asked her, “Did you see?
Did you see?” No. ‘How do you know then?’ She wore it that night! ‘Where did she take it from? Why would she want to use your jewellery?’

To make matters worse, Pam would liberally share these perceived wrongdoings to the neighbours which upset Barbara even more. All these years later Ben remained discreet and careful whenever the details of his narratives involved his wife and he would usually ask me to ‘use my imagination’. Protection of his mother’s identity and loyalty to his wife was an invidious position to be in. At the time, however, everyone in the household went to Ben and expected him to take action. From his facial expressions and tone, I sensed that these memories continued to be painful, as Ben shared during the second interview: “Sometimes she went to the neighbours in the garden. You listen, huh. This is what happens in my family. Everybody came to me. I’m the centre piece.”

This stressful affair went on for about a year with Ben attempting to appease the different parties in order to create peace and harmony at home. In addition to the conflicts experienced during the day, Pam presented with other problems at night because of her ‘sun-downing syndrome’ as shared by Ben. She played with faeces, smeared them on the walls and chased the live-in maids out of her room. Naturally, the live-in maids would end up knocking on the couple (Ben and Barbara’s) bedroom door for help. The night time problems created even more tension as the entire household were unable to have a restful night. Again, Ben ended up being expected to resolve the situation as he vividly described:

“Because when she got up in the middle of the night, "What are you doing in my room? Get out!" She chased them out of the room. When she chased them out, sometimes they try and resist but they cannot. So, they knocked on my door and I got to resolve the situation. I can't sleep after that. So, everybody cannot sleep. So, of course, we became very angry. So angry. Everybody became angry. When you don’t have enough sleep, you're really angry.” (second interview with Ben)

As the only son, it was difficult for Ben. He was the head of the household and caught in between the two important women in his life – his wife and mother – and the live-in maids as well. Whilst he omitted to elaborate upon the exact details, a sense of helplessness and despair - but determination - was evident in his voice:

“So, there was conflict. It was creating a lot of tension in the house when the condition deteriorated. It created very high tension. So, as I said, spouse support is very important. The spouse doesn't go along with you, then, I really cannot imagine what will happen. We were in a crisis. We were in a crisis, I must say.” (second interview with Ben)
The situation was stressful and took a toll on Ben and Barbara’s spousal relationship. He shared that they ended up undergoing counselling sessions at one point in time. In fact, Ben acknowledged that it was because they did not know how to fully manage Pam’s difficult behaviour then and were simply “fire-fighting at the time” in order to deal with the overwhelming series of problems (fifth interview with Ben). This significant piece of past information was facilitated and revealed through the ecomap when I was asking Ben about details of past and present social support and welfare services which the family has utilized. From 1999 to 2002, Ben resorted to leaving Pam outside the house or driving her to two nearby shopping centres and leaving her there with $5 for food, just so there was peace and quiet at home during the day. He had to make this a purposeful routine for at least three times a week from morning until afternoon. Ben did not know at the time that his mother had dementia. Besides, it seemed to be the best strategy he could think of at the time and, according to him, because specific support services were hugely unavailable then: “Because when it first started, we were very disorganized. Because we didn't really know what to do. In the early stage, as I said, we left her outside” (second interview with Ben).

Ben stopped when Pam’s condition worsened and she could no longer buy food for herself. Sensing that something was amidst, he also consulted his church friends and found out from them that Pam might have dementia. He resorted to other means of managing the situation and attempted to seek the best care he could find for Pam. He first sought medical consultation at the General Hospital which was recommended by his church friends and also brought Pam to the hospital’s caregiving sessions but stopped as she had disliked it. Subsequently, Pam attended a Dementia Day Care at the West Coast and that lasted until Pam progressed to a moderate stage of her dementia and the staff were unable to cope any longer. Again, Ben had to search for another centre to care for Pam during the day and he was referred to the Alzheimer’s Disease Association’s Horizon Day Care Centre. This lasted only two months due to his mother’s behaviours that challenged and she became a ‘safety concern’ at the facility. Ben was also fearful of his mother falling and the family was again faced with resolving an ongoing crisis:

“So, we brought her in. Ah, but then [Pause], she couldn't adapt very well to the Horizon Day Care Centre. Couldn't at all. She was trying to get up and walk. Over there, they don't restrain a person. Left her on the wheelchair. So, that was dangerous. Also made me a bit frightened of her. She's not that easy to manage, they found it. Too short. Too short. Then we had, then, we were of course in a fix. Day time, she is here. Night time, she is creating problem for us! Cannot sleep.” (second interview with Ben)
Thus, during the crisis situation, Ben shared that the family was thinking of a nursing/residential home admission for Pam, mainly for the sake of creating harmony at home. However, after Ben and Barbara agreed that this was the best solution, the idea was abandoned after he and Barbara assessed the proposed nursing home environment not to be of a necessary standard, as this emotive slice of data attests:

“And, so my wife and I went to take a look. Show me the ward where my mother would be? So, we went upstairs and the moment we went in, my wife was horrified by what she saw. Stench! Lady walking around with diapers. Soiled. urinate. Nobody changed. And the room was dark. Six.. seven beds in the room. The lady was walking around asking me questions. I think she was demented. But, the smell! So, she was horrified. After that, we came back quite horrified. A bit shaken. My wife said, “I have no heart to do it”. “Fine”, I said. So, it's fire-fighting until we got the Dusk to Dawn Service.” (second interview with Ben)

The family, therefore, decided to persevere until the ‘Dusk to Dawn Service’ was ready to start which was a huge relief for Ben. Eventually, the timely and much awaited for ‘Dusk to Dawn Service’ came to Ben’s rescue when it was started in May 2013. It offered night respite service from 1900 to 0800 hours (Monday to Friday) and was, in the words of the family, “a god-send”. Fortunately, Pam adapted well to the night respite service, so much so that it prompted Ben to increase his mother’s attendance from once a week to five times a week. This service helped to resolve an important conflict in the family. It was clear that Ben was appreciative of the timeliness of the ‘Dusk to Dawn Service’ in addressing the family’s crisis situation. He has even made it his mission to drive Pam to the ‘Dusk to Dawn Service’ every night. From then on, the home situation became peaceful when the night-time problems were addressed. He looked and sounded obviously relieved as he shared how things have turned out:

“My two helpers can have a rest at night and we all can have a peaceful night. Nobody knocking on my door. [Laughs]. And that's how it started. Right on time. Because we were at the cross roads. Without that I think...I don't know where we are.” (second interview with Ben)

For the daytime and weekend, Ben managed to re-organize their two live-in maids to attend to Pam, with Barbara overseeing them for the care provision. I could tell during my Saturday visits to the home that the live-in maids were the ones attending to Pam whilst Barbara gave them the occasional instructions whenever she was around. It was also noted that Ben and Barbara were not providing physical care for Pam. He has also affirmed that. I remember asking Ben about this and he told me matter-of-factly that “they also had no energy to chip in” (third interview with Ben). Although the main crisis has been managed, the family was
still faced with the occasional crisis. For instance, Ben shared that when one of their live-in maids had to return to the Philippines at the end of 2015 due to her own family crisis, he had to face the situation and do some readjustments. In fact, Ben candidly told me that if I had attempted to arrange for any interviews then, he would not have “entertained” me. I have used the ecomap to capture and illustrate this change; to compare Figures 3 and 5.

Engaging with Music Therapy: Upon resolving the main family crisis and better managing the situation, Ben has also been able to contribute actively to Pam’s care through music therapy. He proudly shared how he has been instrumental in introducing music therapy to the ‘Dusk to Dawn Service’ for the benefit of Pam, other attendees and the healthcare professionals. He saw this as his “job” to look for suitable songs for Pam, the older residents and the staff there. He searched Youtube extensively for this meaningful purpose. I could sense his satisfaction whenever he elaborated on this piece of information. There was a certain sparkle in his eyes and tone of excitement in his voice:

“I’m very happy that I can introduce music therapy to the home. So, they used some of these songs to entertain the residents of the homes as well. So, that’s great. It’s meant to be shared with them. Do what they want to do with it. So, I just search and search.” (second interview with Ben)

During the second and third interviews, Ben showed me videos of Pam at the ‘Dusk to Dawn Service’ although he informed me that I could watch the videos but I was not to take any photographs, citing confidentially issues as other people were in the videos. I could see that he was laughing and beaming with pride and joy with a sense of great accomplishment when sharing about the improvement in her behaviour from beginning until the time of her death. The sessions have engaged her to become more responsive and animated. She was clapping, singing along, smiling and playfully patting the professional caregiver's head. He showed me the different types of songs with lyrics which he managed to find from YouTube to contribute to the service and her singing sessions. Examples of songs which Ben has downloaded from YouTube to pass to the professional caregivers at the ‘Dusk to Dawn Service’ were local Malay songs such as “Chan Mali Chan”, “Dayung Sampan”, “Rasa Sayang” and “Burung Kakak Tua”. These local songs also connected the researcher to her childhood. Ben confessed that he had found it “enjoyable”, the singing and all. He shared that he has contributed from three songs to at least 40 songs of various varieties:

“So, I introduced music. Downloaded songs. Give them lyrics. Sing with her and it worked extremely well [Laughs]. Everybody enjoyed it. Even I enjoyed it at the same time. Then, they have their own games. Block building. All these sort of things.
Connect, lah. And, they have food. They just pamper her with cakes and ice cream.”
(Second interview with Ben)

Photograph 19: Ben accompanying Pam during her activities with therapists at the ‘Dusk to Dawn’ service (the digital photograph from an online source was provided by Ben during my fifth interview)

During the third interview, Ben shared that he has also introduced ‘Simulated Presence Therapy’ to the ‘Dusk to Dawn Service’. He showed me a video of Pam talking to the pre-recorded person in the video. “That's her, listening to the person. You play the video on the TV. So, she is talking to you. So, it's like real”, he said. Ben has used it at home on Pam during the period when his other live-in maid had to return to the Philippines. Apparently, he had to do it every day. It lasted for a good half hour each time. If the live-in maids were busy, then he would play it and sit with her. Ben laughingly shared that he would only play the video when necessary.

Role of the live-in maids: Ben was, by virtue, a pragmatic and organized person who preferred to plan ahead. As Pam’s condition deteriorated, he and Barbara decided that it was necessary for them to have two live-in maids instead of one. That way, the live-in maids could each take turns to care for Pam and would be able to focus and provide better care for Pam in addition to doing the household chores. This was because Ben was acutely aware that it was not an easy task to care for Pam:

“But in the course of time, as my mother's condition deteriorated, then, one helper would not be sufficient. So, we had to engage a second one. Right? And, we found that with two persons, it improved the productivity actually. So, beside the normal duties, we had new [Tssk] problems like sleep problem. So, if one person handles the day time, you take care of the ADLs, at night, you can't even rest, what's going to happen to the person, ok? [Chuckles].” (Sixth interview with Ben)

The live-in maids were providing all the physical care for Pam’s activities of daily living which Ben and Barbara were unable to provide on their own. Ben did not feel comfortable handling Pam’s activities of daily living either as this would mean being exposed to her
body. I could tell that he was not comfortable in that regard. Hence, Ben was deeply appreciative of the live-in maids, particularly their compassion, the nature of the care they provided and the patience which they had shown while doing so. In fact, he shared that he has regarded them as part of the family over time because of that. Moreover, Ben was in a delicate situation where he had no siblings to rely or depend on. So, the act of regarding and treating the live-in maids as his own siblings was advantageous and strategic. He was wholly dependent on them to genuinely care for Pam as if they were related to each other. What better way if any than to strategize as such:

“As time went on, they became a part of the family because most of the ADL would be handled by them. I cannot handle. Firstly, because I'm male [Chuckled]. I can't do bathing or changing clothes. And, not fair to my wife to do it either. So, they have to handle it. Even for feeding, she needs a lot of time to feed then. And, we also cannot handle that easily. So, they have to do that. So, I have no siblings! They are like my siblings! [Chuckles. Laughs]. In a way, you know... So, I can tell them to do this and do that. The fact that I have nobody else to call upon, I have two of them who are compassionate [Ben deepened his voice & tone to emphasise], fits in perfectly well. So, become part of the family.”  

(sixth interview with Ben)

Ben was equally mindful of the live-in maids becoming homesick and having adjustment issues due to environmental and cultural differences. He knew the importance of acculturating the live-in maids in order to achieve a win-win situation for both parties. The live-in maids were here to earn a living and he needed his mother to be well taken care of. Helping them to adjust was crucial:

“When they come here, they are coming to a foreign country. And, they need the home support. I'm back to where they come from. I mean, you got to recognize. They come here, there is a period of adjustments, orientation they must go through. Culture is different. Environment is different. So, if you don't help them to adjust, then, they are not... they are not going to be useful to you.”  

(sixth interview with Ben)

Thus, Ben and Barbara consciously created a conducive environment for the live-in maids. For example, they were generous with food, access to the personal computer where the live-in maids could skype with their families in the Philippines and had access to free internet services for their hand-phones. Ben believed that if the live-in maids were well taken care of, they would feel appreciated. He was confident for the appreciation to be mutually reciprocated:

“So, you got to create the environment for them. We are very liberal with them in terms of food. We don't stinch on that. Facilities, we let them use it, know. Just now,
my wife was saying, computers, we give them access. Ya. We do Skype. Teach them how to Skype. So, they must have that connection. So that they feel that they are taken care of. And, they become better people. So, you got to look after them. And, when the hand-phone arrived, that's easy: WIFI. I gave them the WIFI to go and connect. I even bring them to go and buy a hand-phone [Chuckles]. You got to take care of them. Otherwise, how are they going to perform? Both ways. I mean, we appreciate them. They appreciate us. So, it becomes mutual.” (sixth interview with Ben)

Evidently, whatever Ben and Barbara have done and provided for the live-in maids worked out well. The acts of reciprocity were evident in the care provided for Pam. I could sense how appreciative and satisfied Ben was. After hearing from Ben, the ecomap was in a unique position to graphically present the close bond and reciprocity between the live-in maids and the family. Ben confirmed that these were aptly represented by triple parallel lines and bi-directional arrows.

4.4.5 Researcher Reflection

*Forming a Genuine Relationship with the Family:* My impression of Ben was that he was a private/reserved and pragmatic person. For instance, I asked him if anybody at his workplace knew about his family situation. The reply was, “I’m not their full-time staff. I don’t tell them about this”. Also, his stoical façade usually created a serious conversational thread. To build rapport, I engaged in informal chit chats with him on the latest news, our teaching experiences and the healthcare scene – familiar conversational topics. Likewise, he would ask me how my research was coming along and whether the other families were facing similar issues too.

*As a Researcher:* Initially, I felt as if I was grappling in the dark in attempting to fully comprehend and make sense of the data I have managed to gather through my interviews with Ben. Ben was not the type of person who would openly express and display his emotions, least of all to someone like myself whom he knew very well was collecting data for a research. Neither did I expect him to tell me the reason why he cared for Pam for the past 13 years was because “I love my mom”. But, what had concluded his dedication and love for his mother were his actions as based on the consolidated evidences - his sharing, the videos, testimonies from Barbara and the online publications which featured Ben. I remember asking him during the fifth interview if it was a sense of duty or his religion which compelled or motivated him to care for Pam. He confirmed it to be both and added a pragmatic reason: “I have no siblings. So, who else can do it?”

The longitudinal nature of my engagement with this family has provided a conclusive
portrait of a filial son who amongst other things, faithfully drove his mother to the ‘Dusk to Dawn Service’ every evening (shared by Ben during his third interview) without fail and bothered to source for YouTube songs to engage her. Similarly, my conversation with Barbara yielded a convincing testimony. Ben was described by her as a rarity when other people would have sent their mothers to a nursing home. It was also his staunch Christian belief:

“Christianity teaches you to honour your father and your mother. You got to give her the best care. So, home care is the best care. So, I told my wife, at all cost, we got to keep her here until we cannot.” (fifth interview with Ben)

During my last two visits, after the passing of Pam, I could tell that Ben was affected by her passing. He looked solemn and his eyes were red when describing the period when Pam was unwell. A point to note was that during my interviews with Ben before Pam passed away, she was usually in the kitchen with the two live-in maids and Barbara. I was unable to observe any of the caregiving activities taking place except for the sounds and noises coming from the kitchen. Examples, Pam calling, “Grandmother” or sounds of banging on the table for attention as confirmed by Ben. Ben was apologetic that I could not witness the actual goings-on and reasoned that he could not be seen by Pam or else she would confuse him for her grandmother. Hence, my account of things were from his sharing.

Ben also told me something which resonated with what other caregivers have shared during a conference I have attended, that the family actually felt a void or sense of emptiness after the passing of the family member whom they have cared for. Even his live-in maids missed her presence and suddenly found themselves with nothing to do. The two live-in maids have gotten so used to Pam that her physical presence was missed. Ben had shared during the fifth interview, “Feels like something is missing!”

The fact that Barbara was not participating in the research made it quite difficult to understand the nature of her relationship with Pam; apart from what was willingly shared by Ben and the subtle information which he has shared. I could only imagine and draw certain limited inferences. It was only during the last interview when Barbara voluntarily joined in the conversation that I managed to get a gist of it, presented as a dotted line in the ecomap to show a somewhat distantly close relationship. Ben kept quiet and let her talk then. In fact, Ben informed me later that he purposely kept quiet and let her do the talking as he had wanted me to hear from her and validate the congruence of her information with the ones which he had provided so far. Barbara mentioned that what she was sharing then would be
useful information for my data collection. It was also to affirm what Ben has shared.

*As a Nurse/Resource Person:* Although Ben has obviously provided Pam with the best care he could afford, he was having mixed feelings and questioned if he had made the right decision by bringing Pam back from the hospital when her condition took a turn for the worse. The hospital staff were planning to insert lines and tubes into her when she was not eating. His decision to take her home then was because he did not wish for Pam to go through any forms of discomfort and Pam would not have wanted that either. I could sense that he was feeling guilty and blaming himself for her demise. He was also looking for closure. I consoled Ben that he has done his best and given Pam a good quality of life. Furthermore, she also managed to attend her only grandson’s wedding reception, I told him.

4.4.6 Intergenerational Issues

*Spousal conflict:* From the beginning, when I asked Ben if I could interview Barbara as well, he made it very clear that he would be the only one participating in the interview. His exact words were: “It’s best that you interview me and the maids only” (researcher’s note during first interview). Through my engagements with him and eventual conversation with Barbara after Pam’s passing, I understood why. He probably did not wish for Barbara to relive the past emotions should she be interviewed. In the earlier days, there were spousal conflicts which Ben articulated as ‘tension in the house’ when they were still trying to deal with Pam’s difficult to manage behaviour:

“*Anger? Of course! You become so stressed up, you can’t think logically sometimes. So, you cannot have two angry persons running around the house. I leave a little bit to your imagination. When both get agitated, nothing works. It went on for two months before we found solutions.*” (second interview with Ben)

Barbara has described Pam as the typical Peranakan mother-in-law whom she had to live with for 34 years. I could only imagine the kind of strict and idiosyncratic regime she had to put up with even before Pam’s dementia. Peranakan mother-in-laws are typically the matriarch of the household and not easy to live with. Pam’s daily scolding in the earlier years of her dementia, I imagined, would have fuelled such conflict. Nevertheless, the spousal conflict came to a halt when the family found a solution in the form of the ‘Dusk to Dawn Service’ and their two live-in maids.

4.4.7 Case Summary

Family 3 comprised Ben (only son), Barbara (daughter-in-law), Tim (only grandson) and
Pam (person with dementia). Tim was away, studying and working in the United Kingdom for the past 10 years and only returned home each Christmas. The family relied heavily on their two live-in maids for meeting Pam’s activities of daily living. They were a mainly English speaking ‘Peranakan’ family with Christianity as the focal religion. This upper middle income family resided in a double storey semi-detached house. Pam has late-stage Alzheimer’s disease and was diagnosed with the early stages of her condition in 2002. She was already wheelchair bound and totally dependent during my contact with the family. The family received night respite service, information, support and health services from the ‘Dusk to Dawn Service’ and the local Alzheimer’s Disease Association for managing Pam’s dementia and her other medical conditions. Pam passed away peacefully at home on the 6th April 2016. Despite an offer to withdraw the family from the study following their bereavement, they were all keen for their story to remain as part of the research reporting process.

In the earlier days, there were spousal conflicts which Ben articulated as “tension in the house” when they were still trying to deal with Pam’s difficult to manage behaviours. Barbara described Pam as the ‘typical Peranakan mother-in-law’ whom she had to live with for 34 years - Peranakan mother-in-laws are typically the matriarch of the household. Pam’s daily scolding in the earlier years of her dementia may have fuelled a family conflict and was only resolved when the family engaged the ‘Dusk to Dawn Service’ and employed two live-in maids to help with everyday tasks and Pam’s care.

My last interview was on the 11th June 2016 and my monthly to three monthly interactions with this family - for a period of about 12 months - had presented a consistent picture of an intergenerational family where flexible services resolved the family conflict together with person-centred and group activities. This was framed around a diagnosis and understanding (for all) about dementia and what this means. The learning point from Family 3 highlights that a lack of understanding about dementia and what this means and a difficult pre-dementia relationship may impact relational dynamics and how intergenerational members connect with one another and provide timely support for their family member with dementia. Also, for a family unit with a small number of intergenerational family members, the availability of timely external support services becomes a useful and valued resource for the family.
Figure 14: Version 1: Genogram and Ecomap with Ben on 6th June 2015
Figure 15: Version 2 Genogram of Family 3 (co-constructed with Ben in June 2015)
Figure 16: Version 2 Ecomap of Family 3 (co-constructed with Ben in June 2015)
Figure 17: Final Genogram of Family 3 (co-constructed with Ben from June 2015 to June 2016)

11 June 2016

Legend:
- Male
- Female
- Deceased
- Index person
- Nuclear family / household
- Main Caregiver

88 yrs old. Dx AD 15 yrs ago in 2002. Late stage AD. 
H/O HTN. Previously on meds.
Sec 2 education. F/T housewife.
Introverted. Never ventured out on her own.
Mkkien & English speaking.
Passed away 6th April 2016.

65 yrs old.
PT lecturer in SIM x 13 yrs since 2002.
Teaches economics.
6/12 employment contract.
Previously in stock broking.
HTN x 5 yrs (Tab Micardis 10mg ON)
OA L knee since July 2015
Xray done – OA knee.
MAH – surgeon – recommended op
for both knees

65 yrs old.
Degree (BA). Retired.
Previously worked in insurance admin > 10 yrs ago.
Has hyperlipidaemia. (Tab Crestol 5mg EOD).
Supervised maids in care of CR.
Oversaw the purchase of household food & necessities.
Drove CG1 to purchase necessities for CR.

32 yrs old.
Lived & work in London.
Bank officer. Masters in operational research.
Not contributing to care of CR.
Returned yearly for Xmas.
May return to Spore in a few yrs time.
Married recently on 2 Jan 2016

Legend:
- CG2
- Secondary caregiver
- CR
- Care recipient
- • Divorced
- • Very close
- • Estranged / Cut off
- • Poor conflictual
- • Distant
Figure 18: Final Ecomap of Family 3 (co-constructed with Ben from June 2015 to June 2016)
4.5 Intergenerational Family 4 – Main Family Storyline: Valuing a diagnosis

4.5.1 Introduction
Family 4 was initially on my reserve list for recruitment into the study. I only enrolled this family into the study when two of the earlier families - who were recruited in 2015 - withdrew unexpectedly, although, of course, in line with the study protocol. Hence, the longitudinal nature of the research contact with Family 4 was limited to a maximum of six months in order to fit in with the data collection period for this PhD study. Family 4 represents an intergenerational family, Ellie, Ginny, Clara and Elaine, comprising three generations, staying ‘under one roof’ with two sisters, their niece and live-in foreign domestic worker (maid) contributing to the care of a person with dementia in various capacities. Family 4 also depicts the initial challenges the family underwent when not knowing the diagnosis of dementia, and the subsequent intergenerational involvement and peripheral support from the extended family in the care of a person with dementia.

4.5.2 Family 4 – Ellie, Ginny, Clara and Elaine
Overview of Family 4: Family 4 comprised Ellie (eldest daughter, 64 years old), Ginny (second daughter, 63 years old), Clara (grand-daughter, 21 years old) and Elaine (person with dementia, 85 years old) at the point of first contact in January 2016. Clara was Ellie’s only brother’s daughter. The family relied heavily on their live-in foreign domestic worker (maid) from Java, Indonesia (NOTE: See footer) for Elaine’s daily activities of daily living. The live-in maid has been with them for a year. They were a mainly English and Cantonese speaking family with Christianity as the focal religion. This middle income family resided in a five-room HDB high-rise apartment on the seventeenth floor with lift landing in the north-eastern part of Singapore. Photographs 20 to 21 of the outside and inside of their home were taken when I visited the family in June 2016. The family has lived here for about two to three decades. Elaine, widowed when she was about 68 years old, has late stage dementia (Parkinson’s disease) and was diagnosed with moderate stage dementia around 2007 to 2008. She was already wheelchair bound and totally dependent during my contact with the family. Elaine has four other children, either married or divorced with families of their own – a third daughter (59 years old), fourth daughter, Twin 1 (57 years old), fifth daughter, Twin 2 (57 years old) and a youngest son (55 years old).

Footer: Java, the fifth largest island in Indonesia and thirteenth largest island in the world, lies between Sumatra to the west and Bali to the east with Borneo Island to its north and Christmas Island to its south. It is surrounded by the Java Sea to the north, Sunda Strait to the west, the Indian Ocean to the south and Bali Strait and Madura Strait in the east. Indonesia is located between the Indian and Pacific oceans. It shares land borders with Papua New Guinea, East Timor and East Malaysia.
The family received information, support and health services from their family physician, Khoo Teck Puat Hospital’s palliative care team and the local Alzheimer’s Disease Association for managing Elaine’s dementia and her other medical conditions. Sadly, Elaine passed away peacefully in her sleep at home on the 3rd May 2016 but the family all wanted to continue with the study and contribute their lived experience of intergenerational family care.

Photograph 20: HDB apartment block which Family 4 resided in (taken by the researcher on the 30th March 2016)

Photograph 21: Living room of Family 4 (taken by the researcher on the 30th March 2016)

Overview of my encounters with Family 4: A total of seven face-to-face interviews were conducted in Ellie’s workplace premises and her home from January 2016 to July 2016, lasting about 40 to 1 hour 45 minutes each in duration. The interviews included the completion of a 23-item structured questionnaire, co-construction of the genogram and ecomap with Ellie, drawings, audio recordings and digital photographs of the home.
environment and items. A summary of research contacts with Family 4 is presented in Table 9.

Table 9: Research contacts with all members of Family 4

<table>
<thead>
<tr>
<th>Contact</th>
<th>Day and Date</th>
<th>Nature of Contact</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Monday, 25(^{th}) January 2016</td>
<td>Interviewed Ellie during lunch time. The following were completed - Reply form, consent, questionnaire &amp; genogram; genogram was completed ¾-way. No ecomap and audio recording yet. Field note.</td>
<td>1220-1300 hours (40 minutes = 40 minutes)</td>
</tr>
<tr>
<td>2</td>
<td>Friday, 26(^{th}) February 2016</td>
<td>Confirmed via Short Message Service (SMS) on 9(^{th}) February 2016. Ellie called and confirmed the meeting for the 26(^{th}) February 2016. We met during lunch time at 1300 hour. Audio recording was from 1313 to 1358 hour - 45 minutes 11 seconds. Genogram and ecomap to be continued and completed during the next interview. Field note.</td>
<td>1305hr to 1400 hours (55 minutes = 55 minutes)</td>
</tr>
<tr>
<td>3</td>
<td>Wednesday, 30(^{th}) March 2016</td>
<td>Texted Ellie today at 0840 hour to ask her what time we were meeting. She replied to meet at 1200hr to go to her house today. Ellie introduced me to her maid and sister (Ginny). Elaine was sleeping on the day bed. Took pictures of the apartment and framed pictures. Ellie would like to meet up again next week and asked me to call her then. Field note.</td>
<td>1220hr to 1345 hours (1 hour 25 minutes = 85 minutes)</td>
</tr>
<tr>
<td>4</td>
<td>Friday, 8(^{th}) April 2016</td>
<td>Block P’s Green Garden. At one of the pergolas. Audio recording of Ellie from 1252 to 1332 hour – 37 minutes 13 seconds. Field note.</td>
<td>1230 to 1330 hours (1 hour = 60 minutes)</td>
</tr>
<tr>
<td>5</td>
<td>Wednesday, 4(^{th}) May 2016</td>
<td>Received a WhatsApp message from Ellie on the 3(^{rd}) May 2016. I attended the wake on the 4(^{th}) May 2016 to pay my last respect. Met one of Ellie’s nieces. Ginny came from upstairs to meet me first. Introduced me to her niece. Field note.</td>
<td>0845 to 0935 hours (50 minutes = 50 minutes)</td>
</tr>
<tr>
<td>6</td>
<td>Friday, 3(^{rd}) June 2016</td>
<td>Texted Ellie @ 0843 hour to ask her if she was free for an interview. Interview venue was changed to Food Central. Audio recording from 1142 to 1256 hour – 53 minutes 29 seconds. Field note.</td>
<td>1130 to 1315 hours (1 hour 45 minutes = 105 minutes)</td>
</tr>
<tr>
<td>7</td>
<td>Wednesday, 20(^{th}) July 2016</td>
<td>Invited by Ellie to her home for home-cooked “Laksa”, prepared by her live-in maid. She also brought another colleague. Field note.</td>
<td>1215hr to 1330 hours (1 hour 15 minutes = 75 minutes)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td></td>
<td><strong>470 minutes (7 hours 50 minutes)</strong></td>
</tr>
</tbody>
</table>
My rapport with Family 4: Interview schedules were arranged and confirmed with Ellie during the interviews and through Short Message Service (SMS). The interviews were mainly conducted with Ellie in English. Unlike the other four families in the overall study, my interviews with Ellie were conducted mostly at her workplace, that is, four out of the seven times. She would decide on the location and send a text message on the day itself to inform me where to meet. Examples of the chosen venues were the common eateries and garden (see the collection of digital photographs of these venues in Table 10). The only other times I visited their home were when Ellie brought me to her house to take some digital photographs, at Elaine’s funeral wake and during the last visit when Ellie invited me for lunch.

Table 10: Digital photographs of the interview venues at the workplace (taken by the researcher from February to June 2016)
4.5.3 Co-construction and Evolution of the Family Genogram and Ecomap

The family genogram and ecomap took about six months to co-construct and evolve, that is, from January 2016 to July 2016. For this family, I began with the construction of the genogram and ecomap as based on my face-to-face interviews with Ellie. In total, it took about two rounds of validation. The co-construction of the genogram and ecomap with Family 4 was more challenging as compared with the other four families. The reason for this was that Ellie was always in a rush which made her invariably distracted during our time together. She also had some difficulty recalling certain events and information. For accuracy, I had to re-verify the time-line and sequence of events during most interviews with her.

When I first interviewed Ellie face-to-face on the 25th January 2016, I informed her that I would be constructing a genogram and ecomap of the family with her. Using the interview guide, I showed her what this would normally look like. The genogram was only about three-quarter completed by the time the first interview ended. Eventhough I attempted to follow up during the second interview, Ellie was keen to focus and talk about Elaine’s routine and her live-in maid’s contribution first. Hence, I went with the flow and decided to co-construct the genogram and ecomap alongside each interview. The genogram and ecomap eventually evolved through my engagements with Ellie following a span of several interviews until the final one (see Figures 19 to 21). I had to do some revisions with Elaine’s demise as well. In some ways, I utilized the genogram and ecomap to provide a visual guide in helping me elicit information from Ellie in a systematic and sequential manner, and to clarify the relationship within the family and their support systems.

The intergenerational structure of this nuclear family throughout my interactions with them from January 2016 to July 2016 are illustrated in Figure 21 and coded as follows: CG1 indicates the case study participant (CG1 = Ellie), CG2 indicates the other family caregivers (CG2 = Ginny and Clara) and CR indicates the person with dementia (Elaine).

4.5.4 My Personal Encounters with the Family

The daily intergenerational routine and care organization: Previously, Elaine has been staying with Ellie and Ginny until around 2004 when she moved in with Ellie’s only brother and his family after hospitalization following a fall. The decision was then taken for Elaine to have on-going support at home with Ellie’s sister in-law employing a live-in maid for that purpose. Two years later, Elaine requested to move back to stay with Ellie and Ginny following a fall at Ellie’s brother’s home. Moreover, Elaine was also feeling awkward
staying there as Ellie’s brother and his wife were having frequent quarrels then.

From Ellie’s vague recollection, Elaine was possibly diagnosed with early stage dementia during her hospitalization after her fall at Ellie’s brother’s home. Ellie could not be absolutely certain. In the beginning when Elaine started to have the first signs of dementia, Ellie confessed that it was difficult for her and Ginny to accept what was happening. Both of them were in a form of denial and found it hard to believe that their mother had dementia. At the time, Ellie and Ginny did not have any understanding about dementia and could not understand the change in Elaine’s behaviour from a once “very gentle and quiet person” whose entire life was spent “taking care of the children” (fourth interview with Ellie) to someone “very unreasonable”, as Ellie put it. In the beginning, Elaine’s symptoms were not very obvious. The behavioural changes also included Elaine looking for attention, accusing the live-in maid whom she had previously treated well and being suspicious:

“Initially when they said, they treat my mother for dementia and things, I think my sis and I were like, ”Are you sure she got dementia? Because she is like, cognitively she can still do many, many things and know many things. So, I was like, ”Sure or not she got dementia?” Because initial state she is like quite normal! Just a bit of behavioural problem. So, we couldn't believe that she has dementia. Even my sister says, ”Cannot be! You see, she is so smart. She knows a lot of things!” (fourth interview with Ellie)

And, the two sisters continued to question the accuracy of their mother’s diagnosis whilst acknowledging the observed changes in her behaviour:

“Why is her behaviour like that?” Like, there would be often times she would repeat herself. There will be times where you already explained and then she will do it. And, there will be times where she will say things that we consider not true... she will get very upset when we tell her it's not like that. Then, she will get very, very agitated. And then, we also get very agitated because we feel that she is very stubborn, insisting on something which is her view and it's not so.” (sixth interview with Ellie)

As a result, during the early stages of Elaine’s dementia, there were a lot of conflicts. Ellie’s sister, Ginny, would quarrel and have misunderstandings with Elaine and Ellie would come to Elaine’s defence. The arguments were from Elaine’s so-called irrational behaviour. For example, Elaine would think that there was money under the bed and insisted that Ellie and Ginny must pull up the bed and take out the money. Both sisters had no choice then but to play along reluctantly:
“So, we were like, lift up the bed and let her see. You know? "Where got? Where got?" Then, my sister was like... Then, she will say, somebody took her things! Then, my sister said, "What nonsense are you talking about?" And then, they quarrelled. You know? So, there was a lot of quarrelling. So, it was quite difficult.” (fourth interview with Ellie)

By not having a diagnosis or explanation for what was happening, Ellie and Ginny continued to try to convince Elaine about what they thought was the correct thing to do. On her side, Elaine would often feel very upset that they did not understand her, especially when she was accused of lying (sixth interview with Ellie). Ellie recalled that it was “quite traumatic” for both sides until the diagnosis was made and shared. Subsequently, the sisters started to attend talks on dementia by the Alzheimer’s Disease Association and Khoo Teck Puat Hospital which they found to be beneficial:

“All these talks have been very, very helpful for us. Because, after listening to those talks, both my sister and I have a better understanding of dementia and we begin to know how to ... We begin to understand that actually my mother was not lying.” (sixth interview with Ellie)

Initially, Ginny was very resistant to go to the Alzheimer’s Disease Association or Khoo Teck Puat Hospital to attend these talks. But after persuasion from Ellie, she attended the talks and began to appreciate and understand Elaine’s condition. This improved understanding had brought both mother and daughter closer together as illustrated by this poignant scene:

“She could get very close to my mom, even squeeze herself into the bed. The single bed. The hospital bed. To squeeze herself in, to sleep together with my mom on the bed, day time or night time when my mother is awake. So, to be with her. Then, my mother would, even in her late state, when she does not know anything, she would like pat my sister's face, pull the blanket over my sister. That kind of closeness.” (sixth interview with Ellie)

Moreover, the shared experience by other caregivers from these talks was an eye opener and led to a huge turning point for Ginny (Second interview with Ellie). The revelation totally transformed her, leading to a resolution of past quarrels and misunderstandings with her mother:

“Because she understood and I also reminded that you know mother. You know what kind of person. So, after that, was the turning point. Very drastic change. So, when she understood, she knew it's not my mother being mischievous. It's very real. So, after that things became very good.” (fourth interview with Ellie)
It seemed, the quarrels and misunderstandings were actually a form of emotional stimulation for Elaine though. According to Ellie, they kept her mind occupied. Ever since the cessation of the quarrels and arguments, Elaine’s cognitive state had suffered a deterioration which Ellie described as “stony and unresponsive”:

“Nobody to quarrel with. [Laughs] So, she became like that. Very quiet. Because, no more stimulation. Because frequently when people quarrel with you, you got your emotions. But now, it's nothing. Just like that. So, in a way also, no stimulation already.” (fourth interview with Ellie)

Hence, in 2015, the family stopped sending Elaine to St Luke’s Day Care Centre as they felt that she was not receiving any emotional stimulation by being there. Instead, the family has embarked on a peaceful and quiet routine where the live-in maid would perform the expected activities of daily living for Elaine. The routine also included weekend and ad hoc visits by Ellie’s other sisters, her brother, nephews and nieces. A typical weekend was described as such:

“So, what my niece does is, she will come and have breakfast with us. That's why we go out and eat. Then, after that she takes a cab down to my place. And then, go to church. Because afternoon I go to church. She goes to church in the morning. It is like really rushed for her but they still make effort to come back.” (second interview with Ellie)

During the interview, I could sense that at the end, Ellie had good closure and felt satisfied with the love and care which she and Ginny have provided for Elaine in the years before she passed away. Although it was initially challenging and stressful, the sisters felt privileged and found meaning in taking care of their mother after they began to understand her diagnosis:

“But other than that, there is peace within my heart that we have done the best that we could for our mother. The way she went home, there was no suffering. She did not leave behind huge hospital bills for us to clear. So that was something I think everyone of us felt that my mother didn't suffer. And, she'd gone home at the ripe old age of 86 years old. I think like what my sister said, "What more do we... can we ask for? And, when the time comes, god will carry her in his arms back home. And then, I also pray for timing, good timing and that the Lord would prepare us. So, it was really good because 2nd of May was a public holiday.” (sixth interview with Ellie)

Support from the extended family: Generally, the family felt well supported by their extended family and managed to maintain a close link with their other siblings and their children. According to Ellie, they have maintained this closeness through the social media platform
such as WhatsApp that linked all of them together and for them to respond promptly to family emergencies [NOTE: In the ecomap, this very strong relationship is presented with triple parallel lines with bidirectional arrows, indicative of a positive relationship]:

“So, we all keep in touch. Anything is just a phone call away. Like my mother that time when I felt her body was cold, when I felt her hands were cold, her cheek was cold, I just sent a WhatsApp and say, "I feel po po's limbs and hands are cold. Don't know why." Then, they would quickly WhatsApp, "Get an ambulance or whatever, you know." So, the response time is immediate and when we called the doctor, the whole lot rushed down to my place immediately.” (sixth interview with Ellie)

From what was shared, it was obvious that Ellie’s nephews and nieces maintained a close bond and kinship with the family [NOTE: Through the ecomap, triple parallel lines are used to illustrate the very strong bond between Ellie’s niece, Jane, and the family to visually compliment what Ellie has shared and confirmed]. This has continued even after Elaine’s passing as depicted in this sharing:

“That’s why she would be the one, every Sunday, without fail, come down to see ‘po po’. That’s my mother. And then, she will hug, without fail, hug my mother. She and her husband will come down every Sunday, without fail, to have breakfast with us before they go to church. So, they would also take close tab of Ginny and me to make sure we are ok. Even after my mother has and is no longer with us, she still continues. So, we are still very close. For Ginny and I, as we took care of our mother that time and even now, after my mother has left us, my nephew and nieces are still very close to Ginny and me. And in general, all of them are appreciative of what we have done for my mother.” (sixth interview with Ellie)

Role of the live-in maid: Ellie was appreciative of her live-in maid whom she said has done a good job [NOTE: In fact, Ellie agreed that a triple parallel line should be used to depict this very valuable support in the ecomap. Bidirectional arrows are used to illustrate the reciprocal relationship]. According to Ellie, her live-in maid has made a difference for the family by providing quality care for Elaine. It was not just about taking care of Elaine’s daily needs but also how she was being loved, cared for and treated:

“My, this maid is quite nice. She will hug my mother, talk to my mother and, then, she will put my mother to sleep. Quite good. So, it's the quality of the care. Not just meeting her physical needs. My, this helper is really very... she really loves my mother. You can see taking care of my mother. And then, night time when my mother sleeps, after she brings my mother in, she will hold her, pat her until she sleep. It's like taking care of a baby. She will hold her, her face.. touch, touch, touch. Hold her until she sleeps.” (second and fourth interview with Ellie)

Ellie perceived that it was the good quality of care which had prolonged Elaine’s life. For
instance, she shared how the massaging by her live-in maid has helped in promoting Elaine’s bowel movement. She laughingly elaborated on how she has even gotten the live-in maid involved in preparing a nutritious meal for Elaine:

“I think she is able to survive till today because the helper is very good. Without the care of the helper, she's probably gone already. Because my helper takes very good care of her. Morning, she will shower her, then, she will massage her. She will give her food. She eats a whole bowl of porridge, you know. And the porridge is very tasty. My helper would make. And then, she will put in ... we have probiotics, you know. She also puts in Ensure. Puts in all the things. So, it's like a lot of nutrients here and there.” (fourth interview with Ellie)

4.5.5 Researcher Reflection

*Forming a Genuine Relationship with the Family:* Personally, I felt a little awkward having to interview a colleague from my own workplace. Although Ellie had volunteered on her own accord, I was unsure if she would be comfortable to share about some possibly sensitive or confidential information related to her caregiving experience. I could sense a certain invisible barrier between myself and Ellie from the beginning of my contact with her until the end. It could be my own perception. Nevertheless, I felt the awkwardness. No doubt Ellie had shared that she would like to contribute to this research as she felt what I was doing was a noble cause. I suppose, the rapport and relationship building were affected by the short duration of each interview over a course of only six months. Furthermore, what has set Family 4 apart from the other families was the fact that most of the interviews were conducted away from the caregiving environment. The closeness to the family was simply harder to establish without spending real and meaningful time with them in the home environment where caregiving was taking place.

*As a Researcher:* I only found out that Ellie was working in the same organization as me after enrolling her in my study. Frankly, I have never met nor worked with Ellie before until now. From a research perspective, I would rather have a participant whom I have no workplace affiliation with. But by then, I had only managed to recruit another new family, that is, Family 5 through the Alzheimer’s Disease Association, who was able to fulfil the recruitment criteria. The timeline for data collection was simply too short if I were to recruit another family to meet my required number of families for this study. Therefore, I made the informed decision after discussion with my supervisors to proceed with Family 4.

From the beginning, I had made it a point to brief Ellie and assured her on the maintenance of confidentiality on my part. I was taken aback and caught by surprise when a senior
colleague in my department casually informed me that she knew of Ellie’s involvement in this study. My colleague made another mention again after Ellie’s mother passed away and asked me if that would affect the study. My guess was, Ellie and this colleague must have been sharing information as both of their mothers were living with dementia. Besides, Ellie and my colleague were about the same age and, I found out later, knew each other for many years. I recalled Ellie mentioning to me about my colleagues’ mother before. I had to feign ignorance. On my part, I continued to maintain confidentiality but felt that the incidents put me in a compromising position. Another example of Ellie making her participation in this research known to others was during the last interview where she brought another colleague along when bringing me to her house for lunch cum interview. She was telling the other colleague about her participation in my research on our drive to her home.

Ellie was always rushing through the face-to-face interviews. She could only meet me during her week-day lunch time where the interviews were conducted at the workplace eateries or garden. I informed her that I could interview her after work or during the weekends so that it was not so rushed for her. Somehow, she did not take up the offer. I also did not wish to impose on her private and personal time. I felt that the rushed nature of the interview distracted her a fair bit. She would keep looking at her watch and ask me what I would like to ask next. In combination, it affected the smooth closure of each interview session.

Some of the chosen interview venues were not conducive which impacted on the quality of the audio recording. For example, the noises from the ceiling fan at the pergola in the garden area and the noisy occupants at the ‘Food Central’ eatery (see Table 10) had dulled out the audio recordings. I only found out later when replaying the voice recording for my transcription work. My conclusion was open areas tended to produce poorer quality audio recordings. Also, for the open areas without air-conditioning, the temperature was at least 34 degree Celsius and the humidity was high. It affected the concentration of the interviewer and participant.

I found it difficult to extract and sequence data pertaining to time-line for Family 4. Ellie was one of those participants who had difficulty recalling information pertaining to timeline and sequence. I had to patiently ask her repeated questions and over a few interviews just to get it right. For example, in one particular instance, this was what she said when I asked her about when Elaine was first diagnosed with dementia: “I can't remember! But I remembered that it could be the polyclinic, it could be when she was hospitalized.” (fourth
4.5.6 Intergenerational Issues

Sibling conflict: Similar to the other families, Family 4 was also mired with some family conflicts. In the earlier days when Elaine was at the moderate stage of her dementia in which her behaviour was “very difficult” (second interview with Ellie) to manage, one of Ellie’s twin sisters (Emma) had accused Ellie and Ginny of not knowing how to care for Elaine. Although Ellie claimed that she was not angry or upset with this sister, she sounded slightly annoyed as she shared about a particular incident:

“You all don't know how to take care. This and that. Then, she can go all the way to Cambodia and take care of the elderly. At home don't take care [Laughing]. Then, she said she brings my mother back with the maid. Within a few days, the maid wants to come home. She also cannot "tahan" [Malay word for tolerate] my mother. Said, “So dirty!” The B.O. (bowel open). My mother during moderate stage, very difficult to handle. She had constipation.” (second interview with Ellie)

To make matters worse, that same twin sister (Emma) had made some negative comments as well. From what I have gathered during the interview, it seemed like a defence mechanism on Emma’s part. This was also confirmed by Ellie. Again, I asked Ellie whether she felt angry or disappointed with her sister. She vehemently denied and affirmed by disclosing the following information which contradicted her denial of her disappointment:

“Sometimes we say, you see, mother very good right?” She will say, .... Should actually be gone earlier" [in Cantonese]. And she doesn't like it. It's like two of us are taking care of my mother. Not like it’s because she care for us but because she feels that she is obligated. It's like forever she didn't do her part. Maybe she feels guilty or whatever. Whereas if my mother is not around, no more guilt. They can contribute other things. They can go tour. They can do all kinds of things but they never contribute a single cent to their mother. Then, I was thinking, I don't want to go and bother. I don't want to care. To me, if I have enough, buy for my mother. Very happy to buy for my mother.” (fourth interview with Ellie)

Nevertheless, I noticed a tinge of hopefulness when Ellie was talking about her other siblings in relation to contributing towards Elaine’s care. When Ellie declared that she has never asked nor demanded for any of her siblings to contribute, it gave me the impression that she expected them to make an effort to do so at the very least. Somehow, it also became clearer that she seemed less empathetic towards her other twin sister (Emma) for not contributing:

“The other twin sister - hubby and her are working. 2 sons working but she has never said that she wanted to contribute. And, she has worked with the Alzheimer’s
Association. She has gotten all the knowledge that is needed. To me, if you want to provide, good. If you don't want, doesn't matter. Maybe she thinks that if she gives my mother, it's giving to us. To me, I am not going to bother. I'm not going to get angry or what. But I wouldn't say that she is not nice. So, I don't know. Nowadays, she does make an effort to come on Saturday. But she comes on Saturday to play with us, Rummy All and my younger sis, Ginny.” (fourth interview with Ellie)

4.5.7 Case Summary

Family 4 comprised Ellie (eldest daughter), Ginny (second daughter), Clara (granddaughter) and Elaine (person with dementia). Clara was Ellie’s only brother’s daughter. The family relied heavily on their live-in foreign domestic worker (maid) for Elaine’s activities of daily living. They were a mainly English and Cantonese speaking family with Christianity as the focal religion. This middle income family resided in a five-room HDB high-rise apartment. Elaine has late-stage Parkinson’s disease dementia and was diagnosed with moderate stage dementia around 2007 to 2008. She was already wheelchair bound and totally dependent during my contact with the family. Elaine has four other children, either married or divorced, with families of their own - a third daughter, fourth daughter (Twin 1), fifth daughter (Twin 2) and a youngest son. The family received information, support and health services from their family physician, a local palliative care team and the local Alzheimer’s Disease Association. This combination of support helped to manage Elaine’s dementia and her other medical conditions. Elaine passed away peacefully in her sleep at home on the 3rd May 2016 but the family wanted to continue with the study and contribute their lived experience of intergenerational family care.

Similar to the other families, Family 4 also experienced some deep family conflicts. In the earlier days, when Elaine was at the moderate stage of her dementia in which her behaviour was “very difficult” (second interview with Ellie) to manage, one of Ellie’s twin sisters (Emma) had accused Ellie and Ginny of not knowing how to care for Elaine. Although Ellie claimed that she was not angry or upset with this sister, she sounded slightly annoyed in sharing the story. To make matters worse, that same twin sister (Emma) had made some negative comments as well. Nevertheless, Ellie had denied feeling angry or disappointed with her sister. I also noticed a tinge of hopefulness when Ellie was talking about her other siblings in relation to contributing towards Elaine’s care.

On my last interview on the 20th July 2016, I informed Ellie that I have completed all my interviews with her and would be busy with the transcription, analysis and write-up. I also made it a point to inform her that I might need to call on her again if I needed to verify certain
parts of the data. My monthly interactions with this family for a period of about six months had presented a consistent picture of an intergenerational family where the care of the person with dementia had evolved into a peaceful routine with the nieces and nephews providing their aunties - who were the main caregivers - with reliable support after the diagnosis was given. The learning point from Family 4 highlights that a lack of understanding about dementia and what this means may impact relational dynamics and how intergenerational members connect with one another and provide timely support for their family member with dementia.
Figure 19: Version 1 of Genogram of Family 4 (co-constructed with Ellie on 25th January 2016)
Figure 20: Version 1 of Ecomap of Family 4 (co-constructed with Ellie on 26th February 2016)
Figure 21: Final Genogram and ecomap of Family 4 (co-constructed with Ellie from January 2016 to July 2016)
4.6 Intergenerational Family 5 – Main Family Storyline: Care in Transit

4.6.1 Introduction

Similar to Family 4, Family 5 was recruited only in 2016 after two earlier families who were recruited in 2015 withdrew and were unable to continue with the study. Hence, the expected longitudinal nature of the research with Family 5 was set at a maximum of six months in order to fit in with the data collection period for the PhD study. Family 5 represents an intergenerational family, Mindy, Max, Sandy, Shaun and Margaret, comprising three generations, staying ‘under one roof’ with the youngest daughter, son-in-law, granddaughter and grandson contributing to the care of a person with dementia in various capacities. Family 5 also illustrates the changes in living and care arrangement which the person with dementia underwent, that is, transiting from three to two different households, and, eventually, to just one household.

4.6.2 Family 5 – Mindy, Max, Sandy, Shaun and Margaret

Overview of Family 5: Family 5 comprised Mindy (youngest daughter, 59 years old), Max (son-in-law, 58 years old), Sandy (granddaughter, 25 years old), Shaun (grandson, 23 years old) and Margaret (person with dementia, 90 years old) at the point of first contact in February 2016. They were a mainly English and dialect (Cantonese) speaking family with Buddhism as the focal religion. This middle income family resided in an executive HDB apartment in the north-eastern part of Singapore. Photographs 22 and 23 of the outside and inside of their home were taken when I visited them from February to July 2016. The family has lived here for fifteen years. Margaret, widowed when she was 38 years old, had a diagnosis of moderate stage Parkinson’s disease dementia; this diagnosis was shared in 2014. Margaret has four other children, all married with families of their own – an eldest son (71 years old), an eldest daughter (69 years old), second son (65 years old) and a youngest son (61 years old). Margaret used to alternate her living and care arrangement amongst three of her children and their families, that is, her eldest daughter (for three days from Tuesday to Friday), second son (for two days from Friday to Sunday) and Mindy (for two days from Sunday to Tuesday) for the past 30 to 40 years. However, this living and care arrangement reduced to just two families, that is, Mindy and her eldest sister from October 2014 to October 2015 after Margaret was diagnosed with moderate stage Parkinson’s disease dementia. Eventually, this dual living and care arrangement reduced to just one family from October 2015 onwards, upon Mindy’s insistence. Mindy and her eldest sister had a falling out following this. Mindy ended up solely taking care of Margaret thereafter. Family 5 received information, support and health services from the Singapore General Hospital and
the local Alzheimer’s Disease Association for managing Barbara’s dementia and her other medical conditions.

Photograph 22: HDB apartment block which Family 5 resided in (taken by the researcher on the 17th March 2016)

Overview of my encounters with Family 5: A total of six face-to-face interviews were conducted in their home from February 2016 to July 2016, lasting about two to three hours each in duration. The interviews included the completion of a 23-item structured questionnaire, co-construction of the genogram and ecomap with Mindy and Shaun, drawings, audio recordings and digital photographs of the home environment and items. Mindy also contributed digital photographs of Barbara and herself undertaking activities together. A summary of research contacts with Family 5 is presented in Table 11.
### Table 11: Research contacts with all members of Family 5

<table>
<thead>
<tr>
<th>Contact</th>
<th>Day and Date</th>
<th>Nature of Contact</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Thursday, 18&lt;sup&gt;th&lt;/sup&gt; February 2016</td>
<td>Mindy was recruited on 15&lt;sup&gt;th&lt;/sup&gt; January 2016 through the Alzheimer’s Disease Association after I emailed them to request for help to recruit new participants. In-depth interview with Mindy in English. Face-to-face personal introduction and project explanation, informed consent taking, completion of questionnaire. Narrative account - no audio recording yet. Field notes. Next interview was arranged.</td>
<td>1000 to 1200 hours (2 hours = 120 minutes)</td>
</tr>
<tr>
<td>2</td>
<td>Thursday, 17&lt;sup&gt;th&lt;/sup&gt; March 2016</td>
<td>Confirmed via Short Message Service (SMS) on Wednesday, 16&lt;sup&gt;th&lt;/sup&gt; March 2016. Co-constructed the family genogram; Took digital photographs of reports, external environment and pill box. Field notes. Arranged for the next interview to be on the 21&lt;sup&gt;st&lt;/sup&gt; April 2016 at 1000 hour.</td>
<td>1000 to 1200 hours (2 hours = 120 minutes)</td>
</tr>
<tr>
<td>3</td>
<td>Thursday, 28&lt;sup&gt;th&lt;/sup&gt; April 2016</td>
<td>Wednesday 27&lt;sup&gt;th&lt;/sup&gt; April 2016, Mindy texted to cancel our interview session. Changed to the 28&lt;sup&gt;th&lt;/sup&gt; April 2016 at 1000 hour instead. In-depth interview with Mindy. Co-constructed the ecomap. Field notes.</td>
<td>1545 to 1829 hours (2 hours 44 minutes = 164 minutes)</td>
</tr>
<tr>
<td>4</td>
<td>Thursday, 26&lt;sup&gt;th&lt;/sup&gt; May 2016</td>
<td>In-depth interview. Audio recording with Mindy from 1105 to 1235 hour – 1 hour 28 minutes. Field notes. Interruptions from neighbour’s live-in maid. Engaged with Margaret to do exercises, play mah-jong and share her old recipe while awaiting Mindy.</td>
<td>1010 to 1249 hours (2 hours 39 minutes = 159 minutes)</td>
</tr>
<tr>
<td>5</td>
<td>Wednesday, 15&lt;sup&gt;th&lt;/sup&gt; June 2016</td>
<td>In-depth interview with Mindy and Shaun today. Introduced myself to Shaun and went through the PIS with him. Explained the details of the study and the nature of his involvement. Took consent. He completed the questionnaire. Confirmed the genogram and co-constructed the eco map. Audio recording of Shaun from 1054 to 1220 hour – 1 hour 7 minutes 22 seconds. Audio recording of Mindy from 1235 to 1324 hour – 48 minutes 51 seconds. Field notes.</td>
<td>1009 to 1324 hours (3 hours 15 minutes = 195 minutes)</td>
</tr>
<tr>
<td>6</td>
<td>Thursday, 21&lt;sup&gt;st&lt;/sup&gt; July 2016</td>
<td>In-depth interview. Audio recording with Mindy from 1130 to 1308 hour - 1 hour 38 minutes 22 seconds. Field notes.</td>
<td>1015 to 1318 hours (3 hours 3 minutes = 183 minutes)</td>
</tr>
</tbody>
</table>

**TOTAL**                                                                                                                                      | 941 minutes (15 hours 41 minutes) |

*My rapport with Family 5: Interview schedules were arranged and confirmed with Mindy during the interviews and through Short Message Service (SMS). The interviews were*
mainly conducted with Mindy and Shaun in English at the dining area adjacent to the living room with Photograph 24 representing the usual seating arrangement. Margaret’s seat is represented by the seat cushion with stripes. There were times when Margaret would come and sit with us. Mindful of the customary and common practices, I would usually remove my shoes before entering the home and bring along small token gifts, example apples, chamomile tea and such. Reciprocally, Mindy would prepare cold drinks with fresh fruits or cakes when I visited. Mindy was a thoughtful and hospitable host. For example, during my fourth interview, she had prepared a cup of cold water with ice as per my usual request but on noticing that I was having a slight cold, she insisted on warm water for me, saying that it was better for me. She provided a box of tissue too. At times, I was even invited to stay for lunch which I had to decline politely, citing work commitments.

Photograph 24: Seating arrangement for interviews at the dining area of Family 5 (taken by the researcher on the 15th June 2015)

4.6.3 Co-construction and Evolution of the Family Genogram and Ecomap
The family genogram and ecomap took about six months to complete, that is, from February 2016 to July 2016 to co-construct and evolve. For this family, I began with the construction of the genogram and ecomap as based on my face-to-face interviews with Mindy and Shaun. In total, it took about two to three rounds of validation.

When I first interviewed Mindy face-to-face on 18th February 2016, I informed her that I would be constructing a genogram and ecomap of the family with her. Using the interview guide, I showed her how this would normally look like. It was only during the second and third interviews with Mindy that I managed to begin the co-construction of the genogram
and ecomap (see Figures 22 and 23) respectively. I had to do these in phases and patiently collect the pertinent information for the construction of the genogram and ecomap up until the last interview. The reason for this was that Mindy was always eager to share about her conflicts with her siblings. Thus, I felt that it was important for her to do so. On the other hand, Shaun was very focused on what was required. I showed him the genogram which I had done with Mindy and sought his verification and agreement. Thereafter, co-constructing the ecomap (see Figure 24) with him was a straightforward process. During our last interview together in July 2016, I showed Mindy the final genogram and ecomap (see Figure 25) to seek her verification and representativeness of the diagramming. The diagramming over our time together also helped me to connect with Mindy and Shaun and clarify the relationship within the family and their multiple support systems. Plotting the ecomap and genogram took a number of visits and demanded patient, and careful, listening.

On Figure 25, the following codes are used: CG1 and CG2 indicate the case study participants (CG1 = Mindy, CG2 = Shaun), other family caregivers (CG3 = Max and Sandy) and CR indicates the person with dementia (Margaret).

4.6.4 My Personal Encounters with the Family

The daily intergenerational routine and care organization: According to Mindy, Margaret has been taking turns to stay with her and two of her other four siblings for the past 30 to 40 years. This arrangement was not ideal when Margaret started with the onset of her dementia. The frequent changes in living and care arrangement aggravated and worsened her confusion. This was attested by Margaret’s frequent complaints in Cantonese, “I am very confused!” [as shared by Mindy]. She seemed to have forgotten many of her familiar recipes and kept cooking the same herbal soup for Mindy’s second brother and his family. So much so, Mindy's sister-in-law refused to let her cook after that and gradually stopped Margaret from entering the kitchen. Margaret was also complaining of being “very confused” when she was staying with Mindy’s eldest sister. She would start taking more of the medication for "anxiety" [labelled anxious in Photograph 25] which Mindy had labelled on the ‘pill box’ (see Photograph 25). Mindy shared that she purposely labelled the ‘pill box’ in order to monitor Margaret’s frequent states of confusion.

Mindy showed me how she has intuitively relabelled the ‘pill box’ (see Photograph 25) to guide Margaret on how to take her medication correctly, something which she has learnt from the Senior Citizen and Dementia Course in 2013. For example, when taking ‘eldest
brother’ which is Synflex, Margaret must also take ‘youngest brother’ which is for gastric protection. Thus far, using this type of analogy, Margaret has been compliant and Mindy has continued using this method to the present day.

Photograph 25: Relabelled ‘pill box’ in Chinese characters using analogy

Typically, Mindy’s suspicion of Margaret having dementia arose after she took a Senior Citizen and Dementia Course in 2013. Since March 2013, Mindy had started working as an elder sitter for the Alzheimer’s Disease Association every Tuesday and Friday from 1400 to 1600 hours. In October 2014, after doing volunteer elder-sit work at the Alzheimer’s Disease Association, she became even more aware and certain that Margaret has dementia. Thereafter, she tried to convince her second brother and eldest sister about this, but they refused to acknowledge that Margaret had dementia. Mindy's eldest sister even called her a “busy body”, “trouble maker” and “anal retentive/uptight” [as shared by Mindy]. Through her affiliation with the Alzheimer’s Disease Association, Mindy, on her own accord, brought Margaret to Tan Tock Seng Hospital for memory tests. Since then, Margaret was formally diagnosed with moderate stage dementia in 2014. Mindy decided to let Margaret follow up with the Singapore General Hospital for her dementia. She explained that her nephew was a doctor there and she thought that he would be able to facilitate her management. Besides, Margaret’s doctors who were following up on her other medical problems were also located there. However, things did not turn out the way Mindy expected. Her second brother and eldest sister rebutted her as they regarded Margaret’s dementia as an acceptable part of old age. The following was what Mindy surmised:

“I think they all said, ‘Aiyah, dementia! Forget things. No problems. She's so old already’. But it's not. It's her behaviour, her ADL. It's very difficult to take care. I
tried to explain to them. They still think, forgetful...ok. She's so old already. But they still... I am a bit disappointed. I tried to explain. But I think, no use. They still turned the other way and told me, "Don't tell people what to do." (fourth interview with Mindy)

Between October 2014 to October 2015, Mindy’s second brother and eldest sister finally relented to reduce Margaret’s living and care arrangement from three different households for the past 30 to 40 years to just two households. The intent was to lessen Margaret’s confusion as evidenced by what Mindy has observed: “So, for the last 2 years, she was confused as in, when she comes to my place, I realized that, she always get mixed up with her tooth brush” (fourth interview with Mindy).

Meanwhile, since the time of Margaret’s diagnosis, Mindy even attempted to persuade her second brother and eldest sister to attend the caregivers’ session at the Alzheimer’s Disease Association in order to promote a better understanding of Margaret’s dementia. She was hoping that they would eventually agree to Margaret staying at one place only. Her second brother attended a few sessions but her eldest sister refused to go for any. Mindy also consulted the occupational therapist at the Alzheimer’s Disease Association and was advised to try and let Margaret stay at one place. However, when Mindy mooted the idea to her second brother and eldest sister again, they were adamant and disagreeable with her: “Doesn't work. They always use the word, "She has been here 30 years, go round. So, cannot be. Either my sister's place or my place but my sister told me she cannot take seven days. Only three days” (fourth interview with Mindy).

Mindy even went to the extent of arranging for family conferences to discuss and sought things out. However, she shared that she ended up facing challenges from her second brother, eldest sister and even, Margaret herself:

“After that, we have meetings and meetings. A lot of problem and things like, you don't get a helper, I can't look after. I tried day care. I tried rehab. Everything. She doesn't want to go. I went with her, she only want me to accompany.” (fourth interview with Mindy)

Eventually, seeing Margaret’s unimproved state, Mindy decided to take Margaret completely under her roof. This was also in view of Margaret’s constant complaints about the restrictions imposed on her when she was staying at Mindy’s eldest sister’s place. Thus, since October 2015, Mindy decided for Margaret to stay with her instead of shuffling between hers and her eldest sister’s place. Unfortunately, this arrangement was made while
Mindy’s eldest sister was away on a month-long vacation and without her consultation. Mindy’s perceived good intention ended up with an unfavourable outcome. The previously close kinship between the two sisters became strained – Mindy’s eldest sister has stopped talking to her since October 2015 because she deemed Mindy as being “too interfering” and “stealing her mother” from her: “Last year. [Laughs]. I thought I just take her. See how? When my sister comes back, we can have sibling meeting and see how. Unfortunately, a lot of misunderstanding and miscommunication” (fourth interview with Mindy).

Shaun has clarified that the reason for the miscommunication between his mother (Mindy) and his eldest aunt (Mindy’s eldest sister) arose when the four siblings discussed and decided on Margaret staying at Mindy’s place without telling and consulting his eldest aunt (Mindy’s eldest sister). To him, it was just a miscommunication amongst the siblings. Shaun felt strongly that in order to unravel the misunderstanding, only the five blood-related siblings should come together to have a heart-to-heart meeting to sort this out.

The siblings’ squabbles and strained relationship over the care of Margaret have obviously affected Margaret. As shared by Mindy, periodically, Margaret has expressed her own obvious disappointment about how reluctant her five children were in having her in their homes and caring for her. This was one of the primary reasons why Mindy decided to take action. To Mindy, it was simply too heart-wrenching and her only action was to take Margaret in:

“I, one person, can look after five of you. And, why five of you can't even take me? She even asked my husband’s permission. "Max, can I stay with you?" So, my husband said, "Why don't we take her back?" So, that's why we just take her seven days." (fourth interview with Mindy)

According to Mindy, another thing which saddened Margaret was that all this while she has always favoured Mindy’s eldest sister who has promised to take care of Margaret until the end. When things did not turn out as expected, Margaret simply could not accept it and ended up even more confused as shared by Mindy:

“And now, suddenly she can't go. So, that is her thing. In fact when she is here, I have a hard time. First three months. She still thinks that. Then, she asked me. Questioned and questioned, "Why can’t I go back?" (fourth interview with Mindy)

While in her care, amongst other things, Mindy has tried to encourage and promote Margaret’s independence and self-worth by letting her have time alone. Initially, the family
was quite worried that she might not be able to cope or might even suffer a fall. Mindy first started off with just half an hour by going downstairs to run some errands whilst leaving Margaret alone. After doing so, she found that Margaret was able to cope. Also, whilst Mindy continued with her elder-sitter work at the Alzheimer’s Disease Association, her eldest brother and sister-in-law dropped by to look after Margaret every Tuesday and Friday from 1300 to 1500 hours while awaiting the Alzheimer’s Disease Association’s elder sitter to come in from 1500 to 1700 hours to do activities with Margaret:

“So, from half an hour, one hour, now I increase to two hours. Ok. Then, I come back I praise her, "Wah, you are so good, you see. Eldest sister said you are not independent. That's why must get the maid to look after you. "Yes, I don't need. You go off. Three to four hours also can [Laughing]. So far, only try two hours. And she feels very... She felt, “I’m not afraid.” Very good. I think, this thing, it really works for her. She feels proud of herself. "I'm still useful." (fourth interview with Mindy)

Mindy’s eldest and youngest brothers and their wives have chipped in to help. In addition to looking after Margaret when Mindy was doing her scheduled elder-sitter work, they have made it a point to go out with her and Margaret for regular lunches and, then, sometimes to the supermarket for Margaret to engage in grocery shopping activities like picking apples. In spite of the few hours of help from them both, the past 10 months of caring for Margaret on a full-time basis has taken its toll on Mindy. Shaun has candidly described the impact of caregiving on Mindy as such:

“She’s aged a lot. Physically. My mom. And, my grandma is my mom's life, you know. My mom is just taking care of her. My mom has nothing else but take care of my grandma. She lost her life [Laughs] which is kind of very sad.”(first interview with Shaun) [NOTE: To compliment the narrative and add credit to the analysis of this case, the ecomap was employed to present the sacrifices which Mindy has made through the use of a bubble with dotted border. Dotted border implies a past situation, that is, Mindy having to give up her previously carefree life such as indulging in frequent high teas and buffet with her close friend].

Therefore, from late June to early July 2016, Mindy, after encouragement and support, admitted Margaret temporarily in a nursing home for about 12 days. She cited that she was feeling ‘burnt out’ and needed to fly to Hong Kong to attend her daughter’s graduation with Shaun and have some time for herself. Prior to that, she has requested for her second brother and eldest sister to look after Margaret for the 12 days while she was away. It was a strategy to get them involved in Margaret’s care. They refused. Hence, Mindy had no choice but to admit Margaret temporarily to the Orange Valley Nursing Home in the eastern part of Singapore. The location was chosen because of its proximity to her second brother’s home.
Initially, Margaret was reluctant to go but relented when Mindy promised that she would continue to look after Margaret after she returned from her much needed break:

“I still explain to her, "You know, I have to have a break." Otherwise, I said, "I will burn out." She understands me. She's very good. She still asked me to, "You go and enjoy yourself but you get all my other four children to come back and see me."” (sixth interview with Mindy)

After her Hong Kong trip, Mindy said that Margaret was very angry having to stay in a nursing home. Reportedly, this was what she angrily told Mindy: “Next time, you don't bring me to the old folks' home, huh! I don't want to go!” (sixth interview with Mindy). Mindy even raised her intonation to emphasise how angry Margaret had sounded. Although Mindy felt refreshed from her trip, I could sense she was regretful at the same time. As predicted, Margaret was slightly confused and disorientated upon her return from the nursing home. Mindy has actually sworn that this would be her last trip overseas for as long as Margaret was alive. Though she laughingly shared this, I could sense how burdened and guilty she felt.

In Family 5’s case, I merged the genogram with the ecomap in order to provide readers with a visual of the conflictual and estranged relationship the family has with Mindy’s second brother and sister as depicted by the irregular line and hash marks drawn through the line for both diagrams.

*Engagement with Person-Centred Activities:* Mindy shared that her second brother and eldest sister have spoilt and pampered Margaret for the past 30 to 40 years by chauffeuring her around and getting their live-in maids to do all the housework for her, so much so, she has become totally dependent and lacking in confidence. Therefore, ever since Margaret came to stay with her, Mindy has been promoting her mother’s independence and self-worth by engaging her in performing manageable and familiar tasks, such as getting her to wipe the dining table after a meal as how she would have done at the coffee shop which she used to operate during her younger days. The daughter and mother team also did meaningful chores together such as washing dishes: “Now I realized that every time, four or five bowls only. And, she can do it. Very clean!” (fourth interview with Mindy).

When Margaret was anxious or in pain, Mindy would calm her down by praying with her, asking her to chant and telling her stories through Buddhism, the religion which was familiar to her. Mindy has only just started this new tactic since July 2016. Mindy believed this tactic
has worked for now as Margaret has become calmer and has lesser complaints. She has noticed Margaret listening to Buddhist chants. Mindy mentioned that her husband (Max) was a staunch Buddhist. Hence, a room in their house has been purposely set up to house many statues of Buddha and function as a prayer room (see Photograph 26). Margaret would go inside the room and pray and chant accordingly [NOTE: This recent activity has been included in the updated ecomap in which Mindy has confirmed that the use of Buddhist folklore and chants were a strong influence in the care support; thus, she has attributed a double parallel line to this]:

“Oh, at first she burnt the incense stick and one day, don't know two times, three times, forgotten already. So, now I try. I told her, "No need to burn". Now morning and burn. Whenever you feel free, you just pray, pray. So, now she goes in, I think more than eight times, sometimes, ten times, go in to pray.” (fourth interview with Mindy)

Mindy has creatively woven as many interesting and make-up stories as she could through the limited tales and fables which she has heard about Buddhism. With these, she has successfully convinced Margaret about becoming an “angel in heaven” if she behaved and chanted her name out loud to the angels so that they could hear her. This act has managed to distract Margaret from feeling and expressing her pain. Mindy was laughing and giggling as she shared this little “game of distraction” which she has temporarily employed:

“[Laughing]. Then, I said, here, you cannot take care of yourself. You go to heaven, you must save people. So, you must be very good. No need to eat anything. Save people. You have to save. You are an angel already. Then, after that, I realized, she tried her best. Even pain, also withstand. Point, now 3 point pain, she eats medicine. So, I have to try and try and try. Make up this story.” (fourth interview with Mindy)

Mindy has continued to engage and involve Margaret in as many simple activities to make her feel useful and more independent such as preparing her medication with her (see Photograph 27). Previously, Margaret used to play Black Jack with her many grandchildren and was very good at it too.

Lately, Shaun has become busy with his three months course-related internship, part-time work and university studies which left him with very little opportunity to wheel Margaret down to the park downstairs once every two days like he used to. Mindy thought of another creative way to engage her instead. She started bringing Margaret to the bus stop. This was where Margaret used to walk Shaun to when he was in secondary school. Here, Mindy engaged Margaret to count the number of buses coming and going from the bus stop. A very
satisfied Mindy shared that the new activity actually lasted a good fifteen to twenty minutes:

“Now, you have to think of some way to care for ‘po po’ [maternal grandmother]. Now I’m working. I cannot help you. Actually, my son helped me a lot! After he went to work, I realized. Wah! Short-handed! Because, first thing, he brought her down to the park, helped a lot already.” (fourth interview with Mindy)

Photograph 26: Statues and artefacts of Buddha in the prayer room which Margaret offered prayers to (taken by the researcher on the 15th June 2016)

Photograph 27: Margaret and Mindy preparing Margaret’s medication in the ‘pill boxes’ (sent by Mindy via WhatsApp to the researcher on 17th August 2017)
By the later interviews, Mindy and Margaret were quite used to me. For instance, during one of my visits, Mindy was interrupted by her neighbour’s live-in maid. Hence, for the past more than an hour, she left me to engage with Margaret. I acknowledge that the situation I was put in conflicted with ethics permission but I could not avoid discussion with Margaret as she was part of the family [NOTE: This part would be discussed later on in the thesis].

Margaret came out of her bedroom shortly after my arrival. She walked over to the dining area and sat on her padded chair next to Mindy and myself. Apparently, she had asked Mindy if she could ask me questions and Mindy had told her she could ask me any medical-related questions and I would be able to answer them. While Mindy was busy attending to the live-in maid next door, I chit-chatted with Margaret and asked her what she normally did. She showed me the exercises she did and how these were done. She did this exercise once or twice daily, it seemed. I asked her what other exercises she normally did. She told me she normally walked from the gate to the end of the hallway. Again, she started showing me by walking back and forth. Mindy and I gestured to each other as I engaged Margaret to carry out the exercises. Margaret was pleased when praised.

After a while, Margaret went back to the dining area to sit down. She told me she used to run a coffee shop – wiping tables, making coffee. I took the opportunity to ask her to describe the details of what she did then. Margaret used to help her father make deep fried Chinese fritters called ‘Ham Chin Peng’ and ‘Yau Char Kwai’. I asked her how to make them. She described the ingredients but could not provide the exact composition or portion.

Finally, she pointed to her ‘Mahjong’ (NOTE: tiled-based, solitaire game which originated from China) case. I asked her if she could show me how to play. Patiently, she started teaching me how to play the game when I told her I did not know how. She taught me how to match the pattern and sequence them according to a two or three tiles game. Mindy said that she was surprised that Margaret was exceptionally talkative today and could be engaged for so long! She looked quite relieved and pleased that there was someone to engage Margaret while she was busy.

Role of the grandchildren in caregiving: Mindy shared that Margaret preferred Shaun to bring her for walks at the garden downstairs. Whenever Mindy offered to wheel her down, Margaret refused. Mindy rationalized that, "Maybe because she doesn't want to trouble me." (first interview with Mindy). Nevertheless, Mindy appreciated that Shaun was able to help her out by wheeling Margaret to the park downstairs to enjoy the amenities:
Shaun empathised with Mindy and felt that taking care of Margaret on a full-time basis has “affected her life and put a lot of strain on her”. Therefore, he saw the need to try and ‘relieve her burden’. For example, Shaun would wheel Margaret down and push her around for about forty-five minutes at the very most and make small talks about the weather with Margaret: “My Cantonese is not very good. So, really. Then, bring her down. Exercise machine. Just give her something to do. If not, she will just sit down here” (first interview with Shaun). On days when Mindy had to attend to other errands or her work at the Alzheimer’s Disease Association, Shaun would help out by staying at home, attending to Margaret and keeping an eye on her. However, he confessed that he was not really able to engage her in activities:

“I could sense that for Shaun, it was the bond he has with Margaret and a reciprocal act on his part. He mentioned that Margaret has cared for him when he was younger. Therefore, he felt that it was his duty to care for her in return. Shaun went on to share about Margaret’s frequent nightmares and what he usually did to manage the situation. He showed me a short video clip of him and Mindy pacifying Margaret in her room when she was having one of those nightmares and was sleep talking. In the video, Margaret could be heard asking where she was. In her confused state, she was telling Mindy that she was leaving their place to return home the next day:

“So, I'll try to wake her up. Things like that. That's easy. That's the easy part. And, sometimes, she will wake up in the middle of the night and say that she is hungry. Things like that. And, I'll make milo for her. Give her biscuits. That's simple too. Well, she will just say.. She keeps saying, she cannot fall asleep. So, sometimes I'd just sit next to her bed. Pat her. I don't know. I'm not very good at this. I pat her. Then, I tell her to count. I count 100. Something like that. So, ya. That's it. I mean she's my grandma, right? So, she's a member of the family. I can't just like let her be like this.” (first interview with Shaun)
Shaun was obviously angry and felt aggrieved with his uncles and aunties for not doing more, other than simply just bringing Margaret out for a few hours only. He expressed that it was ‘unfair’ and did not make sense that the caregiving responsibility was shouldered by Mindy alone:

“Not very fair. She's the youngest. Doesn't make sense. They're like retirees. They travel a lot like every month! And they don't go to like, Malaysia, this kind. They go to like really faraway places and they enjoy a hell of a time which doesn't make any sense. Like I said again, it's not very fair. Why is my mom doing this?” (first interview with Shaun)

Therefore, in his own way of contributing more to the caregiving and easing Mindy’s ‘burden’ as he called it, Shaun also created another outlet for Mindy, a WordPress blog site. Mindy has confessed to me that the blog site was very useful to her and she appreciated Shaun’s effort in doing so [NOTE: I used the ecomap to capture the essence of this with Mindy agreeing that it should be accorded triple parallel lines to indicate its relative importance and usefulness]. He was acutely aware of the amount of stress that Mindy was experiencing. Shaun shared that he did not have time to talk to Mindy and for her to share her frustrations with him. The blog site was meant as a platform, or channel, for Mindy to write about her feelings, ‘ventilate her frustrations' and ‘de-stress’:

“I need to be working. For crazy ass job! Internship. So, I'm very, very busy. I know she has this blog. Instead of telling me, she can tell somebody on the internet. I don't expect her to tell the whole world.” (first interview with Shaun)

Although Mindy’s daughter (Sandy) worked and studied in Hong Kong, she still maintained close contact with the family, especially with Margaret. However, the family has noticed a decline in Margaret’s pattern of communication with her. Previously, Sandy could easily communicate with Margaret through the various web-chatting platforms whenever she dialled in every day but now Margaret could not hold a conversation for long and Sandy has found it difficult to engage her grandmother. According to Mindy, they used to be able to talk about her daughter’s work and study and Margaret’s activities but now, Margaret has forgotten “a lot of things” and has found it difficult to hold a conversation. “She told me she forget a lot of things. I don't know how to talk”, Mindy said and, hence, her difficulty over the web-chatting platform:

“Either Skype or face time, huh. Now, because she.... Her behaviour is also very strange, weird. She told my daughter in Cantonese, Nothing to talk about. Don't want to talk. So, my daughter try to call two days or three days once. Last time when she
can yak... yak... yak. over the phone, chit chat, my daughter calls her every day, that she can talk. Now, lately, my daughter also sensed that she doesn't talk much. After a while, she will say in Cantonese, Nothing to talk about. Very blunt!” (sixth interview with Mindy)

In July 2016, Sandy came back from Hong Kong for a short holiday. Sandy spent time with Margaret and wheeled her to the park then. The family also went out for meals at the shopping mall. According to Mindy, Margaret was ecstatic and did not wish for Sandy to return to Hong Kong. This was what Margaret expressed as shared through Mindy: “Ha, you came back. Don't go. Come back. Don't go to Hong Kong. Grandma is old already. You come back quickly. Don't go. Grandma misses you very much” (sixth interview with Mindy).

4.6.5 Researcher Reflection

Forming a Genuine Relationship with the Family: Mindy came off as an honest, forthcoming, warm and cheery individual. For example, she informed me that she was “very frank” and would “tell me all her feelings”. She was inquisitive and like an open book. Margaret expressed how pleased she was with me enrolling her as a study participant where she has the chance to share her caregiving experience. She mentioned that she actually felt better that she spoke and shared with me. She regarded me as a “friend” and “sister”, mentioning this fact during most visits. I could empathize with Mindy in her situation through my own personal caring experience. Likewise, Shaun was forthcoming, relaxed and seemingly easy-going. He exuded confidence and demonstrated politeness during the interview. The rapport and relationship building with this family came naturally. Their openness has created an authentic representation of the family genogram and ecomap.

As a Researcher: I had to sensitize myself to Mindy’s comfort level in sharing information. For example, at the beginning of our time together, Mindy asked if I would be mentioning the amount of money in Margaret's savings. This money was used for paying Margaret's medical expenses. I reassured her that such details were unlikely to be presented and that I would show her what I have written about her family before publishing or presenting the write-up. During the last interview, Mindy changed her mind and allowed the amount to be recorded and shared:

“The very sad thing is, actually I don't mind telling you. She has hundred thousand but my sister still thinks, more than that. Thinks that I keep her money. Extra. So, this is a very sad part of me. Don't know why they don't trust me.” (sixth interview with Mindy)
Mindy was obviously curious about the information Shaun was going to share with me. While I was interviewing Shaun, she joined us intermittently, on the pretext of offering refreshments for both of us. Midway through the interview, Shaun tactfully requested for Mindy to go and do her things. At this juncture, I could sense that Shaun was a little uncomfortable (his posture, expression and tone changed) sharing about certain things related to family conflicts and relationships in Mindy’s presence, especially when his opinion differed. Initially, Shaun lowered his tone when he started describing about his parents’ relationship when Mindy was nearby. After looking around and ensuring she was not within earshot, he shared the family story as communicated in this case study.

Mindy would also request for me to ‘play along’ whenever her second brother and his wife came to visit. During my second visit, she told me that her second brother was coming to fetch Margaret for a medical appointment. Mindy shared that this was the first time he had offered to do this since the misunderstanding in October 2015. She cautioned me that her sister in-law would be coming along. If she asked who I was, Mindy told me to tell her that I was from the Alzheimer’s Disease Association. Another instance was when Mindy was supposed to have an afternoon appointment with her second brother and his wife which she had cancelled in place of my visit. Again, she instructed me to just keep quiet and tell them that I was from the Alzheimer’s Disease Association if they asked. This was a conflicted position to find myself in as a researcher and one which challenged my own ethical base and values. Taking sides was a natural part of intergenerational care it seemed when family members were mistrustful of one another, a position that also extended to [unwitting] side-taking by the researcher. This point was regularly discussed in supervision as there was no easy solution to this dilemma.

Similar to Clive from Family 2, I noticed during the earlier interviews that Mindy would usually tell me more detailed family related conflicts when she was not audio recorded. She has also enquired about what I would be asking her for the next interview session, saying that she would like to prepare herself for the impending questions. However, over time, Mindy was able to confidently share the details even when audio recorded.

As a Nurse/Resource Person: Mindy would consult me on Margaret’s health issues such as her headache, backache, depression, eye problem and dementia. She even urged Margaret to tell me her problems when the three of us were seated together. On one occasion, without
hesitation, Margaret told me in Cantonese that her eyes could not see. I advised Margaret to inform the geriatrician during her next appointment about what she has told me.

Mindy would normally tell Margaret that her friend (me) was visiting. She told Margaret to ask me whatever she wanted to ask, telling her that I am “like a doctor”. She explained that whenever Margaret went to the doctor, the doctor had no time for her. Mindy probably knew that I would make time for Margaret’s questions. Mindy was apologetic about it though. I reassured her, telling her that it was an opportunity for me to understand what she was going through and the kind of questions Margaret would usually ask her.

4.6.6 Intergenerational Issues

Conflicts with siblings/extended family: Mindy found it very hard to communicate with her second brother, eldest sister and their spouses. She felt “very stressed” because of “conflicts” and “differences” with them. According to her, they used to be very close before Margaret’s dementia. Previously, Mindy has even helped looked after their children. When Margaret went to her second brother and eldest sister’s place, she would follow. After Margaret stopped cooking because of her dementia, Mindy even took over the cooking. But, the changes in Margaret’s living and care arrangement have “drawn a divide and created two camps” as Shaun put it, of which one camp comprised his second uncle and eldest aunty, that is, Mindy’s second brother and eldest sister. There used to be weekly gatherings either at Mindy’s second brother or eldest sister’s place but these have ceased.

When Margaret’s dementia first started, Mindy used to provide feedback to her brothers and sister after Margaret’s appointment with the doctor. But she has found their responses and actions too stressful to handle and has stopped providing them with feedback since. She shared some examples of the stressors from her eldest sister such as “emailing, messaging and gossiping” about her. It has reached a point of animosity where Mindy’s second brother and eldest sister have sent her hurtful WhatsApp messages. I have demonstrated this contentious acts using an irregular line through the ecomap. In this case, the bidirectional arrows are indicative of negative vibes which have transcended from the messaging. They have also accused her of not reading and replying to the WhatsApp messages. Mindy’s eldest sister also sent Shaun messages to complain about her. I did not pursue the nature of the content as I sensed that it was painful for Mindy to share about the exact details. Mindy consistently told me that the stress was not from looking after Margaret but rather from her second brother and her eldest sister: “Not stressed by her but actually stressed by my brother,
sister to tell me this, what to do and you are wrong. You are not that. They even told me, “You think you are very clever!” (fourth interview with Mindy).

What has made the situation more tense and hurtful was the fact that Mindy’s second brother and eldest sister have often accused her of lying about Margaret’s dementia-related behaviours and making up stories, simply because Margaret behaved normally whenever they see her. Mindy felt that they have not spent enough time taking care of Margaret to notice the subtleties. The way it looked, Margaret, without realization has inadvertently contributed to the sibling conflicts as well:

“I told them she’s no good, all that. So, they said I lied. "Why come here, she looked so good?" She answered me what you know? I tolerated for two hours [Laughing]. After they went off, “Wah, Mindy, very painful. Any Paracetamol to eat? So, it's terrible for me. I'm innocent. [Laughing].” (fourth interview with Mindy)

Mindy shared that another reason for her eldest sister’s behaviour was because of an earlier misunderstanding which Mindy had with her sister’s husband. It seemed he was very angry with her for insisting on Margaret staying at one place and not wanting a maid to look after her. This was what Mindy told them then:

"No. You either go to your place 7 days. Then, I take care. I try without a maid first. Then, he was very angry. Shouted at me and said, No way! So, I said, "Okay, if cannot, then, let me take". So now, his reason is, he's not happy I take my mother away for 7 days. And this is the excuse. He said, because you take her, now I don't want her at all." (sixth interview with Mindy)

The main issue surrounding the sibling conflicts was also over money as highlighted by Mindy. She informed that her second brother and eldest sister always thought that she took Margaret’s money. They seemed to think that Mindy has taught Margaret to tell them that she has “no money!” As Mindy shared her story, she sounded disappointed that her siblings distrusted her and took advantage of her kindness and generosity:

“I show all the receipts. I have to total up. I said, "Why must I do this? If you trust me, I don't have to. I mean, no more like take advantage, I look after. They always said, "Mother's account. Mother's account" It's not that I talked about money. I don't have a salary. Do you all give me? Then, still take advantage. Everything use mother's account. Take taxi. Mother's account, very fast will dry up. $100,000”. (sixth interview with Mindy)

Shaun was equally displeased with his second uncle and eldest aunty. He lamented that they were well to do as compared to his family who lived in a HDB apartment. He also said that
when it came to finances, they did not even contribute much and ended up tapping on Margaret’s “miniscule” savings. In the end, Mindy had to devise a plan to force her siblings to contribute financially to Margaret’s care:

“I come out with a schedule for money. Of course I plan. Maid is one thousand. Very reasonable. I take two thousand from them for the food and all that. So, altogether, three thousand. Take from them but they said, "Mother’s account". So, I feel very sad. Everything is, "Mother’s account". But her account will be dried up one day.” (sixth interview with Mindy)

Though Mindy was disappointed that her second brother and eldest sister were unwilling to cooperate, she was hopeful and has expressed her wish for them to come together. There were even times when she tried to provide a valid rationale for their actions: “And, they still don’t work together. Like I wish that they can come, go together with me but they think that... Maybe they mean well. Don’t want me to follow. Let me have rest time” (fourth interview with Mindy).

4.6.7 Case Summary
Family 5 comprised Mindy (youngest daughter), Max (son-in-law), Sandy (granddaughter), Shaun (grandson) and Margaret (person with dementia). They were a mainly English and dialect (Cantonese) speaking family with Buddhism as the focal religion. This middle income family resided in an executive HDB apartment. Margaret had a diagnosis of moderate stage Parkinson’s disease dementia. This diagnosis was shared in 2014. Margaret has four other children, all married with families of their own - an eldest son, an eldest daughter, second son and a youngest son. Margaret used to alternate her living and care arrangement amongst three of her children and their families, that is, her eldest daughter, second son and Mindy for the past 30 to 40 years. However, this living and care arrangement reduced to just two families, that is, Mindy and her eldest sister after Margaret was diagnosed with moderate stage Parkinson’s disease dementia. Eventually, this dual living and care arrangement reduced to just one family on Mindy’s insistence. Mindy and her eldest sister had a falling out following this. Mindy ended up solely taking care of Margaret thereafter. Family 5 received information, support and health services from a general hospital and the local Alzheimer’s Disease Association for managing Margaret’s dementia and her other medical conditions.

Mindy used to be very close to her second brother, eldest sister and their spouses before Margaret’s dementia. However, the changes in Margaret’s living and care arrangement had
“drawn a divide and created two camps” as Shaun put it, of which one camp comprised his second uncle and eldest aunty, that is, Mindy’s second brother and eldest sister. Mindy consistently told me that the stress was not from looking after Margaret, but rather from her second brother and her eldest sister. What has made the situation more tense and hurtful was the fact that Mindy’s second brother and eldest sister had often accused her of ‘lying’ about Margaret’s dementia-related behaviours and making-up stories. Mindy shared that another reason for her eldest sister’s behaviour was because of an earlier misunderstanding which Mindy had with her sister’s husband. A significant issue surrounding the sibling conflict was over money, as highlighted by Mindy. Shaun shared that his second uncle and eldest aunty were ‘well to do’ as compared to his family. Although Mindy was disappointed that her second brother and eldest sister were unwilling to cooperate, she was hopeful and has expressed her wish for them to come together.

On my last interview, the 11th June 2016 brought to an end a monthly contact time of around six months. The visits revealed a number of unresolved misunderstandings and mistrusts in the siblings who used to have a close relationship. This has affected the care of the person with dementia who got entangled in the sibling conflict. The learning point from Family 5 highlights that a lack of understanding about dementia and what this means may impact relational dynamics and how intergenerational members connect with one another and provide timely support for their family member with dementia.
Figure 22: Version 1 of Genogram of Family 5 (co-constructed with Mindy on 17th March 2016)
Figure 23: Version 1 of Ecomap of Family 5 (co-constructed with Mindy on 28th April 2016)
Figure 24: Version 1 of Ecomap of Family 5 (co-constructed with Shaun on 15th June 2016)
4.7 Summary
The co-construction of family biographies of the five intergenerational families using digital photographs, genogram and ecomap was made possible by the longitudinal nature of the research contact with the intergenerational families. The duration of the contact facilitated both parties (the researcher and the intergenerational families) to build rapport and gain trust from one another towards what was a novel and creative process. The building of rapport and trusting relationships with the individual members of the intergenerational families facilitated the discussion and exploration of difficult subjects and, at times, details which the specific members were comfortable to reveal; implying that this was an important part of the entire process in addition to the physical construction of the families’ biography. Although not all intergenerational family members who were part of the immediate family and identified as integral to the functioning of the intergenerational family unit participated in the study, all the main family members were involved in the interviews and co-construction of the intergenerational family biographies. This entire research process illustrates the undeniably complex and interdependent nature of the intergenerational family networks and relationships. It also indicates the importance of having an in-depth understanding of these complex relationships and how they influence the experience of intergenerational caring in dementia; thus, stressing the need to develop needs-based dementia care which is catered for the intergenerational family.
CHAPTER FIVE
FINDINGS: CROSS-CASE ANALYSIS OF THE FIVE CASE STUDIES

5.0 Introduction
In this chapter a cross-case analysis of the five case studies will be presented, that is, Family 1 – *Olive*, *Pete* and #Angel; Family 2 – *Clive*, *Joy*, *Kit* and Dolly#; Family 3 – *Ben, Barbara, Tim (overseas) and Pam#; Family 4 – *Ellie, Ginny, Clara and Elaine#; and Family 5 – *Mindy, Max, Sandy, *Shaun and Margaret# [NOTE: Study participants are indicated with a * and the person with dementia, a #]. Constant reading and re-reading of the five intergenerational cases resulted in the emergence of three themes that explained and explored the various dynamics in the data, namely: i) Family values, and its supporting sub-themes of culture; religion; and filial piety; second theme: ii) Family support, and its supporting sub-themes of timeliness; internal support network; and external support network; and the third theme: iii) Family bonds, and its supporting sub-themes of relational; closeness and conflict; and challenges. Data analysis also generated a meta-theme ‘Intergenerational Family Connections’ which was supported by three properties: i) Strongly held beliefs and practices; ii) Shared space; and iii) Supporting family togetherness. Taken together, this represents an original and novel contribution to the literature on family care in dementia. Photographs and transcript data will be shared where necessary to enhance the cross-case analysis and the thematic content. However, the chapter will start with a pencil sketch which will outline each participating family as an aide memoir for the reader and to help ground the ensuing cross-case analysis. As a point of reference, the themes and sub-themes are not intended to be hierarchical in order but are numbered in text for ease of reference and presentation.

Family 1 – *Olive, *Pete and #Angel
Family 1 comprised Olive (youngest and only daughter), Pete (second and youngest son) and Angel (person with dementia). The family relied heavily on their live-in maid for Angel’s daily activities of living. They were a mainly Chinese, English and dialect speaking family with Buddhism-Taoism as the focal religion. This lower middle income family resided in a three-room HDB high-rise apartment. Angel, widowed since her 50s, had late-moderate stage vascular dementia. She was wheelchair bound and totally dependent. Angel’s eldest son was residing on the fifth floor with his own family (wife, son and a daughter).
Family 2 comprised Clive (son-in-law), Joy (youngest daughter), Kit (grandson) and Dolly (person with dementia). They were a mainly Chinese and dialect speaking family with Buddhism-Taoism as the focal religion. This middle income family resided in a five-room HDB high-rise apartment. The family has lived here for about 13 years. Dolly, widowed since her 70s, had early stage vascular dementia. Dolly’s two other children - an older son and daughter - have migrated overseas with their families. She has been staying with Clive, Joy and Kit for 20 years.

Family 3 – *Ben, Barbara, Tim (overseas) and #Pam
Family 3 comprised Ben (only son), Barbara (daughter-in-law), Tim (only grandson) and Pam (person with dementia). Tim, recently married, was residing in the United Kingdom. The family relied on their two live-in maids for Pam’s daily activities of living. They were a mainly English speaking ‘Peranakan’ family with Christianity as the focal religion. This upper middle income family resided in a double storey semi-detached house. Pam, widowed when she was 60 years old, had late-stage dementia from Alzheimer’s disease. She was wheelchair bound and totally dependent. Pam had been staying with the family for 34 years. Pam passed away in April 2016.

Family 4 – *Ellie, Ginny, Clara and #Elaine
Family 4 comprised Ellie (eldest daughter), Ginny (second daughter), Clara (granddaughter) and Elaine (person with dementia). The family relied on their live-in maid for Elaine’s daily activities of living. They were a mainly English and Cantonese speaking family with Christianity as the focal religion. This middle income family resided in a five-room HDB high-rise apartment. Elaine, widowed when she was about 68 years old, had late-stage Parkinson’s disease dementia. She was wheelchair bound and totally dependent. Elaine has four other children with families of their own – three other daughters and a youngest son. Elaine has been staying with the family except for the two years which she stayed with Elaine’s only brother and his family. Elaine passed away in May 2016.

Family 5 – *Mindy, Max, Sandy, *Shaun and #Margaret
Family 5 comprised Mindy (youngest daughter), Max (son-in-law), Sandy (granddaughter), Shaun (grandson) and Margaret (person with dementia). They were a mainly English and dialect speaking family with Buddhism as the focal religion. This middle income family resided in an executive HDB high-rise apartment. The family had lived in the apartment for
15 years. Margaret, widowed when she was 38 years old, had moderate stage Parkinson’s disease dementia. Margaret had four other children - an eldest son, an eldest daughter, second son and a youngest son – who are all married with families of their own. Between October 2014 to October 2015, Margaret’s living and care arrangement was reduced from three different households for the past 30 to 40 years to just two households, and finally, to just staying with Family 5 from October 2015 onwards.

5.1 Theme 1: Family Values
As will be seen in the cross-case analysis that follows, the theme of Family Values is strongly influenced by the cultural context in which care takes place, the religious beliefs and practices of the intergenerational Singapore-Chinese families and the practised value of filial piety which dictates respect for one’s eldest relative. For these intergenerational families, therefore, family values was part and parcel of being culturally Chinese in which a combination of Buddhist, Taoist and Confucian beliefs further reinforced this deeply traditional value as will now be shared further.

5.1.1 Sub-theme: Culture
Nature and object held significant traditional cultural meaning and values for the families in this study. Fish was symbolic for surplus, abundance and wealth. It signified one of the ‘Eight Buddhist symbols of good fortune’. Different types of fishes symbolized a different set of meanings. A pair of golden carp symbolized love, domestic felicity, partnership, tenacity, fertility, renewal and abundance. A red or black coloured Koi fish signified success and wealth. A peacock symbolized dignity, beauty, luck and fame, and was regarded as ‘the heavenly phoenix on earth’. For the flower, branch and leave, an odd number was preferred as it was meant to convey the dynamic irregularity of the life force. Unopened buds were always included among blooming flowers, as they represented life’s continuous journey. The Peony flower symbolized beauty, rank, higher social status, luxury and opulence.

The acrylic paintings (see Table 6) completed by Clive from Family 2 were strongly influenced by the aforementioned symbolism and purposely drawn as such to be used meaningfully for his family. Painting 1 is a presentation of two peonies with leaves drawn in a heart shape, accompanied by three Chinese carps and set against a golden peacock. Clive told me how particular he was with the number of leaves drawn, as an even number could potentially bring about a dreaded misfortune. Painting 2 of an Arowana fish, also called
‘Kam Lung Yue’ in Chinese-Cantonese, meaning Golden Dragon Fish, was drawn by Clive for Kit. The Chinese characters on the fish’s forehead, “Lifelong learning and accumulation of knowledge”, were meant to ensure a smooth journey for Kit’s coming university studies. Clive also believed that the fish would endow the family with good luck and prosperity.

Painting 3 is a symbolic painting of Chinese Mandarin oranges, sunrise and Chinese Koi fishes. The oranges symbolize a happy occasion; the sunrise symbolizes a new beginning every day; and the fishes symbolize prosperity and abundance. This particular painting was strategically hung on the wall facing Dolly’s bed, so that she could see it daily upon waking up. Painting 4 of a Chinese Koi fish was hung on the wall between the master bedroom (Clive and Joy’s) and Dolly’s bedroom, with well-intended symbolic meaning to the bedroom occupants. Another major purpose of these symbolic paintings was to create a familiar environment in preparation for Dolly when they move house at the end of 2016 as shared in chapter four.

Table 6: Acrylic paintings by Clive (photographed by the researcher on 26th June 2015)

<table>
<thead>
<tr>
<th>Painting 1</th>
<th>Painting 2</th>
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<tr>
<td><img src="image1.jpg" alt="Painting 1" /></td>
<td><img src="image2.jpg" alt="Painting 2" /></td>
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<tr>
<td>Painting 3</td>
<td>Painting 4</td>
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<tr>
<td><img src="image3.jpg" alt="Painting 3" /></td>
<td><img src="image4.jpg" alt="Painting 4" /></td>
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</tbody>
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For others (for example, Families 1 and 4) Chinese symbolism was presented in other meaningful forms - Chinese characters written against a red coloured rice paper, pasted either at the front entrance or walls on the inside of the apartment (see Photographs 28 and 29). Two red coloured vertical strips usually comprising several Chinese characters, and occasionally a third horizontal strip, were intended as permanent fixtures adorning the gates of their homes and embodying the families’ hope related to themes such as prosperity, peace and good fortune in their everyday lives. For Family 5, a hexagonal shaped object (see Photograph 30), called ‘bagua’ was hung above the front entrance of the apartment, meant to maintain harmony and balance (positive energy or ‘chi’) for the family and protect them from evil spirits and misfortune.

Across the data set, the essence of Chinese culture was strongly depicted in symbolic forms in the shared spaces which the families were residing. The symbolic forms were not just for show in the families’ homes, but an obvious and constant reminder to the intergenerational family members of their shared Chinese cultural heritage and that they were a treasured member of the family, bearing a strong connection with these symbolic forms. Clearly, the presence of Chinese symbolism in these shared spaces depicted deeply rooted traditional Chinese values and practices resonated with intergenerational family members and their interconnected presence in the cosmos. Cultural representation was an integral and everyday part of intergenerational family values and care for a family member with dementia.

Photograph 28: Chinese characters on red coloured rice paper pasted on the left side of the living room wall in Family 1’s apartment (taken by the researcher on the 12th April 2015)

Photograph 30: Hexagonal shaped object hung above the front entrance of Family 5’s apartment (taken by the researcher on the 17th March 2016)

5.1.2 Sub-theme: Religion
During my interactions with all the participants, there was a significant presence and influence of Taoist and Confucian beliefs and practices across the five families regardless of their professed religion. This was in relation to how they have lived and cared for each other.
Taoists worship many different gods (or deities), believe in respecting heaven, worshipping ancestors, a spiritual world existing in parallel with the world we live in and being compassionate to all under the “heavens”. The combination of such beliefs, the ‘Yin’ and ‘Yang’ element of opposites complementing each other, respecting the heavens and ancestral worship connected the intergenerational members of these five families together.

Photograph 31: The two huge drums at the bottom right hand corner are for Taoist devotees to burn incense paper as offerings to their ancestors (taken by the researcher on the 12th April 2017 when visiting Family 1)

Drums, like the ones in Photograph 31, were seen below the block of the apartments in which the families resided. These were for Taoist devotees to continue their religious practice of ancestral worship – burning of incense paper offerings, usually done together by the intergenerational family members as a necessary family affair during designated occasions. For Family 1, this obvious religious devotion could also be seen by the presence of Chinese deities such as Ji Gong (Buddhist monk who possessed supernatural powers to help the poor and stand up for injustice), Kuan-Yin or Goddess of Mercy (Chinese Protection Goddess) and God of Wealth which were strategically placed on the prayer altar (see Photographs 32 to 34), alongside the family’s ancestral tablet (see Photograph 35), in their apartment’s living room. Here, Olive and Pete were fulfilling their mother (Angel’s) staunch Buddhist-Taoist belief, with Pete taking charge of the family’s prayer altar comprising the three deities and their family’s ancestral tablet. He would usually offer joss sticks and fresh fruits to the deities and his ancestors. In this way, ancestral worship has kept the intergenerational family connected with each other.
Photographs 32 to 34: Chinese deities from left to right such as Ji Gong (Buddhist monk who possessed supernatural powers to help the poor and stand up for injustice), Kuan Yin or Goddess of Mercy (Chinese Protection Goddess) and God of Wealth (there are five different God of Wealth but essentially, they supposedly bestow good fortune on the worshipper) at the prayer alter in the living room of Family 1 (taken by the researcher on the 12th April 2015)

Photograph 35: Ancestral tablet on the altar in the living room of Family 1’s apartment (taken by the researcher on the 12th April 2015)
Family 5 also had a designated prayer altar in a dedicated prayer room (see Photograph 36), nicely adorned with figurines and amulets of Kuan-Yin or the Goddess of Mercy and Buddha and the ancestral tablet. The prayer room provided an opportunity for the daughter (Mindy) to support and connect with her mother who was living with dementia (Margaret). Although there was no evidence of any prayer altar for some families (for example Family 2), the intergenerational family members still went about fulfilling the spiritual wishes of the person with dementia (Dolly). Additionally, the intergenerational family members from the five families were even praying for each other. For instance, Shaun prayed to Buddha for the wellbeing of his entire family (parents, sister and grandmother - Margaret):

“I mean that's what religion is for right? People praying. Ask for something. Higher order. I don't know. I always wish say... wish that... make sure everything is ok, you know. Like when I pray, I always hope that my grandma's ok. My mom's ok. My dad's ok. My sister's ok. My friends are ok [Laughs]. I'm ok. Yeah. So, my grandma is part of my wishes [Chuckles].” (first interview with Shaun)

Photograph 36: Prayer altar in the prayer room of Family 5. Framed pictures, figurines and amulets of the Goddess of Mercy and Buddha. On the extreme right is the ancestral tablet (taken by the researcher on the 15th June 2016)

Finally, with regard to religion, the funeral rituals which Families 3 and 4 underwent during the passing of their mothers who were living with dementia (Pam and Elaine), I felt, were important to share as these formed a significant part of the Chinese culture and served as an illustration of what these intergenerational families have experienced, and how they supported and connected with each other. It was crucial to share how these two families dealt with these rituals which were underpinned by filial piety (see next sub-theme), and partly
from the belief that relationship between the living and dead were symbiotic akin to the necessary harmonious balancing between ‘Yin’ and ‘Yang’. Also, the continued presence of loved ones did not end with their passing.

Although the two intergenerational families were Christians, the wake was carried out in a familiar Chinese religious manner, apart from the Christian funeral decorations or motifs. Similar to Chinese religious funeral rituals, the intergenerational family members were taking turns to keep all-night vigils during the wake to watch over the bodies of the deceased family member with dementia at the families’ residences. The wakes were held for about three days for the two families to allow relatives and friends to pay their last respects. When I managed to pay my last respect at Elaine’s funeral, I made the typical and very Chinese monetary contributions known as ‘baijin’ or ‘white gold’ to the family as expected and anticipated, a practice to help deflect funeral costs. Furthermore, the intergenerational family members were still wearing mourning colours such as black, blue and white for the period following the funeral, a typical Chinese practice following the traditions of filial piety as will now be explored.

5.1.3 Sub-theme: Filial Piety
What was strikingly similar across the families and their values was the element of Confucian respect for their elders, filial piety and reciprocity, of course with notable variations across the five families in the manner in which it was expressed and demonstrated. In two of the families (Families 1 and 5), ancestral worship, or veneration, was a prominent element of filial piety in their household. During my interviews, this element of the Chinese traditional religion centred on the ritual celebration of their ‘deified ancestors’. Confucianism requires the living to pay respect to one's ancestors, an aspect of filial piety. Prayer was usually performed at the household altar in a designated part of the house containing the ancestral tablet of their ancestors or deceased relatives such as the ones I saw in the living room and designated prayer room for Families 1 and 5 as mentioned in the previous sub-theme on religion.

My interviews and engagement with the intergenerational families also revealed a deep sense of filial piety for various reasons as shared by the different members of these families. With Family 1, Pete took charge of the family prayer altar, a role he automatically assumed when Angel had dementia. Olive was more verbally expressive about her filial responsibility: "It's a sense of filial piety. We have been living together all this while. My mom was the one who
had been looking after me. She cared for me when I was sick” (third interview). Thus, it was a sense of filial piety and reciprocity on Olive’s part. This was similarly so for Ellie from Family 4 as revealed through this slice of data: “Then, you know, I still remember, when I was a baby, she's so happy with me. She's so happy to clean my backside. She's so happy doing it. So, now when I do it, I must feel the same way” (fourth interview). On the other hand, Pete did not use similar expressions but was obviously affectionate towards his mother (Angel) as mentioned in chapter four. During my interview with him, he had mentioned how painful it was to see Angel living with dementia. I could only conclude from the painful expression in his eyes that these were sincere words borne out of filial love for his mother.

My interactions with Family 2 also revealed a deep connection and sense of respect and admiration (traits of filial piety) for the person with dementia (Dolly). The dedication and devotion towards the care of the person with dementia was testimony enough to indicate the sense of filial piety. Congruent with the emphasis of filial piety, Dolly was always treated as a respected member of the family and intentionally involved in major family events. For example, the intergenerational family members engaged her in participating in the grandson’s (Kit) enrolment into National Service and university application.

Although the intergenerational family members in Family 3 were Christians, Ben shared that Christianity also emphasised “to honour thy father and mother”, a similarity to Confucianism. One of the intergenerational family members, Mindy, from Family 5, felt that filial piety was an essential part of the Chinese culture: “We are Chinese. I always think that, you know, Chinese, even mother, we have to be filial” (sixth interview). Mindy also recited in our time together the “24 Exemplars of Filial Piety” which is a compilation of tales about filial piety by a historical Chinese scholar. Clearly, the family values of filial piety were even translated to the grandchildren in this study where one of the grandchildren (Shaun from Family 5) articulated his strong stance that as a Chinese, one must always be filial, reciprocal and respectful towards one’s elders:

“We're an Asian family. So, we have to do this kind of stuff. And, my mom brought me up. Everyday she takes care of me. So, I have to do the same for her next time. I try my best. I try to relieve the burden of my mom.” (first interview with Shaun)

And, Shaun went on to share why he felt it was important to provide care for his grandmother with dementia: “I mean she's my grandma, right? So, she's a member of the family. I can't just like let her be like this” (first interview). Filial piety was an inherently innate cultural
value which was held in high regard and closely observed and adhered to by the intergenerational family members in this study.

5.2 Theme 2: Family Support
Family support used to be a given for families in Singapore when they were mostly residing in multigenerational households in a ‘kampong’ house like the one seen in Photograph 37 [NOTE: Kampong means village in the Malay language], bearing similarities to the courtyard houses of our ancestors in China in the olden days. The previous ‘kampong’ set-up was ideal for multigenerational members from the immediate and extended families, young and old, to look out and care for each other, and provide internal support network for daily living needs and housework, emotional support, and informational support (information and knowledge). However, the general dwelling infrastructure has evolved into multi-storey high-rise apartments (see Photograph 38) with isolated features which indirectly advocated privacy, thus minimizing meaningful interactions and support, especially from the extended family who is an important part of the internal support network. This has inadvertently and evidently hindered the deliverance of strong internal support network from the extended family, especially in the context of dementia care.

Families are relegated to staying in different units, blocks or estates island-wide with the intergenerational members who are residing ‘under one roof’ in an apartment unit having to strive on their own, like in the case of the intergenerational families in this study. Family support was expressed through three sub-themes: timeliness; internal support network; and external support network which will now be explored in greater depth with reference to the whole data set.

5.2.1 Sub-theme: Timeliness

The issue with timeliness of support was a common occurrence across the five families but its meaning varied according to the context in which it was experienced. This variation in meaning will now be developed further.

Timeliness related to diagnosis of dementia and its relevant management: Timeliness related to a diagnosis of dementia and its management appeared to rely heavily on when the immediate and extended members from the five families decided to seek professional help. For example, Olive’s brothers were of the belief that little, or nothing, could be done for Angel and were unsupportive of Olive when she suspected, and wanted, to seek medical help to ascertain Angel’s diagnosis. To them, dementia was irreversible and not worth the financial outlay: “a waste of money” being the reason given. In contrast, Ben took a while to recognize that Pam’s difficult and challenging behaviour was due to the onset of dementia. Ellie and her sister (Ginny) were in denial. Equally, Mindy’s siblings regarded Margaret’s cognitive changes as a “normal process of aging” rather than anything pathological as Shaun shared: “The other camp always believe that my grandma is depressed!” (first interview).
Clearly, the denial and indecision through the intergenerational filter had affected the timeliness in arriving at a care decision which was frustrating as elaborated upon by Shaun:

“It's been going on for one year [indecision in the family]. Timed it already. How long more? I mean how long more do they need? So, yeah. Yeah. My grandma does not have long to live also” (first interview).

Overall, it could be concluded that the delay in seeking diagnosis was due to a lack of awareness about dementia by family members and a weakened relationship for some too. Conversely, supportive, proactive and motivated families were pivotal in ensuring timely diagnosis. This was the case of Dolly. Because Clive was intimately observant of her routine behaviour, he was able to plan ahead and identify the changes and, therefore, initiate early consultation with the physician. The timeliness in her diagnosis had allowed Clive and Joy to seek help and implement shared activities to [hopefully] slow down the progression of her dementia. However, this was an exception and not the rule. A lack of awareness about dementia contributed significantly to dementia being an “invisible” condition in society as compared to other more prominent conditions, such as stroke and diabetes. Shaun from Family 5 neatly described this conundrum:

“Because dementia is very invisible. You can always... If the guy’s an amputee, the guy is an amputee. There needs to be this icon. Like a dementia icon. So, maybe like X has dementia. So, definitely more... a lot of popular people have dementia. It's very well known. So, it needs to have more publicity, I guess. Because it's very invisible, dementia” (first interview with Shaun)

**Timeliness of support from the immediate and extended family:** The expected first line of support from the immediate and/or extended family for the person with dementia and/or the main person providing the care did not come in a timely manner. For some, support was more grudgingly provided, slow to arrive or did not come at all in spite of direct and repeated requests. As an illustration, Olive was left to struggle with her mother’s physical, emotional care and expenses and Olive’s brothers were facing personal challenges of their own at the onset of Angel’s dementia. Although Olive’s eldest brother and his family were just staying on the fifth floor apartment unit above them, the care and living arrangement was hampered by the design and infrastructure of the dwelling. In Family 2’s case, Joy’s other siblings were already residing overseas before Dolly had the early signs of dementia. Timeliness of support is one thing, but it even came to a point where a telephone call from Joy’s siblings as a simple gesture of support was not forthcoming. Such intergenerational conflicts and arrangements had a profound impact on the everyday care that was conducted.
**Timeliness of relevant support resources or services:** The delay in timeliness of relevant support resources or services, such as respite care and informational support for these families, was another highlighted issue. When Olive, Ben and Mindy from Families 1, 3 and 5 respectively were in need of temporary respite care, the service was simply unavailable and institutionalization of the family member with dementia became an imminent choice for some. For example, Olive and Mindy were forced to make the heart-wrenching decision to place their mothers temporarily in a residential home. Often, last minute requests like this, or requirements which did not allow sufficient time for the approving process to commence, were not only a stressful affair for family caregivers, but also something which stretched the already limited - or ‘unprepared’ - service. Alternatively, families like Ben and his wife (Barbara) struggled on their own with the help of their live-in maid while awaiting, for example, for the ‘Dusk to Dawn Service’ to materialize.

**Timeliness in engaging a live-in maid:** Timeliness in engaging a live-in maid was dependent on the behaviour of the person with dementia and whether the immediate family members or member(s) in the household were able to cope with the caregiving role. For instance, Olive tried to engage external support (day care) and her extended family in looking after Angel during the initial phase until these were no longer feasible options. In contrast, Ben found it challenging to look after Pam’s physical needs on his own as he felt uncomfortable dealing with his mother’s more intimate anatomy and he had his own health issues and advanced age. Ellie and Ginny were also both working full-time. Hence, the three families employed a live-in maid to help meet the care demands. However, Families 2 and 5 were not so keen on such an arrangement feeling that they were still able to manage without outside support. On this latter point, Mindy from Family 5 shared that even though her siblings insisted that she hired a live-in maid, she was adamant that this was not going to happen. According to her, Margaret (the person with dementia) was still relatively independent and only required limited supervision. Moreover, her husband (Max) and son (Shaun) preferred not to have a “stranger in the house” and Shaun argued that his grandmother (Margaret) “just needed someone to understand her” and believed that “the maid would not be able to understand her as well” (first interview) as his mother (Mindy). My interviews with all the families have revealed a similar reluctance. Chinese people are very private and dislike their homes being shared with outsiders and not part of the family. Therefore, in dementia care, having a live-in maid is always a last resort in caregiving and this was played out in the discussions and relational dynamics seen across the five case studies.
5.2.2 Sub-theme: Internal Support Network

The intergenerational family structure of the five families was formed by an extensive internal support network whether family members were in a single/nuclear family household, extended family household or other forms of living arrangements. As observed, the immediate family members appreciated a close and supportive relationship with extended family members as part of this elaborate yet essential internal support network. Although, support for older people would be the primary responsibility of the immediate family members, the extended family members were expected to render informal support in the provision of instrumental activities of daily living, activities of daily living, financial and/or emotional support. Beyond that, formal and external support may be sought from the external support network (next sub-theme) if the family has exhausted all avenues of informal support through the internal support network comprising the immediate and extended family as mentioned under the previous sub-theme, timeliness.

As seen in the cross-case analysis, the main caregivers from the families in the studies (Olive, Clive, Ellie and Mindy) were willing to accept the caregiving responsibility, but wished for their extended family (their siblings or the children of the family member with dementia) to show their support by being equally involved in the care and/or showing concerns for the person with dementia. The nature and degree of support needed was dependent on the stages of dementia. Whatever it was, the main caregivers expected at least some contributions and involvements from their extended family. For Olive from Family 1, reasonable support from this important internal support network meant more involvement in Angel’s care, that is, financial support from her two brothers and more frequent visits from her eldest brother and his family. Unfortunately, certain traditional perception of gender-specific support still remained an expectation of the immediate and extended family. This was evidently so in the case of Olive and Pete when he implied that Olive ought to take care of Angel as she was the unmarried daughter who was living with Angel. Hence, it was only befitting that she shoulder the responsibility for Angel instead:

“Therefore, my brother said, "You are currently the one staying with mom, also unmarried. Therefore, the responsibility is on you!" In addition, this brother has experienced something similar before. He feels that many people owes him for his sorry state. Therefore, he doesn't bother about anything. He is in his own world. He doesn't feel like facing his own mom to deal with her.” (second interview with Olive)

Mindy, from Family 5, had wished for her eldest sister and second brother to provide their support by sharing the caregiving load instead of her shouldering it by herself. For Ellie,
from Family 4, support from her internal support network comprising her siblings, nephews and nieces meant either material or dedicated physical presence.

Spousal support was also an important source of internal support network for the married family caregivers (Clive, Ben and Mindy). It could be seen that this essential support was pivotal in helping them cope positively and have meaning in their caregiving role(s). These caregivers were especially appreciative of the support and understanding from their spouses. Similarly, all the adult children in the data set (Joy, Ben and Mindy) were appreciative that their spouses were supportive in allowing their mothers to stay with the family under the same roof. Ben, from Family 3, had even endorsed and rated “spouse support as probably the most important” (fourth interview). For him, the deep appreciation could well be related to his wife’s (Barbara) willingness to allow Pam to stay with them even when her prior relationship with Pam had been strained with earlier conflicts and allegations. Joy, from Family 2, was appreciative that Clive was genuinely concerned and caring towards her mother (Dolly). It also afforded Joy with the opportunity to continue her full-time work without much worry.

Another source of support from the internal support network was the grandchildren. Although, support from grandchildren was not demanded, nor expected, it was welcomed by the main caregivers. The two grandchildren (Kit and Shaun) who participated in this study were playing a supportive role as they were still actively undergoing formal education. The explanation for this stems from a long Chinese tradition which is highly appreciative of the role education plays in attaining one’s success in life. Hence, it is understandable for parents in this study to place significant expectations on their children to pursue academic success above everything else, including the child providing intergenerational care at home. In the case of the two recruited grandchildren from Families 2 and 5, their involvement, if any, seemed to be more of wanting to support their parents who were providing the care as depicted in this sharing:

“So, I help my father print the music notes and things to draw. Then, help convert the songs online to his phone to play the songs. Just helping my father. For the pictures, he will search online from Google. Then, I help him to print it out. Then, the music notes, it's like, use Microsoft. Then, draw the circles, add the numbers, the colours. Then, print out.” (first interview with Kit)

The study has also revealed a pervasive use of information and communication technology by the intergenerational families as a means to connect with their internal support network,
that is, their immediate and extended family members, as well as to obtain and receive information on dementia to support caregiving activities. All family caregivers, at the very least, owned a mobile phone as a primary device with some owning a secondary device, such as mobile tablet, personal laptop and/or desktop computer. These devices became useful tools in aiding their caregiving journey, for instance by accessing information via the world-wide web (for example, Google search) and video-sharing website (for example, YouTube); connecting with their internal support network, that is, the immediate and extended family via online social media and social networking service (for example, Facebook), cross-platform and end-to-end instant messaging application (for example, WhatsApp), instant messaging app (for example, Skype, Messenger), video call and audio chats (for example, FaceTime), journaling/reflecting their caregiving experience via a blog site (for example, WordPress) and taking digital photographs and videos using their mobile devices.

These technological advances were woven into the fabric of daily care at home with the world-wide web especially frequently consulted to search for information related to dementia. Access was at all points of the diagnostic and caring journey especially when the families encountered doubts which needed clarification, usually in the absence of healthcare professionals. In other words, the internet was a quick reference point to help families within the internal support network to make a better decision, as Clive explained:

“*We had to check the internet for information. Not anxious but in a relaxed manner, searching for ways to help her [Dolly]. Because things which the doctors have told us are perplexing. Why is it that the medications prescribed for her can cause all those side-effects?*” (third interview with Clive)

Apart from the world-wide web, video-sharing websites like YouTube was another important source of information to support care within the internal support network. Family caregivers (Clive, Kit, Ben, Mindy and Shaun) from Families 2, 3 and 5 have used YouTube as a source for accessing engaging songs and Buddhist musical chants. The songs and musical chants have been meaningfully used to engage Dolly, Pam and Margaret. Those family caregivers like Clive and Mindy who were not so internet literate relied on younger members (Kit and Shaun) to assist them with the sourcing. Some caregivers (for example, Ben from Family 3) were also quick to add that they have also used YouTube to entertain themselves as a means to ‘de-stress’ or ‘unwind’ at the end of a long day.

Online social media and social networking service (Facebook) was used for connecting with family members who were residing locally, as well as overseas, whereas instant messaging
app (Skype, Messenger), video call and audio chats (FaceTime) were mostly used to connect with those who were residing overseas. Obviously, the intergenerational families in this study overcame the geographical distance apart through the use of information and communication technology in their attempt to receive emotional support and maintain connection with their internal support network.

For family members who were residing locally, cross-platform and end-to-end instant messaging application like WhatsApp was sporadically used. Ellie mentioned that her family had even purposely created a ‘WhatsApp Family Chat’ to facilitate instant responses and help from nephews and nieces when needed. Some of the families have also used the cross-platform and end-to-end instant messaging application (WhatsApp) as a communication tool with their external support network (next sub-theme), that is, the healthcare professionals or providers from the hospitals whom their family members with dementia were having follow-up with.

Digital photographs and videos were also used for several purposes within the internal support network, such as memorabilia for the family caregivers and to keep track of the changes across time and as a form of reminiscence for the family member with dementia. So far, all families in the study have shared that they have taken photographs and videos of the family member with dementia and activities which they felt were relevant. Another form of support for family caregivers within the internal support network was journaling/reflecting their caregiving experience via an online blog site. Evidently, Mindy’s son, Shaun, created another outlet for her, a WordPress blog site. The blog site was meant as a platform, or channel, for Mindy to write about her feelings, ventilate her ‘frustrations’ and de-stress.

5.2.3 Sub-theme: External Support Network

The families were reliant on their external support network in which the nature and degree of reliance was dependent on which point of the care trajectory they were at and for various reasons as seen in the cross-case analysis. For example, Families 1, 3 and 4, who employed a live-in maid to help with the provision of activities of daily living for the person with dementia, had done so for several reasons:

- Working full-time, apart from Ben who was on part-time employment, and health issues or poor health – Olive, Ben and Ellie.
- Unable to secure help from immediate or extended family member(s) within the internal
support network – Olive.

• No other siblings to rely on – Ben.

• Advancing age - Ben and Ellie.

• Support services, such as day care, were not customized to suit the individual family’s needs. For example, the opening and closing hours conflicted with the family caregivers’ working hours – Olive and Ellie.

• The family member with dementia having challenging or difficult behaviours – Pam.

• Caregivers being unable to perform the activities of daily living themselves - Ben.

Apart from the usual healthcare institutions or acute hospital follow-up appointments, the families were referred to the local the Alzheimer’s Disease Association which was identified by the families to be a very important and useful external support network for them. Most participants shared that they were only made aware of the Alzheimer’s Disease Association and its range of dementia-related services upon formal diagnosis of their family member with dementia at the acute hospital. They wished they had known of its existence even beforehand. Usually, these family caregivers would participate in the activities offered by the Alzheimer’s Disease Association’s Caregivers’ Support Group as they have found these particularly useful as a platform to obtain psychosocial and informational support. For instance, the Caregivers’ Support Group enabled the family caregivers to share practical caregiving tips with each other:

“I should say it is from the ADA, the Caregivers’ Support Group, I learnt a lot of information from and when I returned, I see how to handle. For example, recently I saw my mother’s tooth problem and I was able to know how to handle from another caregiver. When I face such situations, I am also at a loss. But in the support group, I got to know another caregiver and she will help and tell me how I can handle. So, I understand the severity of it. Actually, from the ADA’s caregiver support group, I knew things to pay attention to at the advanced stage.” (sixth interview with Olive)

Apart from the support group, the Alzheimer’s Disease Association’s Memories Café was appreciated by those families who could still benefit from its activities and social interaction. The café is away from the usual environment for family caregivers who used to attend support groups held in more formal settings such as dementia day care centres. The programme has given the people with dementia (Dolly and Margaret) the opportunity to meet others similar to them. In fact, Clive and Joy from Family 2 shared that they have been bringing Dolly to this café without fail. However, for some family caregivers like Ben from Family 3 whose mother (Pam) could no longer engage in the service, the Alzheimer’s
The Alzheimer’s Disease Association had become a platform for them to obtain information, have recreation and network with other family caregivers, as shared:

“The Alzheimer’s Disease Association is more for me to participate and also to enjoy sometimes. They do have some fun activities to enjoy. They have a lunch for us every year. Sponsored. Not bad. You meet other caregivers.” (second interview with Ben)

The professional/formal caregivers at the Alzheimer’s Disease Association were often useful in providing directions for the family caregivers to negotiate their way better through the myriad of health and social services which formed part of their external support network. For the family caregivers in the study, finding an appropriate service was perplexing and frustrating. This was one of the many concerns which Ben had shared before – the overwhelmingly long list of health and social services which family caregivers were often bombarded with and were clueless about. Moreover, as part of the external support network, these formal caregivers were also deemed as good resources for family members to learn different dementia-related management strategies from.

Apart from the dementia-related support services which were offered by the Alzheimer’s Disease Association, the family caregivers were also receiving information on management strategies from the acute hospitals (another important and relevant source of their external support network) which their family member with dementia was following up with. Recently, with the piloting of new palliative programmes, some hospitals with established geriatric or older people care services offered home visit services for the person with dementia who was at the end stage which only Family 4 was qualified for. Ellie and her family were very appreciative of the home visit service by the assigned doctor and nurses. According to her, the quarterly visit per year meant that the family did not have to struggle to bring her mother (Elaine) to the hospital for follow-up. For caregivers like Olive from Family 1, whose mother Angel has not reached end stage, it proved frustrating as she could not obtain a conclusive staging for Angel’s dementia from the physician and was, therefore, unable to benefit from the programme.

Beyond the external support network from hospitals and the Alzheimer’s Disease Association, family caregivers who were unable to secure support from their internal support network were often required to enrol their family member with dementia at a day care centre. Unfortunately, most day care centres (an often utilized external support network) were not specifically geared towards people with dementia. The limited numbers of day care centres
which could help had admission criteria that families found punitive and all had long waiting time. In addition, the day care centre’s opening and closing hours often conflicted with the family caregivers’ own work schedule, thus posing a further hurdle for some caregivers like Olive from Family 1. Others, like Ellie from Family 4, countered the challenge by asking the live-in maid to accompany the person with dementia to the day care centre. Family caregivers were also forced to explore other support services from their external support network when their family member with dementia progressed to the next stage, which the day care centre was often not equipped to handle. Often times, family caregivers found themselves having to re-adapt to a new situation and struggle on their own while awaiting enrolment, or admission, to another support service which could provide support.

Respite care, a useful source of external support network, was sought when the family caregivers in the study suffered from poor health, burn out or the inability to cope with their family member’s challenging behaviour. As mentioned under the sub-theme timeliness, utilization of a residential or nursing home as a form of support for respite care became an unavoidable option. However, these were not specifically geared towards people with dementia. For those facilities which were person-centred, such as the ‘Dusk to Dawn Service’, only Family 3 was able to afford it. Access and fairness to service support was an important finding of this study.

For family caregivers who were working full-time, a supportive workplace culture and environment as part of their external support network was something that the participants appreciated and yearned for. A supportive workplace for participants meant employers, managers or colleagues who were empathetic and understanding of their caregiving situation. Ellie elaborated on a particularly positive and supportive experience at her workplace:

“So, my helper doesn't know what to do. Called me. So, I told her, ok. Then, the moment I said, ok, then, my boss from inside said, "Ellie, put down the phone. Just go home. Go home. Actually, I wanted to make my way to go home. I have to walk home. My home is very near to school but I saw one of my colleagues and he drives. And, he told me, "Ellie, I drive you home." You know. I said, "It's ok. I can run home." “No. No. No. Don't run. I will fetch you home." So, that is the kind of support I have. So, I did have a lot of help. I think I'm really appreciative. My director, he's very, very kind. So, it does help to have supportive superior who understands. Sometimes when you care for elderly, there are unpredictable times where you need to go home.” (sixth interview with Ellie)
The other family caregivers (Olive, Joy and Ben) from Families 1, 2 and 3 had differing feelings and perceptions about their workplace culture and environment. Olive felt that her last organization did not have supportive practices in place for caregivers like herself. She cited the leave scheme of 18 days as insufficient to cover her own and her mother’s (Angel) medical follow-up with the Chinese and western physicians respectively. Most of the time, she ended up applying for no-pay leave for the days which exceeded her annual leave. Some caregivers (Joy and Ben) who were feeling stressed at home also chose not to disclose their home situation for fear of repercussions.

The analysis of what was shared by these working family caregivers seemed to reveal differences in workplace culture and environment. For some, the workplace culture and environment was perceived and deemed as a supportive component of their external support network whilst some caregivers have disclosed a certain element of mistrust and, therefore, reservations in disclosing their actual family situation.

5.3 Theme 3: Family Bonds

Strong family bonds ensure the maintenance of intergenerational family relations in the Chinese family kinship system. As the data indicated, it is through these strong family bonds that the immediate and extended family connect across households to provide social and economic support, such as shared labour, socialization of the children and support for the older person with dementia. However, as I have alluded to already, some of the families have found maintaining communication between the immediate and extended family members challenging. Sadly, others have ended up having to sever relational ties with the extended family. On a positive note, there were also families who thrive against adversity and developed an even stronger and closer family bond within the immediate or with the extended family. Notwithstanding, traces of strong family bonds were evident within the immediate intergenerational families and it is this aspect of the research findings that will now be developed.

5.3.1 Sub-theme: Relational

The strength of the kinship tie in the mother-daughter relationship does not develop overnight. Rather, it has developed based on the duration of time spent, the meaningful activities done together and the shared values between mother and daughter. For example, in Family 1, Olive, the only filial daughter and youngest in her family, had always resided with, and been very close to, her mother, Angel. The mother-daughter bond was so strong
that Olive was even relating about her foreseeable difficulty in accepting Angel’s eventual death. This was what she tearfully shared: “Because the mother-daughter kinship bond has developed over so many years. It's not easy to terminate this bond. Not so easy. I find it very difficult to do so!” (fourth interview). This strong bond was clearly visible from the affections and fusses bestowed upon Angel during my longitudinal visits which extended to the old and present day photographs that Olive showed me during our time together. It is precisely the aforementioned strong relational and family bond that provided the impetus and determination for Olive to carry on with the care demands of her mother, Angel, at the expense of her own health, career and sibling relations.

Similarly, Joy was very close to her mother, Dolly. They had been living together before and after Joy got married and started a family of her own. Although Joy did not verbally tell me about the close bond they shared, the non-verbal cues as seen during my longitudinal visits with the family and the digital photographs (see Photograph 39), and Clive’s comments about the mother-daughter relationship, provided sufficient evidence to attest to the closeness: “My wife and her mom still have a little bit of squabble because they are mother and daughter because they are very... too close” (third interview with Clive). The kinship tie and bond between the mother and daughter has become even closer as shared, from the time Dolly started having dementia to the present day.

Ellie and Ginny from Family 4, who, since young have been staying with Elaine, also shared a very close relationship and bond with their mother. Interestingly, the mother-daughter relationship became even closer after the sisters gained a better understanding of dementia: “Then, my mother would, even in her late state, when she does not know anything, she would like pat my sister's face, pull the blanket over my sister. That kind of closeness” (sixth interview with Ellie). Like Olive, Joy and Ellie, Mindy’s (from Family 5) close relation with her mother, Margaret, never once wavered even when challenged by the issues arising from Margaret’s dementia. Moreover, Mindy, being the youngest, had always been accompanying and assisting Margaret whenever she was needed to organize family gatherings and get-together. That close filial kinship relation and devotion was aptly described by Shaun as: “My grandma is my mom's life” (first interview).

The nature of the kinship tie related to the mother-son relation was a little different in that it was not as emotionally and physically intimate. Interestingly, when I asked Ben from Family 3 about his relationship with Pam, he provided an almost instantaneous reply with his usual
Photograph 39: Doing Chinese New Year Shopping together. Clockwise from the left – Joy and Dolly (from Clive who took the picture in Feb 2015)

stoic demeanour: “Of course she dotes on me. I'm the only child. But I don't talk much to her. I mean, boys” (second interview). It is well-accepted that ‘Peranakan’ mothers dote on their sons and, perhaps, more so in Ben’s case with him being the only child. For Ben, it was a sense of duty, his religion and pragmatism which compelled him to care for Pam in a relational and reciprocal manner. Pete, from Family 1 on the other hand, was Angel’s favourite son and he had confessed to me that it was “very painful” for him when his mother had dementia. The actions demonstrating the close mother-son relationship was apparent during my visits where I frequently observed Pete’s displays of affection such as kissing Angel on the cheek and hugging her affectionately before going out and after returning home. Before the onset of dementia, this physical display of affection was rarely displayed.

In developing the relational dynamic, factors in maintaining the grandparent-grandchild/grandchildren kinship tie were important, such as spending regular and meaningful time together, role modelling, and observing filial piety entrusted to the grandchildren by their parents. As seen in the data, Dolly and Kit’s grandmother-grandchild relation demonstrated a unique and close intergenerational kinship bond, one that was filled with deep respect. The following is a description of this bond:

“Because at home he regards Po Po [Maternal grandmother] as a very important member. In fact, he has very little interactions with his own "Ah Ma" [Paternal grandmother]. He has more interactions with Po Po. When he was very young, she
really looked after him. Childcare, taking bus, looking after him. Therefore, his meals, everything was cared for by Po Po. The relationship is very good.” (third interview with Clive)

Additionally, strong kinship bond and filial values have determined how the grandchild regarded the grandmother with dementia. For example, one of the grandchildren’s beliefs was to “just treat her as usual, just like my grandmother” (first interview with Kit). The grandchildren were particularly appreciative of their grandmothers who had cared for them in their younger days, as shared: “I mean she's my grandma, right? So, she's a member of the family. I can't just like let her be like this” (first interview with Shaun). The parents’ positive role modelling as mentioned in chapter five had also shaped the grandchild/grandchildren’s view, thereby influencing the positive relationship with the grandmother.

The only mother-in-law-son-in-law relation that can be analysed from the data was that of Dolly and Clive from Family 2. Through my time with the family, theirs was a very close relationship in which Clive has made conscious effort to engage Dolly on a daily basis through activities such as the example seen in Photograph 40.

Photograph 40: Clive and Dolly engaging in their routine daily activity

It was not just the daily routines which depicted the close relationship. Clive was intimately familiar and took a genuine interest in Dolly’s overall well-being. I recalled asking Clive why he thought of using a particular method of engaging his mother-in-law in the daily care routine. He reasoned that it just came naturally and implied that the actions resulted from a “genuine intent from the heart”. The sincerity could be heard in his voice as he shared those words.
5.3.2 Sub-theme: Closeness and Conflict
In this study, some of the families found that doing meaningful bonding activities brought them closer together such as going out for a meal (see photograph 14) and arranging medication in the ‘pill boxes’ (see photograph 27). For example, for Family 2, Joy shared that it was “through exercise and communication with the family members” that they “have become closer within the family” (first interview). Moreover, even the younger generation appreciated the family time together with one particular grandchild, Kit, describing that he “enjoyed spending time together with his family” (second interview).

Photograph 14: Going out for a meal at a café. Clockwise from the left - Kit, Joy and Dolly (from Clive who took them in March 2013)

Photograph 27: Margaret and Mindy preparing Margaret’s medication in the “pill boxes” (sent by Mindy via WhatsApp to the researcher on 17th August 2017)
Moreover, the time spent doing engaging and meaningful activities together have brought previously less expressive and seemingly ‘distant’ relationship between the person with dementia and family caregiver towards one that was closer. For example, Pam and Ben from Family 3 had a closer mother-son relationship through the ‘Dusk to Dawn Service’ activities which Ben was actively contributing to and involved in. Photograph 19 is an example of their activity together.

Photograph 19: Ben accompanying Pam during her activities with therapists at the ‘Dusk to Dawn Service’ (the digital photograph from an online source was provided by Ben during my fifth interview)

The genuine acts of concern from the family member with dementia created a sense of satisfaction and appreciation from the family members providing the care. Evidently, all it required was a simple act of being considerate and thoughtful from the person with dementia. The following was what Clive from Family 2 shared about Dolly’s show of concern and acts of being considerate and appreciative which had touched him:

“In the morning, she is very concerned about us. In the morning when I return home tired, she saw me eating. After that, she will tell me, "You haven't eaten? Hurry up, go and eat." She knows I need to go and sleep in a short while. Then, I said, "I bring you for a walk. Very hot. I bring you for a walk. She said, "You go and sleep first. My walk is not necessary." Her telling me all these has two aspects. Another aspect is, she cares about me. Looking at her thinking, she is satisfied with the entire care process.” (fourth interview with Clive)

Likewise, the family caregivers would usually reciprocate the positive behaviour and actions of the family member with dementia as demonstrated in this shared example from Joy (Family 2) on the considerations related to a particular meal preparation:

“For example, breakfast, we know certain food, she doesn't really like to eat and we changed to something else. For example, if we boil something, she wants something softer right? Then, we want crunchy ones, we scoop out the crunchy ones first. Then, let the balanced ones cook longer so that we can eat the crunchy food and she can eat the softer ones. Do together. She doesn't want to be too spicy, then we scoop out
her portion already, then, the balance, we put chilli [Laughs].” (second interview with Joy)

For family members who were less expressive, closeness was demonstrated through their behaviour and acts of concern. For example, closeness between Kit from Family 2 and his grandmother, Dolly, was evident in the photographs of them seated together in the park and the spontaneous acts of putting on a cardigan for Dolly when she was unwell as shared in chapter five. Indeed, some family caregivers shared that the process of caregiving had brought about unity in the family: “At the end of it all, we still need a unified approach. So, in spite of all the scolding, frustrations and anger, it did result in better unity internally” (fifth interview with Ben from Family 3). Other family caregivers also shared that their involvement in the caregiving process created a sense of appreciation from the extended family and rallied together the members of the immediate and extended family:

“After that, all of them do appreciate what Ginny and I do for my mother and I would say, we are still a very close knit family. We care for one another and if there is any problem in our midst, we would help out in that sense. We will see what we can do to help out. So, we are still very close. For Ginny and I, as we take care of our mother that time and even now, after my mother has left us, my nephew and nieces are still very close to Ginny and me. I think it has brought us closer. Because some of our siblings are divorced. They went through hardship. So, one reason why our nephew and nieces are close to us is because we have been helping them.” (sixth interview with Ellie)

However, caring was not all about a positive experience, as important as this was in maintaining close family bonds. Caring for the person with dementia brought out many strong emotions amongst the immediate and extended family members who were providing, or required to provide, care at home. During the course of the dementia, at times the caregiving issues ignited, or magnified, long-standing family conflicts so much so that the relational bonds became weakened. As mentioned previously, this was manifested in the case study involving Olive’s eldest brother from Family 1 who was resentful towards her and had actually accused her of attempting to seize the one and only possession left behind by their late father – the three-room HDB apartment - for herself. To Olive this was one of the key reasons why her eldest brother was reluctant to initially render his support. Another example was Angel’s favouritism towards Pete. Thus, Olive felt resentful towards him for not showing his concern during the earlier days of Angel’s dementia. Underlying conflicting relationships, if left unresolved, ran the risk of deepening and hardening the opposing positions taken up by intergenerational family members. For example, when Olive operationalised the Parents’ Maintenance Act on her two brothers, the family relations
worsened from ‘distant’ to ‘conflicted’.

For Ellie and her sister (Ginny) from Family 4, it was a natural role acceptance by them as unmarried daughters. On the other hand, Clive and Joy from Family 2 were hoping for Joy’s eldest brother, who was residing overseas with his family, to, at least, show more concern for Dolly by making more frequent and regular contacts via telecommunication. Their hopes turned to anguish and disappointment when Joy’s eldest brother did not even carry out the minimal expectation.

Fault-finding and unfounded accusations from family members who were deemed as unsupported also led to family conflicts. In the earlier days, for Family 4, when Elaine was “difficult to manage” (second interview with Ellie), one of Ellie’s twin sisters (Emma) had accused Ellie and Ginny of “not knowing how to care for her”. The accusations did not go down well with Ellie. Equally, Shaun was aggrieved and resentful of his uncles and aunty for their lack of support in addition to their seemingly ‘unhelpful comments’:

“They like to give a lot of comments that don’t help a lot and make the situation worse. They like to say a lot but they don’t do stuff. I’m just pissed off, these ten days, they didn’t do much… No one talks anymore [chuckles]. So, [chuckles], it's like a battle ground.” (first interview with Shaun)

Conflicts also arose resulting from misunderstanding and miscommunication which were usually unintentional. This further worsened pre-existing familial relations which were already “distant” to begin with, such as the case of Joy and her eldest brother. This could lead to further difficulties if there was very little opportunity for clarifications to be sought, as seen in this extract:

“Another reason is, the wife called up to say that we are in the wrong. This situation, do you know what it is? It is very difficult to explain to this type of people. So, we don’t plan to go over. Going over means there will be contact. When there is contact, there will be problem.” (fourth interview with Clive)

The data indicated that conflict can also arise once members of the immediate and extended family were not mutually trusting of one another. For instance, for Family 5, Mindy’s siblings have demanded for her to show them receipts to indicate what she had spent on Margaret. During my sixth interview with her, she further disclosed the deep distrust her sister has of her and how this has affected her: “She has hundred thousand but my sister still thinks, more than that. Thinks that I keep her money. Extra. So, this is a very sad part for
me. Don't know why they don't trust me.” Others like Ellie from Family 4 had a similar encounter about the lack of thrust from her sibling, that is, one of her sisters was reluctant to support them financially: “Maybe she thinks that if she gives my mother, it's giving to us” (fourth interview with Ellie).

Spousal conflicts arose when the family member had difficulty in managing the behaviour of the relative with dementia. Ben from Family 3 described this as “tension in the house” when they were still trying to deal with Pam’s difficult to manage behaviour. The conflict was a residual effect and fuelled by a prior tenuous relation between the spouse and the person with dementia. Nevertheless, the spousal conflict came to a halt when the family found a solution in the form of the ‘Dusk to Dawn Service’ and their two live-in maids.

5.3.3 Sub-theme: Challenges

Strong familial and relational bonds and a concerted effort by members of the immediate and extended family (internal support network) and, as necessary, relevant support from external support network, are very much needed to overcome the challenges outlined in the sub-theme heading above. Maintenance and sustenance of strong intergenerational kinship bonds only seemed to work effectively by virtue of the elaborate, interconnected and interdependent nature of the close Chinese kinship system. For example, the amount of effort put into the care of the person with dementia was usually dependent on the nature of relational bond family members have with each other as noted under the sub-theme, ‘relational’.

Noticeably, some intergenerational members of the five families have attempted to invest more time and effort by performing more meaningful activities together as an immediate family, or with the extended family if possible, whilst others have given their minimal efforts due to various reasons. To take but one example, Olive, from Family 1, knew the importance of strong intergenerational ties in garnering support for Angel, but was constrained by the relative lack of commitment from her extended family. However, from the latest developments appertaining to the healing sibling relations, there may be hope yet in salvaging the intergenerational ties provided the immediate and extended family continues to come together and have meaningful activities together. This step towards reconciliation was seen in the data in how Olive and Pete now brought Angel for outings ‘down memory lane’ and the immediate and extended family coming together to celebrate Angel’s 86th birthday.
Nevertheless, the specific challenges faced by the families in this study were identified as:

- The geographical distance apart between the immediate and extended family
- Small family unit
- Weakened relationship between the immediate and extended family
- Family conflicts
- Perceived gender-specific roles
- Advanced age of the family caregivers
- Lack of awareness about dementia
- Relevant dementia support resources or services
- Underdeveloped person-centred and family-centred dementia support resources or services
- Unequal access and fairness to service support
- Unsupportive workplace culture and environment
- Intergenerational unfriendly dwelling infrastructure

These issues require timely actions and support from policy makers and relevant authorities. Otherwise, the intergenerational families in this study and countless others like them, will be perpetually left to cope with the responsibility of caring for a family member with dementia without access support themselves. Moreover, many of the intergenerational family members in the study were, and are, working members of society who need these roles protected and acknowledged going forward.

5.4 Meta-theme: Intergenerational Family Connections

Drawing on the shared themes, sub-themes and analysis to date, the data revealed the existence of a meta-theme which has been identified/named as Intergenerational Family Connections and which works to hold the thematic and narrative structure together of the cross-case analysis. As will be shared, Intergenerational Family Connections works to transcend the data as a meta-theme and links together the theme headings in this chapter so that a cohesive and integrated model emerges from the data to explain the relational dynamics that exist in the everyday lives of Singapore-Chinese families caring for a person with dementia in the home setting. I will now outline further the properties of Intergenerational Family Connections drawing on the data and preceding text in this chapter to highlight the meanings and contexts of its application.
The first property of Intergenerational Family Connections is culturally grounded and is the significant presence and influence of strongly held beliefs and practices. This was evident across all these families and it connected together the intergenerational family members and the person with dementia regardless of their professed religion. For example, the families’ religious devotion, beliefs and practices were notably evident with the presence of Chinese deities such as Buddha, Ji Gong, Kuan-Yin or Goddess of Mercy and God of Wealth which were strategically placed on the prayer altar, alongside the ancestral tablet in the families’ homes, and during the funerals – a reminder to the intergenerational family members of the spiritual faiths and beliefs which they shared and connected with. Such deities were represented in many of the photographs in the preceding chapter. The intergenerational family members have even affirmed that they were carrying on the tradition and faith because of their family’s staunch beliefs. Indeed, some family members made it their obligation to assume responsibility of the family’s prayer altar comprising the deities and ancestral tablet. No matter which god, the intergenerational family members and the person with dementia shared a common spiritual connection - to pray for each other’s health, safety, well-being, redemption and/or salvation.

The second property of Intergenerational Family Connections is shared space. This space moves beyond the geographical location of the home and connects intergenerational family members sharing deep emotional bonds and physical contact with each other on a daily basis. These bonding connections were ‘reinforced’ through the many decades of shared togetherness, learning one another’s idiosyncrasies and adapting to one another’s needs. The data, and my own observations, revealed the presence of symbolic forms in the shared spaces, the time and effort spent by each intergenerational family member(s) performing meaningful, engaging and memorable activities together, such as the time-consuming and elaborate artworks by the son-in-law with his mother-in-law in Family 2 - artworks which connected culture and precious memories as one. Moreover, whilst living together in this shared space, the intergenerational family members naturally underwent a long standing history of togetherness and connectedness, that is, from as early as the time of their own birth and marriage until the present day. Their shared and rich history and biography together were filled with numerous memorable family events such as marriages, births, birthdays, first day at school, graduating from junior college, enrolment into National Service and university application; memories that stretched across two to six decades worth of occasions and events for the adult children, children-in-law and grandchildren. So much so that these intergenerational family members would often muse longingly about the past as they related.
fond childhood memories and events they shared with their beloved mothers, mother-in-laws or grandmothers. The shared space became shared memories across the generations. It is precisely this long established history and family biography that participants in this study built together that made it difficult for these intergenerational family members to accept, or let go, when people with dementia progressed to late stage dementia or eventual death, as seen in the study.

This closeness was evident in the third property of Intergenerational Family Connections, namely supporting family togetherness. For the intergenerational family members in the study, the deep connections were not necessarily bound by blood ties; rather, it was through a loving and giving reciprocal relationship that transpired from the decades spent together and of which the caregiving act was just one other activity in a life-time of togetherness. The reciprocity shown by the intergenerational family members in this study was from their gratefulness and repayment of what the person with dementia had done for them previously, and now, in the present. It was a dynamic that did not stop. In fact, the intergenerational members in the study have shared their deep appreciation of the person with dementia whom they shared have taken care of them when young and shown concern for them all this while. Concurrently, I saw a deep connection in the form of filial and unconditional love being displayed and expressed through actions, art work, affections and spoken words. For example, the “24 exemplars of filial piety” by a Chinese scholar of the Yuán Dynasty was cited by one of the daughters in this study when she explained why she chose to care for her mother. The stories in the exemplars covered not only unconditional but sacrificial love for one's parent(s) as well. I saw filial love so deep that one daughter expressed her unwillingness of losing her beloved mother whom she had tirelessly cared for nine years. I saw a mother-in-law living with dementia who prayed for her only grandson's safe journey abroad and sacrificed her daily walks so that her son-in-law could rest after his night shift. Reciprocally, the son-in-law invested time to co-create artwork with his mother-in-law with dementia and cared for her.

In summary, the meta-theme of Intergenerational Family Connections highlights the importance of family connections and how these influence the intergenerational family members and person with dementia within the context(s) in which they live and socialise. A heuristic as shown in Figure 26 draws together the data in this chapter and displays the relationships, and inter-relationships, that exist. Arguably, Figure 26 also informs health and social care practitioners who are involved with families of the importance of making
anticipatory goals and to be aware of the current and future supportive mechanisms that sustain family connections for intergenerational Singapore-Chinese families of people with dementia.

In the context of the intergenerational Singapore-Chinese families of people with dementia, making anticipatory goals would mean that health and social care practitioners need to better understand the relational dynamics and connections of the intergenerational families. Only then can supportive mechanisms in the form of preventive or interventional support be recommended and put in place, especially when potential intergenerational conflicts and challenges are predicted or identified. Several examples from this present study will be shared to illustrate this. For example, in chapter four, from the beginning stage of Angel’s dementia until the earlier part of my research encounter with the family, Olive’s relation with her siblings was strained. At one time, she was even accused by her eldest brother of attempting to grab the one and only possession left behind by their late father – the three-room HDB apartment - for herself. She reckoned, this was one of the reasons why her eldest brother was reluctant to help initially. It continued until the house ownership was transferred to her. A further point of contention with Olive was the fact that Angel had always shown favouritism towards Pete and, yet, it was Olive who ended up caring the most for her. This was the reason why Olive felt angry with Pete for not showing his concern for Angel during the earlier days of her dementia. Arguably, working with the three siblings on their pre-existing issues and exploring ways to address these could have served to better improve the siblings’ relationship in the earlier days and hastened reconciliatory efforts. Such an anticipatory and preventative intervention may have ameliorated the many emotional struggles that Olive went on to experience.

Keeping with this case, Olive’s eldest brother was facing marital problems of his own when Angel started having dementia. Pete, on the other hand, was still bitter about his own divorce and had yet to come to terms with Angel’s dementia. Recommending and providing support to Olive’s two brothers could have helped them to cope better with their own personal struggles. Such an anticipatory helping action may have allowed them to better contribute towards the care of their mother, Angel, rather than leaving Olive to take on the majority of the caregiving tasks for their mother.

5.5 Summary
This chapter has highlighted the everyday experiences of intergenerational family members
caring for a family member with dementia as described during the longitudinal interviews and directly observed in this study. An important meta-theme within the data has been how the intergenerational families maintained their family connections and how these influence the intergenerational family members and person with dementia within the context(s) in which they live and socialise. As the data from the five intergenerational families illustrates, this extends to relationships, and inter-relationships, that exist. Analysis indicates the relational dynamics that exist in the everyday lives of intergenerational Singapore-Chinese families caring for a person with dementia in the home setting. This dynamic process is likely to occur throughout the caregiving trajectory of dementia, with the needs of the intergenerational family changing whilst the family attempts to re-adapt along the way. A potential model for further research and practice serves to inform health and social care practitioners who are involved with families of the importance of making anticipatory goals and to be aware of the current and future supportive mechanisms that sustain family connections for intergenerational Singapore-Chinese families of people with dementia.
Figure 26: A model of Intergenerational Family Connections (IFC)

Intergenerational Family Connections

- Meta-Theme
- Theme
  - Family Values
  - Family Support
  - Family Bonds
  - Sub-Themes
    - Culture
    - Religion
    - Filial Piety
    - Timeliness
    - Internal Support Network
    - External Support Network
    - Relational
    - Closeness and Conflict
    - Challenges
CHAPTER SIX
DISCUSSION

6.0 Introduction
This chapter begins with a review of the present study’s findings on family connections, relational dynamics and how these may inform health and social care practitioners who are involved with intergenerational Singapore-Chinese families on two main areas. First, the importance of making anticipatory goals and second, to be aware of the current and future supportive mechanisms that sustain intergenerational family connections for families living ‘under one roof’ where one member has dementia. The study’s findings are taken into account within the broader context of the past and current literature and its implications for education, practice, policy and research in dementia made visible. This chapter concludes with an outline of the study limitations and methodological reflections.

6.1 Contribution to Knowledge
This study presents an original and novel contribution to the literature on intergenerational family care in dementia and the first time such a longitudinal qualitative study in family care and dementia undertaken in Singapore. Digital photographs, ecomaps, genograms and transcript data were used in the study design which included intergenerational family members residing together as part of a family unit. This led to an in-depth understanding about the everyday caregiving experience of intergenerational family members of people with dementia ‘under one roof’, within the shared context of their family construction. The study contributes an original and significant knowledge through the development and presentation of co-constructed family biographies through the use of digital photographs, ecomaps and genograms, the identification of three distinct properties and the development of the meta-theme, ‘Intergenerational Family Connections’. This meta-theme links together the theme headings of the emergent model from the data which depicts and illustrates the family connections and relational dynamics that exist in the everyday lives of intergenerational Singapore-Chinese families caring for a person with dementia in the home setting. The generate model and its meta-theme of ‘Intergenerational Family Connections’ could help to inform health and social care practitioners on the importance of making anticipatory goals and to be aware of the current, and future, supportive mechanisms that sustain intergenerational family connections for intergenerational Singapore-Chinese families of people with dementia.
6.1.1 Summary of Findings

The co-construction of family biographies through the use of digital photographs, genograms and ecomaps with the intergenerational members from the five families in the presented study provided a detailed, and new, understanding about the intergenerational family, intergenerational family systems and the everyday caregiving experience of intergenerational family members of people with dementia, their relational dynamics and how they connected with one another. Through the use of cross-case analysis to understand the everyday caregiving experience of the five intergenerational families, three themes emerged, namely: i) Family values, and its supporting sub-themes of culture; religion; and filial piety; ii) Family support, and its supporting sub-themes of timeliness; internal support network; and external support network; and iii) Family bonds, and its supporting sub-themes of relational; closeness and conflict; and challenges. This study also generated a meta-theme ‘Intergenerational Family Connections’ which was supported by three properties: i) Strongly held beliefs and practices; ii) Shared space; and iii) Supporting family togetherness.

As seen in the heuristic diagram in Figure 26, the data in this study suggests the relational dynamics that exist within the intergenerational families and how they connected with each other. Arguably, Figure 26 also informs health and social care practitioners who are involved with families of the importance of making anticipatory goals and to be aware of the current and future supportive mechanisms that sustain family connections for intergenerational Singapore-Chinese families of people with dementia.

The focus on relational dynamics and connections within an intergenerational Chinese family system, has not been traditional in both research and service provision in dementia studies; hence, a more complete understanding of the intergenerational family experience in dementia and, therefore, intergenerational family support needs may have been overlooked up until this point in time. A critical and more in-depth understanding of the potential model of relational dynamics and intergenerational family connections, gained through knowledge of the intergenerational family biography may allow health and social care practitioners, policy makers and relevant authorities to address the needs of intergenerational families in transition to provide informed, individualised, and needs-based care. This will be returned to later in the chapter.
Figure 26: A model of Intergenerational Family Connections

- **Meta-Theme**: Intergenerational Family Connections

- **Theme**: Family Values, Family Support, Family Bonds

- **Sub-Themes**: Culture, Religion, Filial Piety, Timeliness, Internal Support Network, External Support Network, Relational, Closeness and Conflict, Challenges
6.1.2 Intergenerational Family Connections

The findings of the present study complements some of the previous works undertaken in family systems and chronic illness which examine the psychosocial demands and time phases of an illness (for example, dementia) and are thought to affect a family’s experience of living with chronic illness (Rolland 1984, 1987a, 1987b, 1988, 1990, 1994, 1998). The aforementioned family systems model (Rolland 1984, 1987a, 1987b, 1988, 1990, 1994, 1998) suggests a biomedical, psychosocial and strength-oriented perspective in which family relationships are viewed as a resource, and emphasises the possibilities for resilience and growth, not just a person’s liabilities and risks (Walsh 1996, 1998). This present study examined the everyday caregiving experience of intergenerational families of people with dementia across a longitudinal period leading to the development of a model to understand their relational dynamics and how they connected with each other on an everyday basis. Once the relational dynamics and connections of the intergenerational families are better understood, only then can supportive mechanisms be recommended and put in place.

Another point to draw upon is the way most models on family systems construct the meaning and composition of the family unit. For instance, Rolland’s (2012) system-based, biopsychosocial model broadly defined the ‘family’ as all persons involved in the family unit and caregiving, but it did not clearly include members outside the nuclear/immediate family. His earlier work in 1988, and the case examples provided then, also bore a similar conclusion. As seen in this present study, the intergenerational families transcended beyond the nuclear/immediate family to include the extended family who are usually related and connected by birth, marriage and adoption. It is precisely this collectivist form of intergenerational family network, as compared to the often Westernized and individualistic type of family structure, which forms the internal support network for the intergenerational Chinese families. An understanding of this collectivist form of intergenerational family network is thus important in ensuring that the intergenerational family unit remains resilient for as long as possible. Such a cultural family construction is important as it enables supportive mechanisms to be put in place when potential intergenerational conflicts and challenges are predicted or identified.

Furthermore, earlier works on family systems and chronic illness seem to focus on the history and values of families and how components of family functioning impact on a family’s interaction with a chronic illness (Rolland 1988). Thus, the research focus in the present study has shifted from the biomedical, psychosocial and time phased aspects of
dementia as a chronic illness to the subjective and co-constructed biographical, everyday experience of intergenerational family members caring for a family member with dementia. In my own work, this co-construction was seen to be supported by sharing a deep connection with one another through ingrained strongly held beliefs and practices with this work taking place in a shared space where the intergenerational family found meaning in caregiving, namely supporting family togetherness. It is this positive caregiving process that researchers such as Nolan et al (1996), Frankl (2006) and Keady and Harris (2009) have emphasised in their attempt to provide a more balanced and rounded account of the caregiving experience.

The present study, therefore, suggests supporting intergenerational Chinese families through their cultural grounding in strongly held beliefs and practices which connect the intergenerational family members and the person with dementia. For instance, the intergenerational family members and the person with dementia share a common spiritual connection - praying for each other’s health, safety, well-being, redemption and/or salvation. As presented, Shaun from Family 5 prayed to Buddha for the wellbeing of his entire family (parents, sister and grandmother - Margaret):

“I mean that's what religion is for right? People praying. Ask for something. Higher order. I don't know. I always wish say... wish that... make sure everything is ok, you know. Like when I pray, I always hope that my grandma's ok. My mom's ok. My dad's ok. My sister's ok. My friends are ok [laughs]. I'm ok. Yeah. So, my grandma is part of my wishes [chuckles].” (first interview with Shaun)

This finding highlights the need for support services to provide a family specific cultural focus as based on the intergenerational Chinese families’ beliefs and practices which should be individualized, and not subjected to a generic biopsychosocial-based and time phased family life cycle as suggested by earlier works on family systems (Rolland 1988; Rolland 1994).

Several studies have attempted to suggest that caregiving changes over time, resulting in ‘temporal’ models which try to identify key transitions or points of change (Aneshensel et al 1995; Keady 1999; Kobayashi et al 1993; Nolan et al 1996; Wuest et al 1994) when suggesting preventive or interventional support. The assumptions about the nature of the dementia caregiving experience based on these studies use samples mainly derived from Caucasian or white caregivers and the experience may not necessarily be applicable to caregivers of other ethnicities, particularly, in the case of the reported study, where intergenerational Chinese caregivers have specific cultural beliefs and practices that hold a
significant influence on care practices. Hence, such temporal and sensitizing models need to be extended to consider cultural diversity. That said, cultural considerations in caregiving for a person with dementia have been receiving some attention in the literature (Connell & Gibson 1997; Janevic & Connell 2001) although this focus is lacking in the local Singapore context.

Unlike the earlier works and Western-based temporal models of caregiving (see for example: Aneshensel et al 1995; Keady 1999; Kobayashi et al 1993; Nolan et al 1996; Wuest et al 1994), the present study has highlighted the need to enhance the relational dynamics as depicted in the everyday, long standing history of togetherness and connectedness of the intergenerational families in the shared spaces they call home. For example, the designated spaces in the families’ home (Families 1 and 5) in which ancestral tablets were displayed and connected the families to their ancestors and each other. Also, the acrylic paintings which were purposely drawn by Clive (from Family 2) for and in collaboration with his family. Their shared deep emotional bonds through a loving and giving reciprocal relationship and constant physical contact with each other should not be underestimated.

Indeed, Deist and Greeff (2017) found that family connectedness, spirituality, acceptance, optimism, positive communication patterns, social support, economic resources and the effective management of symptoms were necessary factors in helping families adapt to caring for a family member with dementia. Researchers have also speculated that because caregiving is a cultural norm in Eastern societies, it may be a protective mechanism against caregiver distress (Gupta & Pillai 2002; Lai 2010; Shaw et al 1997; Yeon & Levkoff 2001) just as may the case in African American cultures (Haley et al 1996). Studies on Chinese American caregivers also support this hypothesis to some extent (Hinton & Levkoff 1999). In addition, some studies have suggested that Asian family caregivers with high levels of dependence on the extended family may well be contented with just that in order for them to undergo the caregiving journey (Lee & Sung 1998; Youn et al 1999). The model of ‘Intergenerational Family Connections’ presented in this study also proposes for any potential conflicts and challenges to be identified and addressed by working with the immediate and extended members of the intergenerational family.

A study on family dynamics and personal strengths among dementia caregivers (Elnasseh et al 2016) suggests that families with strong family values were more connected and flexible, as also seen in this PhD study. Moreover, ethnic, racial, and spiritual beliefs and prevailing
cultural norms can strongly influence family values concerning health and illness (McGoldrick et al 2005; Rolland 2006; Walsh 2009). The literature also asserts that culture, beside influencing values and beliefs toward caregiving, influences caregivers’ motives, coping styles, roles and responsibilities in caregiving, caregiving outcomes, and the use of family services, resources or support (Chan 2010; Dilworth-Anderson & Gibson 2002; Dilworth-Anderson et al 2002; Knight & Sayegh 2010).

As depicted in this present study, family values of the intergenerational Singapore-Chinese families were strongly influenced by the cultural context in which care took place, the religious beliefs and practices and the practised value of filial piety which dictated respect for their older family member with dementia. For these intergenerational families, family values was part and parcel of being culturally Chinese in which a combination of Buddhist, Taoist and Confucian beliefs further reinforced this deeply traditional value. Existing theories on caregiving and culture support that caregiving patterns are influenced by traditions and values, particularly in caregivers of Asian ethnicity. Jones (1996) also reported that Asian caregivers in their study were deeply and positively involved in providing care for a family member. Additionally, Jones et al (2001) found that being highly involved in caregiving roles was significantly and positively correlated with overall health among Chinese caregivers. Although the relationship between health and caregiving was not a component which was determined in this present study, the intergenerational family members who participated had consistently shared that they found joy and denied feeling burdened when looking after their family member with dementia. Their burden was more associated with conflicts within their internal support network, particularly siblings, as will be discussed later in the chapter.

Nature and object held significant traditional cultural meaning and values for the intergenerational families and connected them to each other in this present study. Across the data set, the essence of Chinese culture was strongly depicted in symbolic forms in the shared spaces which the families were residing. The presence of Chinese symbolism in these shared spaces depicted deeply rooted traditional Chinese values and practices such as the display of Chinese deities and ancestral tablets in the shared spaces of Families 1 and 5 (refer to Photographs 32 to 36 in chapter 5). According to Hinton et al (2008), religiously and spiritually based symbolic meanings are likely key resources that caregivers (such as Chinese caregivers) draw upon to shape their motivations and approach to the everyday process of their caregiving experience, just like, for example, the acrylic paintings which
Clive from Family 2 drew for his family. Nevertheless, despite increasing knowledge on ethnic differences in family caregivers’ experiences, the extent to which caregiver interventions are culturally tailored to address these differences is still relatively unknown (Napoles et al 2010) and under-researched in Singapore. A systematic review (Napoles et al 2010) of the literature published from 1980 to 2009 suggests that more caregiver related studies focused on cultural tailoring are needed. In addition, none of the studies in the literature mentioned much about symbolic forms and their significant influence as observed in this present study. Even Hinton et al’s (2008) study which briefly mentioned religiously and spiritually based symbolic meanings, failed to examine whether this has served to connect intergenerational families together. This present study hopes to shed some initial light on this topic area, especially through Family 2. For example, Clive has consciously connected his family together through the many paintings which he has purposely drawn. He believed that, for instance, the fish which he has drawn would endow the family with good luck and prosperity. As seen in chapters four and five, the major purpose of some of these symbolic paintings was to create a familiar environment in the shared space to prepare Dolly (the person with dementia) when the family moves house at the end of 2016. Also, one of Clive’s fish paintings was meant as a motivation for his son (Kit) when he enters university.

Religion and spirituality are important for intergenerational families providing care to a person with dementia (Milne & Chryssanthopoulou 2005; Gerdner et al 2007) as observed in the present study. However, in Singapore, very little research work has been done which examines the relevance of religion and spirituality among intergenerational Chinese family caregivers and how this important element has connected them together. This research gap is of particular concern in view of the rapid increase in the projected number of older Singaporean Chinese, including those with dementia. It is also a gap that requires urgent redress as the Asian Chinese religious and spiritual traditions which is deeply rooted in Confucianism differ significantly from other religions, such as the Judeo-Christian traditions. Previously, a descriptive, naturalistic field study using qualitative interviewing techniques by Acton and Miller (2003) was used to collect data from family caregivers of people with dementia in the United States to investigate spiritual meaning in caregivers of family members with dementia. In this study (Acton & Miller 2003), spirituality was described as a connection between a higher power, others, and oneself. In other studies, spirituality was frequently reported as a personal resource by family caregivers as they saw caregiving of a family member with dementia as the challenge which was ordained by God.
and a somewhat sacred responsibility (Jones et al 2002).

In fact, the significant presence and influence of Taoist and Confucian beliefs and practices across the five intergenerational families regardless of their professed religion in relation to how they lived and cared for each other suggest how the intergenerational members of the five families have connected with each other. As Taoists, they worshipped many different gods (or deities), believed in respecting heaven, worshipping ancestors, a spiritual world existing in parallel and interconnecting with the world they lived in and being compassionate to all under the ‘heavens’. Respecting the heavens and ancestral worship connected the intergenerational members of these five families together. Indeed, Ikels (1980) has even suggested that the older person is seen as a connection to the ancestors of the family (intergenerational Chinese family), and upon death, it is believed that he or she would join the ancestors who are being worshipped. This was as shared in chapter 5, for example, on how Olive and Pete (from Family 1) were fulfilling their mother (Angel’s) staunch Buddhist-Taoist belief, with Pete taking charge of the family’s prayer altar and ancestral tablet – offering joss sticks and fresh fruits to the deities and ancestors.

Filial piety, a core value of the Chinese culture, originates from the very traditional Confucian philosophy of more than 1,000 years (Li 1997; Sung 1995, 1998; Zhan et al 2006) and is the core value on which many other values derive from (Wing 1995). As seen in the present study, within the context of the Chinese culture, providing care to their older family member with dementia was an obligation as well as a traditional and highly regarded practice and belief by the intergenerational family members. For example, Mindy, from Family 5, shared that filial piety was an essential part of the Chinese culture: "We are Chinese. I always think that, you know, Chinese, even mother, we have to be filial" (sixth interview). Importantly, the literature supports three important conditions governing filial piety which were observed in the present study: respecting one’s parents, not bringing dishonour to parents, and taking good care of parents (Sung 1995). This precise element of Confucian respect for older people, filial piety and reciprocity, was represented across the intergenerational families in this study. In fact, Jones (1995) described elements of filial piety such as ‘paying respect’ based on feelings of gratitude, indebtedness, and responsibility as the primary descriptor of care for older parents by caregivers from Asian ethnicity. This inherently innate cultural value was held in high regard, and closely observed and adhered to, by the intergenerational family members in this present study. Several studies have suggested that the stronger the caregivers’ affiliation with, and endorsement of, filial piety,
the greater the likelihood of carers perceiving caregiving with positive regard and supporting the care of older people (Lai 2010; Lin & Yi 2013). One daughter (Mindy from Family 5) from the present study even recited the “24 Exemplars of Filial Piety” which were deeply ingrained in her and dictated her filial acts.

In the present study, the shared filial responsibility of the person with dementia was an expectation of the intergenerational family caregivers with more siblings. Those with more siblings were co-residing with the person with dementia, while their siblings were expected to assume other filial duties. This finding partly resembles the earlier work of Bengtson et al (1990), whose analysis of the data from seven countries concluded that the number of family members is predictive of intergenerational contact or support. Contrary to this position, the eldest son, who has traditionally been expected to live with, and provide care to, ageing parents in Asian societies, is no longer the case - as seen in the present study. For example, the eldest sons from Families 1, 2 and 5, much to the disappointment of their female siblings providing care. As shared by Olive from Family 1 during my first interview with her: “My brothers don’t care! I was the one who insisted on bringing ma ma to see the doctor when she kept losing her way and ended up at the police station.” Similarly, Joy also articulated her frustration during my second interview with her: “Very fed-up! Chinese New Year card also didn't send. Keep telling people that he missed her. Hypocrite! Last time, also didn't care.”

Filial piety would also determine if the intergenerational caregivers were likely to use formal support services. According to Yeon and Levkoff (2001) and Sung (1994), filial obligation affects one’s motivation to use formal services. As such, the strong emphasis on filial obligation could well be a deterrent in family caregivers’ unwillingness to use formal services (Yeon & Levkoff 2001). This was seen in this present study when the intergenerational families were deciding on triggering their external support network. I will return to this later.

The findings from this study also suggested that timeliness related to a diagnosis of dementia, and its relevant management, appeared to rely heavily on when the immediate and extended members from the five intergenerational families decided to seek professional help. As revealed in the data, there was a general lack of awareness about dementia. Some of the intergenerational family members in this study have attributed dementia to being an ‘invisible’ condition in society as compared to other more prominent conditions, such as
diabetes, hypertension and stroke. This seems consistent with findings from other studies involving caregivers of people with dementia (Jones et al 2006). In fact, according to Ayalon and Arean, (2004) and Guo et al (2000), this phenomena is prominent in the Asian community where older people generally receives a later diagnosis of dementia in which timely intervention and treatment are no longer feasible options. This was the outcome for most of the intergenerational families (Families 1, 3, 4 and 5) in the present study where the receipt of a diagnosis of dementia was already at the moderate stage for their family member with dementia.

The delay in seeking diagnosis for the person with dementia was generally due to a weakened relationship between the intergenerational family members. This was seen in Family 1 where Olive had a difficult time convincing her two brothers during the earlier days. As shared in chapters 4 and 5, she was even forced to make her brothers commit financially by bringing the matter to the Family Tribunal Court which operationalised the Parents’ Maintenance Act. Moreover, in this study, carers identified that dementia would become more ‘visible’ in society if more prominent public figures with the condition spoke out (Jones et al 2006).

Conversely, supportive, proactive and motivated families were pivotal in ensuring timely diagnosis, as seen in Family 2 in which Dolly’s repeated buying of groceries had actually triggered the family’s suspicion that something was wrong. This is an important consideration as the intergenerational family members are the ones who are residing in the shared space with the person with dementia and may also have noticed difficulties in communication and personality or mood changes as compared to the formal caregivers (NICE/SCIE 2006). Therefore, family pro-activeness is of particular importance in the dementia trajectory, particularly at the time of its onset and early signs (NICE/SCIE 2006).

Difficulty differentiating between memory problems that are a ‘normal process of ageing’ and those that signal the onset of dementia and the belief that little, or nothing, could be done, were hindrances to timeliness in diagnosis in the present study. For example, Olive’s (Family 1) brothers were of the belief that little, or nothing, could be done for Angel and were unsupportive of Olive when she suspected, and wanted, to seek medical help to ascertain her diagnosis. To them, dementia was irreversible and not worth the financial outlay “a waste of money” being the reason given. Interestingly, amongst Chinese caregivers, there are even notable differences in their aetiological understanding of dementia (Ramsay 2016) depending on geographical location. For Taiwanese caregivers, pathology is
the attributable cause of deterioration for their older family member, while for the mainland Chinese and Hong Kong caregivers, deterioration of their older family member is part of normative aging (Ramsay 2016). Meanwhile, like the mainland Chinese and Hong Kong caregivers, a study on 150 community-dwelling lay Asians in the United States found that participants had difficulty distinguishing between memory problems that are part of normal ageing and those that signal the onset of dementia (Werner 2003). Recently, Singapore’s Institute of Policy Studies reported a Mental Health Literacy study, conducted between March 2014 and March 2015 by the Institute of Mental Health (Singapore), found that a common misconception of dementia is that it is part of the natural ageing process and that nothing could be done to lower the risk of developing it (Ho 2015). This suggests that more concerted efforts would need to be done to increase awareness about dementia to the general public in Singapore.

Although the intergenerational families in the present study did not express memory loss as a normal part of ageing in relation to cultural acceptance, cultural norms may have led them to accept the memory problems as ‘normal’ until a more significant degree of impairment occurred, thus further delaying diagnosis for a family member with dementia (Hinton et al 2005; Jones et al 2006). Denial that the older family member may likely have dementia as seen in the cross-case analysis of the five intergenerational families, was also a common finding in other studies (see for example: Jones et al 2006). In any case, denial may well be culturally-based, or related to a lack of awareness, or both. Ultimately, the implications from the general lack of awareness has led to seeking medical help only when the intergenerational families are faced with unmanageable behaviours of the family member with dementia. In several studies, Asian people are unlikely to even report symptoms of dementia in general to medical professionals unless family caregivers require help with behavioural issues (Kim et al 1989; Watari & Gatz 2004; Wu 1975; Xiao et al 2014).

The delay in timeliness of relevant support resources or services, such as respite care and informational support for the intergenerational families in the present study, was another highlighted issue. For example, when Olive, Ben and Mindy from Families 1, 3 and 5 respectively were in need of temporary respite care, the service was simply unavailable and institutionalization (temporary placement in a nursing home) of the family member with dementia became an imminent and difficult choice. Olive and Mindy even shared that it “broke their heart” when they were forced to make the difficult choice of admitting their mothers temporarily into a nursing home. This finding is congruent with Gibson and
Anderson’s (2011) study in which diagnosing dementia, and adequately connecting families with information and supportive services, were identified by family caregivers to be challenging processes. Gaining a definitive diagnosis by physicians took three months to a year to make and there was often little in place to systematically link families with community organizations. Similar to the intergenerational family caregivers in this present study, the caregivers in Gibson and Anderson (2011) and Innes et al.’s (2011) studies were not adequately provided with information about the disease, or about community resources when needed. Obviously, this caused intergenerational members in this study much distress as they were caught ‘in limbo’ and unable to make timely decisions.

Timeliness in engaging a live-in maid was dependent on the behaviour of the person with dementia and whether the immediate family members, or member(s) in the household, were able to cope with the caregiving role. Having a live-in maid was always a last resort in the shared space of the home and this played out in the discussions and relational dynamics seen across the five families in the PhD study, a finding that bore similarities to the work of Tew et al (2010). Researchers have even argued that while this shared space is the ideal caregiving space for older people in which the live-in maid needs to be positioned, the home is usually deemed as a private and secure space which is accessible only to the intergenerational families (Teo et al 2006). Chinese people are usually wary of ‘strangers’ unless the person is part of the family (Miahouakana Matondo 2012). Hence, while the live-in maid being placed as caregiver for the older people with dementia in the home space is a solution to resolve the care crisis within the family realm, the ambivalent positioning of the live-in maid - who is still regarded as a ‘stranger’ within the private space - remains uncomfortable and accepted with reluctance by the intergenerational families. As shared by a grandson (Shaun) in the present study, he was certain that the live-in maid would not be able to understand his grandmother due to cultural and language barriers. At one level this concern is understandable as the 239,700 live-in maids in Singapore are generally Indonesians and Filipinos who constitute about 80 to 90 percent, with other nationalities (mainly South and Southeast Asian from Sri Lanka, Myanmar, India, Thailand, and Bangladesh) making up the rest (Ministry of Manpower 2017; Yeoh & Huang 2009).

Some of the cited reasons in engaging a live-in maid included intergenerational family caregivers feeling ‘uncomfortable’ when dealing with their parent’s intimate care needs, health issues and having to work full-time. For example, some intergenerational caregivers in this present study, like Ben from Family 3, felt uncomfortable dealing with his mother’s
(Pam) more intimate care needs even though he was seen as the primary caregiver. In addition, he did not have siblings to depend on. As suggested by McDonnell and Ryan (2011) in their review of 56 research articles on men caring for a relative with dementia, sons in Eastern society, who are portrayed as the primary caregiver, usually receive assistance from their wives to perform direct physical care for their mothers. In this case, the son’s role assume a more coordinating or supervisory role as opposed to a hands-on role. However, in the present study, Ben was forced to employ a live-in maid as he did not wish to impose on his wife (Barbara) to perform direct physical care for his mother, Pam. Perhaps, due to her prior conflicts with his mother (Pam) as shared in the earlier chapters and through this sharing: "most of the ADL would be handled by them. I cannot handle. Firstly, because I'm male [chuckled]. I can't do bathing or changing clothes. And, not fair to my wife to do it either. So, they have to handle it" (sixth interview).

The intergenerational family structure of the five intergenerational families was formed by an extensive internal support network whether or not family members were in a single/nuclear family household, extended family household or other forms of living arrangements. For instance, Ellie’s (Family 4) nephews and nieces still maintained a close bond and kinship with the family even though they were not residing ‘under one roof’. One of the nieces would “visit every Sunday, without fail”. As stated by some Chinese scholars, the extended family is an essential structure of the intergenerational Chinese family (Guo 1989, 1995; Ma 1986). This may be best understood from the cultural perspectives that the extended family assists in fulfilling tasks throughout the family life cycle, such as providing care for ageing parents and grandparents. In particular, the Chinese nuclear/immediate family is not completely independent, but anchored within an extended family network and has constant physical interactions, and emotional and financial exchanges, with their other intergenerational members (Xu & Xia 2014). This was also seen in the present study. The findings from the present study were consistent with Chinese cultural norms derived from Confucianism and a collectivist way of doing things and remaining connected. For instance, as shared by Ellie from Family 4 and when I attended Elaine’s wake after she passed away, the children and grandchildren from the extended family came together to make the funeral arrangements and provided their support.

In the case of the present study, the extended intergenerational family members were expected to render informal support in the provision of instrumental activities of daily living, activities of daily living, financial and/or emotional support. As noted in other studies
involving Chinese and Korean caregivers, the extended family is always a key source of support (Jones et al. 2002; Kua & Tan 1997; Lee & Sung 1998; Xiao et al. 2014) and some researchers (Gupta & Pillai 2002) have even argued that the larger the support network, the lesser the level of caregiver burden. This is a similarity expressed by the intergenerational families in this present study. Also, high levels of social support, especially from within the family, are associated with higher resilience (Wilks & Croom 2008). Consequently, these characteristics can lead caregivers to experience ‘uplifts’ in caregiving (Pinquart & Sörensen 2003) as seen in the case of Clive from Family 2 who was well supported and appreciated by his wife (Joy) and son (Kit).

On the other hand, a larger support network does not always necessarily translate to lesser burden. Burden only decreases if the perceived and expected filial contributions are delivered. For example, Mindy from Family 5 consistently told me that the stress was not from looking after Margaret, but, rather, from her second brother and her eldest sister: “Not stressed by her but actually stressed by my brother, sister to tell me this, what to do and you are wrong. You are not that... They even told me, "You think you are very clever!"” (fourth interview). Unlike the West, in Chinese societies, it is a common and expected norm that older people live with their intergenerational families, as residential arrangements, support, and care are supposed to be best handled within the family (Hu & Chou 2000; Petrus & Wing-Chung 2006).

As seen in the cross-case analysis in chapter 5, certain traditional perceptions of gender-specific support still remained an expectation of the immediate and extended family (male siblings) in which the unmarried daughter was automatically identified as being responsible for taking care of the family member with dementia. The limited findings from the literature suggests gender differences in intergenerational support, and that some men may align care to a feminised activity (Baker et al. 2010; Pan 2002) especially if they hail from a particular culture (Chinese) in which females (the unmarried daughter and/or daughter-in-law) have traditionally been tasked to provide care for older people. Studies on the experiences of family caregivers of people with dementia in Singapore and Malta also found the same gendered expectation (Innes et al. 2011; Kua & Tan 1997). In Korea, daughters and daughter-in-laws are also most likely to provide care (Kim 2001), due to prevailing traditional cultural expectations on the expected role of women in caregiving. Above all, the patriarchal notions of Asian familialism (Leitner 2003; Sen & Stivens 1997) continue to influence the expectations of male members of some of the intergenerational Chinese families in this
present study. As shared by Olive from Family 1: “Therefore, my brother said, ‘You are currently the one staying with mom, also unmarried. Therefore, the responsibility is on you!’” (second interview).

Furthermore, daughters are much more likely to become their mother’s primary caregivers (Leopold et al. 2014) as also seen in this present study. Parents are more likely to experience a switch in caregivers if they have more sons than daughters, or have a higher number of children (Scommegna 2016). This was the case for Family 5. Here, the person with dementia (Margaret) had to transit between her three adult children. Often, the choice of a primary caregiver was related to expected gender norms and availability, rather than adult children’s competing obligations such as work or family (Scommegna 2016). Typically, the aforementioned findings supported the data in the present study.

Spousal support was also an important source of internal support network for the married family caregivers in the present study. Although there is a general abundance of literature on caregiving, the literature has yielded scant studies involving son-in-laws in dementia caregiving, as evidenced by a critical appraisal and review of 56 papers between 1999 and 2010 with only one study where a participant was the son-in-law (McDonnell & Ryan 2011). Prior to that, a study in the mid 1990s (Globerman 1996) also had a son-in-law as a study participant. In both studies, obligation was frequently expressed as originating from their family value or culture of origin, request from spouse and reciprocity. Similarly, there was only one mother-in-law/son-in-law relationship in the present study. Theirs was a very close relationship in which the son-in-law (Clive) had made conscious effort to engage his mother-in-law (Dolly) who was living with dementia on a daily basis through meaningful activities. The relationship was one based on mutual reciprocity with the son-in-law expressing that the caregiving was done out of sincerity and from the heart. Although examination of men as primary caregivers has gained momentum in research (Kaye & Applegate 1990), the significance of the support of male relatives in assisting women caregivers is still not adequately addressed. Nevertheless, assistance from men (husband and other male relatives) appeared to be particularly important to a female caregiver’s ability to sustain their caregiving role (Jones 2002), a position seen in the present study.

However, through this present study, the role of the son and son-in-laws as caregivers of the person with dementia may be better understood. As the data suggested, their contributions as caregivers were greatly appreciated and relied upon. Similarly, Brody and Schoonover
(1986) found that for married daughters who are working, there was more reliance on their husbands to provide direct and indirect care of their parent who was living with dementia. These daughters were appreciative of the support from their husbands in welcoming their parents to live with them, helping financially, accompanying the parents for doctor’s appointments, providing transportation, maintaining household equipment, and assisting with activities of daily living (Jones et al 2002). Additionally, the sharing of filial responsibility between the working adult daughters and their caregiving spouses had brought about a degree of reciprocity (Jones et al 2002). As such, the process of sharing responsibility in providing care for the family member with dementia contributed to the intergenerational family members becoming more bonded and connected, a feature which was seen in the present study, especially in Families 2 and 5.

Another source of support from the internal support network was the grandchildren. Although, support from grandchildren was neither demanded, nor expected, it was welcomed by the main caregivers in this present study. The two grandchildren (Kit and Shaun) from Families 2 and 5 respectively, were wanting to support their parents who were providing care for their grandmothers living with dementia. This implied that their parents’ positive role modelling and close relationships with them were influencing factors. For Kit, the reason why he helped out was to “lighten” his father’s (Clive) “workload”. This complements earlier studies (Celdrán et al 2012; Orel et al 2004) that suggest that caregiving activities by grandchildren were based on parental directives and their own initiative. Grandchildren also acknowledged the influences their parents have in their relationships with their cognitively impaired grandparent. Furthermore, the relationship with their caregiving parents became enhanced as a result (Celdrán et al 2012). Similarly, in the present study, the bond between the grandchildren and their caregiving parents became even closer and stronger. That said, support and non-support can alternate over time within the internal support network of the intergenerational family (Neufeld & Harrison 2003). For instance, Olive’s (from Family 1) two brothers were initially unsupportive but, when they eventually accepted Angel’s diagnosis of dementia and came to terms with the situation, became more involved and were progressively more supportive.

In the area of information and communication technology, the literature lacks clarity on what intergenerational family caregivers do with the wide range of available information and communication technology, such as through the world-wide web (for example, Google search), video-sharing website (for example, YouTube); online social media and social
networking service (for example, Facebook), cross-platform and end-to-end instant messaging application (for example, WhatsApp), instant messaging app (for example, Skype, Messenger), video call and audio chats (for example, FaceTime), blog site (for example, WordPress) and mobile devices, especially how these forms of technology have assisted intergenerational family members in connecting with each other. The closest is a study by Powell et al (2008) which investigated the perspective of informal caregivers (that is, the spouse, son or daughter, grandson or granddaughter) on information and communication technology, including telecare and internet-based resources, but not how they have used these to connect or network with each other and provide support.

As seen in chapter 5, the present study indicated a use of information and communication technology across the five intergenerational families as a means to connect with their internal support network, that is, their immediate and extended family members, as well as to obtain and receive information on dementia to support their caregiving activities. This is not surprising as internet-based information and support systems for family caregivers are mushrooming (Eisdorfer et al 2003; McHugh et al 2012; Pierce et al 2002; White & Dorman 2000) and these are important for the intergenerational families to communicate with their extended family for support and, possibly, to resolve family conflicts.

Dementia-related websites for family caregivers have also proliferated, with the likes of the locally designed and developed Virtual Dementia Home Series which provides family caregivers of people with dementia with information on a dementia-friendly home environment and links to, for example, other useful dementia websites (see www.dementiahomeseries.com.sg). Towards the end of the 1990s, Bass et al (1998) claimed that informal advice and support from information and communication technology sources increases self-confidence in decision-making, and in some cases reduced caregiver strain. Currently, apart from what has been observed in this present study, there is a dearth of studies that examine the use of information and communication technology by intergenerational family members as a means to maintain their internal support network and meaningful connections.

The intergenerational families in the present study were reliant on their external support network in which the nature, and degree of reliance, were dependent upon which point of the care trajectory they were at. Reliance on the live-in maid became a necessity for some, especially the caregiving daughters who were working full-time. A decade ago, Singapore
women’s labour force participation rate was already at 55.6 percent with rates highest for women in the so-called ‘sandwiched generation’, that is those aged between 50 and 54 years old (Yeoh & Huang 2009) and older. A local study by Yap and Seng (2009) found that family caregivers of people with dementia preferred to rely on their own family (immediate and extended) in caring for their family member with dementia. The live-in maid was not a preferred choice. However, the need to juggle the competing demands of the home and the workplace were exacerbated by the declining, extended household and concomitant help from the extended family (Huang & Yeoh 1996). This combination of factors has pushed the intergenerational families in this present study to become reliant on the live-in maid. Furthermore, the lack of, or absence of, pro-family work policies was another trigger (Yeoh & Huang 2009) which has led some of the intergenerational families to turn to hiring a live-in maid to care for their family member with dementia.

In this study, the live-in maid resided in the same household as the intergenerational families and the person with dementia (Families 1, 3 and 4) and whose main duties were to attend to the ‘hands-on’ care of the family member with dementia whilst performing the family’s household chores. The live-in maid is central to these intergenerational families in terms of the specific benefits she brings. For example, in Family 1, Olive described her maid’s role as one of “utmost importance” as she was dependent on her for her mother’s (Angel) activities of daily living and daily feedback on Angel’s condition. According to Olive, her live-in maid had been caring for Angel long enough to be familiar with her condition and behaviour. In fact, during my interviews with the family, she would be the one attending to Angel’s activities of daily living and providing all the specific details about Angel to Olive. Without her input, it would have been difficult for Olive to know about Angel’s condition in detail.

For Family 3, the live-in maids were providing all the physical care for Pam’s activities of daily living which Ben and Barbara were unable to provide on their own due to their own advancing age. Ben did not feel comfortable handling Pam’s activities of daily living either as this would mean being exposed to her body. I could tell that he was not comfortable in this regard. Hence, Ben was deeply appreciative of the live-in maids, particularly their compassion, the nature of the care they provided and the patience which they had shown whilst attending to their mother. In fact, he shared that he has regarded them as being “part of the family”, a situation that emerged over time. Moreover, Ben was in a delicate situation where he had no siblings to rely or depend upon. Consequently, the act of regarding and
treating the live-in maids as his own siblings could be considered both personally advantageous and strategic.

The aforementioned findings bear similarities to the limited number of studies on live-in maids (Basnyat & Chang 2017; Lin & Belanger 2012). A recently conducted qualitative study in Singapore involving primary family caregivers and live-in maids (Basnyat & Chang 2017) has described the live-in maid as someone who provides physical support, emotional and mental relief and a means for the family caregivers to return to their previous routines – much like the caregiving experiences of Families 1, 3 and 4. Similar to Family 3, a qualitative study in Taiwan involving live-in maids (Lin & Belanger 2012) revealed a fictive kin experience where employers (family caregivers) have treated the live-in maids like siblings. The researchers have suggested the evolution of this type of relationship as a strategy by employers (family caregivers) and employees (live-in maids) to negotiate the family boundary involving live-in care. Although this present study has not included the live-in maids as study participants, it has shed some light on the involvement of the live-in maids in the care of the person with dementia and how this has supported the intergenerational family members in their everyday lives and redefined their family boundary.

Apart from the usual healthcare institutions or acute hospital follow-up appointments, the families were referred to the local Alzheimer’s Disease Association which was identified by the intergenerational families in the present study to be a very important and useful external support network for them. This was consistent with the findings from a study in which family caregivers indicated that Alzheimer’s Australia was an important and useful source of information (Xiao et al 2014). Moreover, whilst the Singapore government has been playing a major role in shaping the eldercare landscape and putting long-term plans in place for the older population, it remains apparent that the nation will continue to be faced with a shortage of facilities in home nursing, home medical, home help services and dementia care facilities (Kua & Tan 1997; Mehta 2002; Yeoh & Huang 2009). The current eldercare facilities are not fully accessible to the majority of Singaporean families who are unable to match their financial and social resources with the services (Yeoh & Huang 2009). This suggests and calls for more initiatives in the provision of external support services, as will be discussed later under implications of the study.

The intergenerational family caregivers in this present study were often required to enrol their family member with dementia at a day care centre. Unfortunately, most day care centres
did not cater for people with dementia. In addition, there were limited number of day care centres with admission criteria that the families found ‘punitive’, coupled with a long waiting time for admission. Furthermore, the day care centre’s opening and closing hours often conflicted with the intergenerational family caregivers’ own work schedule, like in the case of Olive from Family 1 when her mother (Angel) was first diagnosed with dementia. 

Oftentimes, the intergenerational family caregivers in the present study found themselves having to re-adapt to a new situation and struggle on their own while awaiting enrolment, or admission, to another support service which could provide support. This was the case for Ben from Family 3 when the family had to struggle on their own while waiting for the ‘Dusk to Dawn Service’ to begin. The same set of frustrations was reported in a study in Malta where the family caregivers of people with dementia had to reorganize their family life to accommodate their caregiving responsibilities due to the limited availability of suitable services for their needs (Innes et al 2011). They also cited the lack of respite care available to family members to facilitate continuation with their working or personal lives (Innes et al 2011).

Similar to previous research on Vietnamese Americans of Asian origin (Meyer et al 2015), the intergenerational family caregivers of this present study were unwilling to place their family member with dementia in respite care, such as a nursing or residential home. Like their Vietnamese Americans counterparts, their extended family was the most preferred choice when it comes to caring for their family member with dementia. Furthermore, the reluctance from the intergenerational families in this present study when deciding on respite care was also due to the fact that the facility, or centre, did not specialise in caring for a person with dementia. For the intergenerational family carers involved, this made a difficult situation more stressful, especially when their extended family members were unwilling to provide support. For example, Olive from Family 1, and Mindy from Family 5, were forced to make the difficult decision to place their respective mothers in a residential home, albeit temporarily. Thomas et al (2002) argue that the main purpose of respite care was to relieve family caregivers from caregiving. Salin and Astedt-Kurki (2007) have also argued that the greatest challenge for respite care providers is considering the dynamics between the family caregiver and person with dementia and how to ensure that the care offered meets the expectations, and standards, of both.

A supportive workplace culture and environment was something that the intergenerational family members who were on full-time employment in this present study appreciated and
wanted. A supportive workplace for them meant employers, managers or colleagues who were empathetic and understanding of their caregiving situation. Studies have shown that supportive workplaces are important enablers for employees to successfully continue full-time work and care for their older parents simultaneously (Gautun & Hagen 2010; Vreugdenhil 2014). Indeed, Wagner and Neal (1994) found that a supportive workplace offering help to caregivers when needed was seen as essential. However, some caregivers in the present study did not quite perceive their workplace culture and environment as being supportive. As discussed, there was a certain element of mistrust and, therefore, reservation in disclosing their actual family situation. This may likely be due to the lack of clarity in employers' long-term commitment to elder care support initiatives (Wagner & Neal 1994). Olive from Family 1 was open enough to reveal using her annual leave provisions to negotiate the space between care and work. She is not alone. A survey of Norwegian workers reported that many caregivers of an older parent found it difficult combining care responsibilities with work, with one in three using vacation leave in order to help their parents (Gautun & Hagen 2010). Therefore, changes in the workplace itself, such as increased flexibility in the place, hours, and time of work and the training of reporting officers to increase their awareness and responsiveness to employees care responsibilities, will be important future considerations (Hammer & Neal 2008).

Strong family bonds ensure the maintenance of intergenerational family relations in the Chinese family kinship system. As the data indicated, it is through these strong family bonds that the immediate and extended family connect across households to provide social and economic support, such as shared labour, socialization of the children and support for the older person. However, some of the intergenerational families have found maintaining communication between the immediate and extended family members challenging. Sadly, like Family 2, it is highly likely that others have ended up having to sever relational ties with the extended family. On a positive note, there were also families who thrive against adversity and developed an even stronger and closer family bond within the immediate, or extended, family.

As seen in this present study, the strength of the kinship tie in the mother-daughter relationship did not just develop overnight. Rather, it has developed based on the duration of time spent together, the meaningful activities undertaken together and the shared values between mother and daughter. For some, the mother-daughter relationship became even closer when a better understanding of dementia was gained. This improved understanding
had brought, for example, a mother living with dementia (Elaine) and her daughter (Ginny) - from Family 4 - closer together, as illustrated by this poignant scene which was shared in chapter 4:

“She could get very close to my mom, even squeeze herself into the bed. The single bed. The hospital bed. To squeeze herself in ... to sleep together with my mom in the bed, day time or night time when my mother is awake. So, to be with her. Then, my mother would, even in her late state, when she does not know anything, she would like pat my sister's face, pull the blanket over my sister. That kind of closeness.”

(sixth interview with Ellie)

Similarly, Netto et al (2009) found that some caregivers feel emotionally closer to the person with dementia and other members of the family after the onset of the condition as caregiving necessitated more frequent interactions in the relationship. In fact, in the present study, the stronger mother-daughter relational bond provided the impetus, and determination, for one daughter (Olive from Family 1), to carry on with the care at the expense of her own health, career and sibling relations. This develops earlier thinking that a closer caregiver-reported relationship is associated with more satisfaction in the caregiving role (Walker et al 1990), a point extended to the intergenerational families in this present study.

Moreover, in this PhD study, the nature of the kinship tie related to the mother-son relationship was a little different in that it was not as emotionally and physically intimate as the one between mother and daughter. It was a sense of duty, religion and pragmatism which compelled a son (Ben from Family 3) to care for his mother (Pam) in a relational and reciprocal manner. Before the onset of dementia, physical displays of affection were rare in some of the sons from this study, such as Pete from Family 1 and Ben from Family 3. This could possibly be explained by Confucian restraint of emotional expression in the Chinese culture. Restraint serves the purpose of attaining individual and family harmony through emotional regulation as Liu (2014) has posited.

With regard to the relationship between grandchildren and grandparents who are living with dementia, only a limited number of studies exist (see for example: Attar-Schwartz et al 2009; Beach 1997; Blanton 2013; Celdrán et al 2011; Celdrán et al 2012; Celdrán et al 2014; Hamill 2012). In developing this relational dynamic, factors in maintaining the grandparent-grandchild/grandchildren kinship tie in this present study were important, such as spending regular and meaningful time together, role modelling, and observing filial piety entrusted to the grandchildren by their parent(s). In fact, all these acts have brought about a strong
intergenerational family connection as shared through Kit from Family 2 during my second interview with him:

“Like quite close with my parents also. Like, enjoy spending time together. But she [Dolly] has never forgotten me [smiling]. Because she sees me for twenty years already.”

Some researchers have suggested that a grandparent living with dementia can have a strong impact on the grandchildren. This could include the deterioration of previous bonds with the grandparent (Hodgson 1992; Kemp 2005). However, the data in the present study provides a contradiction. Other studies (Beach 1997; Celdrán et al 2009) have also provided several positive consequences on adolescent grandchildren. As seen in this present study, the grandmother-grandchild relationship demonstrated a unique and close intergenerational kinship bond, one that was filled with deep respect for the grandmother with dementia. The strong kinship bond and filial values also determined the grandchild’s positive regard of the grandmother living with dementia. Furthermore, the grandchildren in this present study were particularly appreciative of their grandmothers who had cared for them in their younger days and had enjoyed a positive relationship with them. Studies suggest that if grandparents cared for their grandchildren and shared a positive relationship with them before the onset of dementia, grandchildren usually provide care for their grandparents as auxiliary, or even primary, caregivers (Celdrán et al 2011; Dellman-Jenkins & Britain 2003; Fruhauf et al 2006). Therefore, the finding in this present study suggests that prior strong bonds between the grandparent and the grandchild before the onset of dementia and continuity of these bonds thereafter, supports the notion of intergenerational family connectedness which is resilient against the adverse circumstances caused by dementia. During my interviews with Kit and Shaun from Families 2 and 5 respectively, both have affectionately shared about their grandmothers taking care of them since young. Both were also providing auxiliary care for their grandmother on their own accord.

Engagement in meaningful activities is highly regarded and deemed as beneficial for people with dementia by healthcare providers, family members, and researchers as this allows meaningful bonding between the intergenerational family members (Green & Cooper 2000; Hasselkus 1998; Kane 2001; Morgan & Stewart 1997; Nolan et al 1995). However, gaps in current knowledge on how people with dementia, especially those in the early to moderate stages engage in meaningful activities and the role of their families in helping them sustain this involvement, still remain (Marshall & Hutchinson 2001; Nolan et al 2002) especially
with regard to the intergenerational Chinese family. Therefore, the present study may serve to address this gap in understanding.

As noted in this present study, some of the intergenerational families found that doing supportive and meaningful bonding activities with the relative with dementia brought them closer together and connected them meaningfully. For example, in Families 2 and 5, the family members with dementia (Dolly and Margaret) were meaningfully engaged by their intergenerational family members to perform household chores and activities together as part of their everyday routine. Likewise, an interpretive phenomenological study conducted with eight families involving family members and their family member with dementia, has found the families becoming more involved with each other despite the many losses (Phinney 2006) and conflicts with the extended family brought about by dementia. Thus, the findings from the present study provide further ecological validity and elaboration on how families ought to work together in coping with the everyday caregiving demands (Hellström et al 2005; Keady & Nolan 2003) and taking the opportunity to bond with each other. Moreover, the time spent in engaging and doing meaningful activities together has managed to transform previously less expressive and seemingly ‘distant’ relationships between the person with dementia and the intergenerational family caregivers towards one that was closer. For example, Pam and Ben from Family 3 had a closer mother-son relationship through the ‘Dusk to Dawn Service’ activities which Ben was actively contributing to and involved in.

The above finding is in contrast to the findings from previous studies that have suggested that there is a loss of intimacy over the course of caregiving between the caregivers and the person with dementia (Chesla et al 1994; Wuest et al 1994). The possible explanation for this conflicting findings could be the differences of the ethnic groups being studied and the subsequent emotional and relational aspects of caregiving, as also highlighted in a review by Dillworth-Anderson and Gibson (2002). This further reinforces the need to conduct more studies on non-Caucasian population to shed additional light on the caregiving experience, in particular related to the intergenerational Chinese family. As it is, cultural expectations on family relationships, filial piety and reciprocity vary across cultures, suggest that closeness between family members may present differently (Fauth et al 2012).

The genuine acts of concern from the family member with dementia created a sense of satisfaction, and appreciation, from the family members providing the care in this present
study. Evidently, all it required was a simple act of being considerate and thoughtful from the person with dementia. Likewise, the family caregivers would usually reciprocate the positive behaviour and actions of the family member with dementia. In this present study, Clive from Family 2 shared about Dolly’s show of concern and acts of being considerate and appreciative, acts which had touched him. A review of studies on caregiving relationships found that stronger pre-diagnosis relationships helps maintain well-being when caregiving (Quinn et al 2009). Caregiving can also change the relationship between family members; however, the ability of the person with dementia to persist with activities of daily living have been found to have an impact on perceptions of the quality of the relationship (Quinn et al 2009).

Caregiving of the family member with dementia was a natural role acceptance by unmarried daughters as seen in this present study. According to Braun and Browne (1998; cited in Bowen 1978), Chinese families are still highly respectful of family hierarchy and the role of women as caregivers. Previous works by Jones (1995, 1996) and Jones et al (2001) described women caregivers (Asian American Chinese and Filipino) as strongly committed to caring for older parents regardless of their degree of involvement in other roles, such as working full-time. As shared earlier, there is also a likely gender difference in terms of how caregiving is perceived by sons as compared to daughters. Olive’s brothers from Family 1 and Ben from Family 3 were not as ‘hands-on’ and were more accustomed to delegating their caregiving roles to the live-in maid or the females in the household (see also: Fitting et al 1986; Innes et al 2011).

However, caring was not all about a positive experience, as important as this was in maintaining close family bonds. In the present study, caring for the person with dementia brought about many strong emotions amongst the immediate and extended intergenerational family members who were providing, or were required to provide, care at home. Nevertheless, it is not uncommon for negative interactions, such as conflict and dissatisfaction with support, to be present in caregivers’ relationships (Strawbridge & Wallhagen 1991; Semple 1992; Merrill 1996, 1997; Fudge et al 1997) and even be embedded within supportive relationships (Tilden & Galyen 1987; Shuster et al 1990), especially in small, kin-focused networks (Neufeld & Harrison 2003). This was evident in the internal support network found in the five intergenerational Chinese families of this present study.
Finally, an in-depth understanding of the intergenerational family experience, anticipated and predictable trajectory of family functioning, and relational issues between intergenerational family members, may provide valuable insights to the actual impact of dementia on an intergenerational family unit. Furthermore, as highlighted in the family caregiving literature, family relationships determine the outcome of interventions (Luscombe et al. 1998; Schumacher et al. 1998; Fisher & Lieberman 1994) and are influenced by a family’s transgenerational history of illness and belief systems (Rolland 1988). Therefore, an in-depth understanding of the everyday experience of the intergenerational family providing care for the person with dementia as evidenced in the previous chapters of this thesis would serve to better inform health and social care practitioners in their decision making. Broader implications of the study for education, practice, policy and research are now discussed below.

6.2 Implications

6.2.1 Recommendations for Education

- Participation and involvement of intergenerational families and their family member with dementia in training curriculums of health and social care practitioners may add value to the curriculum in Singapore (and elsewhere) on dementia. Consistent with the literature, intergenerational family caregivers and their family member with dementia usually desire to participate actively towards enhancements in service provision by health and social care practitioners. Therefore, their inputs should be sought when designing training curriculums; for example, through invited focus group sessions, workgroup and patient groups.

- Challenges faced by intergenerational family caregivers who are providing care and working part-time or full-time are currently not adequately addressed. It is recommended to integrate topics on challenges faced by intergenerational family caregivers who are providing care and working part-time, or full-time, into the relevant curriculum on eldercare or gerontology to facilitate a better understanding by health and social care practitioners and policy makers.

- In Singapore, the current Civics and Moral Education programme, which started since the 1980s across the different levels of education, is focused on teaching pragmatic values to achieve social cohesion and economic success, rather than moral education which ought to emphasise the deeper Confucian value of filial piety (Tan & Chew 2007). To prevent over-reliance on the state, filial piety in the current syllabus is pragmatically slanted to focus on making children feel obligated to support their older parents, rather
than based on altruism. This is unlike the traditional emphasis of filial piety which is family-oriented, based on love and respect, and taught in the education syllabus. The consequential outcome was the Singapore Parliament being forced to enact the Maintenance of Parents Act (MPA) in 1995 to deter adult children from shirking their filial obligations (Ministry of Health 1984; Parliament of Singapore 1995). It is recommended to revise the Civics and Moral Education programme across the different levels of education in Singapore to include moral education with a deep emphasis on Confucian family values of filial piety; for example the “24 Exemplars of Filial Piety”, but tailored to suit the modern context to ensure that while this significant part of the Chinese culture is reinforced, citizens of Singapore are still able to achieve the government’s overall aim of achieving social cohesiveness and economic success.

6.2.2 Recommendations for Practice

- The findings in this study related to timeliness in the provision of information and support services suggest that more individualized and person-centred services at residential areas can be offered to intergenerational families and people with dementia. For example, the ‘Dusk to Dawn Service’ should not only be accessible to those who can afford it. More individualized and person-centred services ought to be offered to intergenerational families and people with dementia at residential areas; for example, the HDB estate in accordance with their specific needs and financial means.

- Additional training, coordination, and cooperation amongst relevant agencies may enhance the ability of existing health and social care practitioners to help intergenerational families both during and following the diagnosis of dementia, especially with regard to difficult to manage behaviours of people with dementia. Therefore, health and social care practitioners need to undergo relevant training to be equipped with the necessary knowledge and skill set.

- Implementation of public health education and publicity messages to directly address aspects of layperson beliefs about the aetiology of dementia may serve to enhance the general public’s awareness about dementia. In view of the likely constraints faced by intergenerational family caregivers in attending educational and informational talks on dementia, it is recommended for locally customized and more accessible online information to be made available for them.

- Intergenerational family members and healthcare professionals (for example, doctors and nurses) who are in direct contact with the person with dementia often make the decision not to reveal the diagnosis of dementia to the person with the condition for fear
that the person with dementia may not be able to accept this reality. Perhaps this misconception can be addressed through better awareness that the person with dementia has the right as a person to know what is wrong, and is encouraged to make decisions about their own present and future care needs.

- The study has revealed a pervasive use of information and communication technology by the intergenerational families as a means to connect with their internal support network, that is, their immediate and extended family members, as well as to obtain and receive information on dementia to support caregiving activities. It is recommended that health and social care providers harness the use of information and communication technology, such as social media platforms and customized dementia websites, to facilitate intergenerational families’ connection with their internal and external support network.

6.2.3 Recommendations for policy
- The availability of formal support services to suit the needs of intergenerational families and the person with dementia in Singapore is currently not individualized, and is inadequate and too slow to meet the escalating demands related to a fast ageing population. It is recommended to establish more individualized and targeted formal support services (for example, person-centred day care and respite care services which are similar to the ‘Dusk to Dawn Service’) in tandem with the needs of intergenerational families and the family member with dementia.

- Intergenerational family members are working and providing care concurrently, which implies that the workplace would need to have a supportive culture and environment. It is proposed for employers to design compulsory flexi-work schedule, leave policies of a longer duration and support services to support employees with genuine caregiving responsibilities. Examples of such policies and services include flexible work arrangements (such as flexible work schedules, reduction of hours to part-time, job sharing, working from home or tele-work and compressed work weeks); longer paid parent-care, sick, vacation, or personal leave policies; unpaid leave (at time periods beyond the government-mandated time-frame); and support services (such as resource and referral services, information services, counselling, support groups, workshops and seminars on care-giving issues). It would be helpful for employers to invest in on-site dementia day care centres for employees’ family members with dementia in order to help those employees better focus on their work, especially when the carer’s internal support network is unavailable, or unwilling, to help.
In order to ensure continued care of the person with dementia by the intergenerational family, the intergenerational family connections should be sustained and enhanced. Hence, health and social care practitioners and policy makers need to look at ways to incorporate existing family systems interventions which target family values, family support and family bonds. For example, incorporating and organizing mandated and routine residential, community and workplace intergenerational family activities.

6.2.4 Limitations and Recommendations for Future Research

- The cultural context in which care of the person with dementia takes place, the religious beliefs and practices and the practised value of filial piety by the intergenerational Singapore-Chinese families providing care for a family member with dementia, needs to be examined on a larger cohort of intergenerational Chinese families, followed by other ethnic groups such as the Indians and Malays, to explore whether the theoretical model of ‘Intergenerational Family Connections’ developed in the study is transferable to the Chinese and other ethnic groups in Singapore.

- The researcher would also like to emphasise the importance of being a cultural insider when conducting research involving the intergenerational Chinese family. This helps to facilitate the sensitization towards cultural and customary practices; for example, the need to remove foot wear when stepping into the home and bringing along small token gifts during visits as described in chapter four. Also, the typical and very Chinese monetary contributions, known as ‘baijin’ or ‘white gold’ during funerals, to help the family of the deceased to deflect funeral costs.

- It is recommended to disseminate and share information on the model intergenerational family connections, and the innovative methodologies used for data collection through book publication, seminars and conferences.

- Explore the intergenerational family experience across the trajectory of dementia and include a broader base to extend beyond the geographical boundaries. This would include the extended family who is residing overseas through inclusion in further research. Interviews could be conducted via emails and social media platforms.

- Following the caregiving journey until after the person with dementia has passed away in future research will allow researchers to better understand the intergenerational family values, particularly the essence of filial piety in which one may see how the intergenerational family members carry on with their everyday lives whilst maintaining connectedness with their family member with dementia who has passed away and is now living in the other ‘parallel world with ancestors’.
• Examine the caregiving experience of intergenerational families involving a male family member with dementia in future research. This is in view of the fact that relational dynamics involving the care of a male family member with dementia are suspected to vary as compared to those reported in the present study.

• Examine the caregiving experience and role of the live-in maid as a support network for the intergenerational family and person with dementia.

• The use of mixed methodologies, such as the innovative use of digital photographs, genograms, ecomaps and family interviewing to document the experiences of intergenerational families, were beneficial in enriching the data of the present study. Further application and enhancement of such methods would develop the social science field further.

6.2.5 Study Limitations

• It is recommended for future studies to include the person with dementia in intergenerational studies in Singapore, albeit with careful planning and adherence to considerations of the Mental Capacity Act (Department of Health 2005; Singapore Statutes Online 2016). Furthermore, the possible inclusion of the person with dementia in research would provide valuable insights into how older people experience dementia within the intergenerational family setting ‘under one roof” and extend methodological knowledge in this area (see for example: Dewing 2007; Hubbard et al 2002; Hubbard et al 2003).

• The local Alzheimer’s Disease Association would need to be convinced through the findings of the present study. As shared in chapter 4, Dolly and Margaret from Families 2 and 5 were purposely included and engaged by the main caregivers (Clive and Mindy) during interviews. The information they shared were undeniably rich with life experiences and narratives abound with teaching moments. Clearly, this indicates the potential for the person with dementia to play an active participatory role in future research work, and provide a rich contribution to the research process.

6.3 Methodological Reflections for Future Work

Genograms: When constructing the genogram for the five families as seen in the illustrative figures in chapter five, ‘going with the flow’ when collecting information about the intergenerational members of each family was an important consideration. The researcher had to take advantage of ‘natural’ openings during her interactions with the families in order
to obtain the information needed, link questions to the specific caregiving experiences of each member and which were clear to them. It was noted that when sufficient levels of trust were established, it was ‘easier’ to explore sensitive issues, such as existing and past family relationships, that were relevant to the provision of care for the person with dementia living at home. Moreover, the genograms assisted in providing a visual representation of the families’ connection and relationship with their extended family. For example, in some cases, the family’s connection and conflicted, or estranged, relationship with other siblings, which was initially not revealed, became more apparent with the completion of the genogram.

Relating to the specific co-constructed genograms in chapter five, the use of the genogram has assisted the researcher in drawing out sensitive information which the five families were initially wary of sharing, but eventually shared as they began to appreciate the visual representation of their family. Most families even mentioned how amazed they were upon seeing the elaborate construction of the genogram. For example, interviewed intergenerational family members were willing to verify and confirm the distant and estranged/cut-off relationship upon seeing the constructed genogram. This has also provided the impetus for the researcher to ask more detailed questions on why this was so and if this had any impact on the long term care of the person with dementia.

Ecomaps: Ecomaps, visualized with circles representing various systems in the families’ ecology were used, as seen in chapter four. Lines connecting these circles to each intergenerational family represented the researcher’s assessments of the quality of the relationships between these systems with the individual family. The ecomaps were co-constructed in close discussion and confirmation with the intergenerational families. For example, three solid lines running in parallel represents a very close or strong relationship, such as the lines connecting Clive, Joy, Kit and Dolly, and Clive, Joy and Dolly with the Alzheimer’s Disease Association and the recreational activities with Clive, Joy and Dolly in Family 2. A dotted line represents a distant or tenuous relationship, such as Dolly’s relationship with her own extended family – her eldest sister. An estranged or cut off relationship was depicted by hash marks drawn through the line. An estranged or cut relationship is depicted in chapter four between Families 2 and 5’s extended family. The ecomap has facilitated further probing in accordance with the intergenerational family’s comfort level to discuss such events further. For example, Clive from Family 2 had even gone on to reveal that the family would be changing their email address and telephone.
number after they move to their new house to cut off all ties with their extended family. The motivation here was to start a new life with a new beginning.

In the ecomaps in the study, arrows were strategically used to indicate the flow of energy. In this context, energy would mean the amount of effort or investment put in by the intergenerational family, or by its members and the support services. For example, the three solid parallel lines connecting Family 2 with the Alzheimer’s Disease Association indicated a strong relationship. The line ends with arrows pointing from the family to the Alzheimer’s Disease Association and from the Alzheimer’s Disease Association to the family, suggesting that the family invests a great deal of energy in the Alzheimer’s Disease Association and receives a great deal of support in return. In fact, Clive and Joy from Family 2 had made it a point to accompany Dolly to the dementia café which was organized by the Alzheimer’s Disease Association every weekend. Family 2, as depicted in their ecomap, had a limited support system appertaining to the care of Dolly. In fact, the only strong reciprocal relationship they had was with the Alzheimer’s Disease Association.

Taking such factors into account, the co-construction of the genogram and ecomap with the intergenerational families facilitated a relational process that led to in-depth conversations and disclosure about the participant’s experiences of supportive, and non-supportive, systems in their ecology. The use of the genogram and ecomap supported the ongoing and iterative question-posing which was integral to the generation of data for this overall study. Furthermore, the process of genogram and ecomap construction paved the way for the generation of additional interview questions.

Photographs: Digital photographs of the inside and outside of the house and the specific objects were taken as these represented the context of the family’s caregiving experience. In order for this to succeed, the researcher also made a conscious effort to co-produce the digital photographs with the intergenerational families. The effort led to contributions of digital photographs from the participating intergenerational families of their family outings and of doing everyday things together. The intent was to meaningfully link these images with the ecomaps, interview field notes, audio-recording and transcripts to bring more meaning to the researcher’s engagement with the intergenerational families and give readers a visual lens as to what the researcher saw during her time with the intergenerational families. The interactional nature of the digital photographs with the ecomaps, interview field notes, audio-recording and transcripts was not merely just combining visual with graphical, textual and
audio data, but as a contribution to the methodology of photo elicitation. The interactional nature of the digital photographs in the preceding chapters can be seen in, for example, the paintings (see Tables 6 and 7) which served to compliment the field observation of Clive’s caregiving effort and expressed purposeful intent in providing and preparing care for Dolly. The many digital photographs provided a visual link to the other data which depicted a supportive and kindred family. Moreover, the digital photographs as shared by consenting intergenerational families in this study also provided the researcher with an additional lens into the families’ routine and affections for the person with dementia which the researcher had limited, or no opportunity, to experience and observe first-hand at times.

6.4 Concluding Remarks
This thesis is the first of its kind in Singapore that has used a case study approach towards understanding the everyday caregiving experience of intergenerational family members of people with dementia living at home. This created the unique opportunity to work with a number of intergenerational families providing caregiving for a family member with dementia in order to develop an in-depth understanding of their everyday caregiving experience. A new theoretical model on ‘Intergenerational Family Connections’ has been constructed and has value in informing health and social care practitioners who are involved with intergenerational families on the relational dynamics that exist within the intergenerational families, how they connect with each other, the importance of making anticipatory goals and to heighten awareness about the current and future supportive mechanisms that are required to sustain intergenerational family connections for Chinese-Singapore families of people with dementia. It is hoped that the present study has paved the way for future work on research and practice related work on this important but, to date, overlooked area.
REFERENCES


**APPENDIX 1: PRISMA CHECKLIST (Liberati et al 2009)** – used to guide the systematic and structured literature review for this study

<table>
<thead>
<tr>
<th>Section topic / #</th>
<th>Checklist item</th>
</tr>
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<tbody>
<tr>
<td><strong>TITLE</strong></td>
<td></td>
</tr>
<tr>
<td>Title</td>
<td>1 Identify the report as a systematic review, meta-analysis, or both.</td>
</tr>
<tr>
<td><strong>ABSTRACT</strong></td>
<td></td>
</tr>
<tr>
<td>Structured summary</td>
<td>2 Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.</td>
</tr>
<tr>
<td><strong>INTRODUCTION</strong></td>
<td></td>
</tr>
<tr>
<td>Rationale</td>
<td>3 Describe the rationale for the review in the context of what is already known.</td>
</tr>
<tr>
<td>Objectives</td>
<td>4 Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).</td>
</tr>
<tr>
<td><strong>METHODS</strong></td>
<td></td>
</tr>
<tr>
<td>Protocol and registration</td>
<td>5 Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.</td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>6 Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.</td>
</tr>
<tr>
<td>Information sources</td>
<td>7 Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.</td>
</tr>
<tr>
<td>Search</td>
<td>8 Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.</td>
</tr>
<tr>
<td>Study selection</td>
<td>9 State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).</td>
</tr>
<tr>
<td>Data collection process</td>
<td>10 Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.</td>
</tr>
<tr>
<td>Data items</td>
<td>11 List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.</td>
</tr>
<tr>
<td>Risk of bias in individual studies</td>
<td>12 Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.</td>
</tr>
<tr>
<td>Summary measures</td>
<td>13 State the principal summary measures (e.g., risk ratio, difference in means).</td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>14 Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I²) for each meta-analysis.</td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>15 Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).</td>
</tr>
<tr>
<td>Additional analyses</td>
<td>16</td>
</tr>
<tr>
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</table>

**RESULTS**

<table>
<thead>
<tr>
<th>Study selection</th>
<th>17</th>
<th>Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study characteristics</td>
<td>18</td>
<td>For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.</td>
</tr>
<tr>
<td>Risk of bias within studies</td>
<td>19</td>
<td>Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).</td>
</tr>
<tr>
<td>Results of individual studies</td>
<td>20</td>
<td>For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.</td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>21</td>
<td>Present results of each meta-analysis done, including confidence intervals and measures of consistency.</td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>22</td>
<td>Present results of any assessment of risk of bias across studies (see Item 15).</td>
</tr>
<tr>
<td>Additional analysis</td>
<td>23</td>
<td>Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).</td>
</tr>
</tbody>
</table>

**DISCUSSION**

| Summary of evidence | 24 | Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers). |
| Limitations | 25 | Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.., incomplete retrieval of identified research, reporting bias). |
| Conclusions | 26 | Provide a general interpretation of the results in the context of other evidence, and implications for future research. |

**FUNDING**

| Funding | 27 | Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review. |
APPENDIX 2: SEARCH STRATEGY AND OUTCOME

Date performed 31st July 2017

<table>
<thead>
<tr>
<th>Search Terms (Using Boolean)</th>
<th>Limits</th>
<th>Source</th>
<th>Selected / Total search results</th>
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<td>English language only</td>
<td>ABSEES (The American Bibliography of Slavic and East European Studies)</td>
<td>2/43</td>
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<td>1997 to current</td>
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<tr>
<td>All studies</td>
<td></td>
<td>Cumulative Index to Nursing and Allied Health Literature (CINAHL)</td>
<td>0/2</td>
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<td>EBSCO Host Research Databases</td>
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<td>International Journal of Alzheimer's Disease</td>
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<td>The Gerontologist</td>
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<td>Other sources –Dementia; Dementia and Geriatric Cognitive Disorders; East Asian Archive of Psychiatry; International Journal Of Geriatric Psychiatry; International Psychogeriatrics; Journal of Ethnic And Cultural Diversity in Social Work;</td>
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<td></td>
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<td>End-reference list</td>
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Number of selected articles / Total search results including duplicates **19 / 5,810**
APPENDIX 3 - SUMMARY ON THE NUMBER OF ABSTRACTS IDENTIFIED BY EACH SEARCH

Example of search performed via ABSEES (The American Bibliography of Slavic and East European Studies) on 31st July 2017. Search terms, Intergenerational AND family caregivers AND dementia were used. Yielded 43 search results. Selected 3 out of 7 articles; 2 could not be accessed (with 1 older than 1997); 2 were duplicates found within this search and other databases / on spousal caregiving only.

**Record 1**

**Title:**
A longitudinal study of predictors of nursing home placement for patients with dementia: The contribution of family characteristics.

**Authors:**
Fisher, Lawrence, U California, Dept of Family & Community Medicine, San Francisco, CA, US
Lieberman, Morton A.

**Source:**

**Page Count:**
10

**Publisher:**
US: Gerontological Society of America.

**ISSN:**
1758-5341 (Electronic)
0016-9013 (Print)

**Language:**
English

**Keywords:**
contribution of multigeneration family characteristics to prediction of nursing home placement, elderly patients with dementia, 2 yr study

**Abstract:**
The caregivers of elderly patients with dementia (N = 164) were followed for 2 yrs to determine if characteristics of the multigeneration family predicted nursing home placement (NHP) over and above the effects of patient demographics, severity of patient disease, and characteristics of caregivers. Clinical assessment occurred at baseline, and caregivers were assessed by questionnaire and interview at baseline and every 6 mo. No patient demographic, severity, or caregiver characteristic significantly predicted NHP. Families scoring high on emotional closeness, high on negative family feelings, and low on family efficiency institutionalized their ill elders at a significantly higher rate than other families, especially at low levels of patient severity. The findings argue that a careful examination of the multigeneration family should increase the prediction of NHP and the relevance of services offered to these families. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

**Subjects:**
*Dementia; *Family; *Intergenerational Relations; *Nursing Homes; *Prediction; Elder Care

**Classification:**
Neurological Disorders & Brain Damage (3297)
Nursing Homes & Residential Care (3377)

**Population:**
A longitudinal study of predictors of nursing home placement for patients with dementia: The contribution of family characteristics.

Database:
PsycINFO
Abstract:
This article reports the findings from a study designed to identify qualities of the multigeneration family system that affected the relationship between the demands of Alzheimer's disease on the family and the health and well-being of (a) spouses, (b) offspring, and (c) offspring's spouses or "inlaws." Members of 97 families of patients with Alzheimer's disease, recruited from four University-affiliated Alzheimer's Centers, completed detailed questionnaires and participated in a 45-minute telephone interview to assess care-strain, personal stress, appraisals of three major domains of family life (World View, Structure/Organization, and Emotion Management), and three health and well-being indices (Anxiety/Depression, Somatic Symptoms, and Well-Being). Multivariate multiple regression equations, run separately for each of the three groups of family respondents and each of the three family domains, indicated: (1) no significant associations between the severity of the elder's disease and family member health and well-being; (2) female family members reported poorer health and well-being than male family members; and (3) caregiver strain was negatively associated with family member health and well-being. Further, appraised family qualities were associated with the health and well-being of the three groups of respondents differently: directly for offspring, interactively with severity of patient disorder for inlaws, and not at all for spouses. The data suggested that some family qualities served a protective function, whereas others exacerbated the negative effects of caregiving by affecting personal health and well-being. The findings are interpreted in terms of the different roles and expectations for care-giving placed on spouses, offspring, and inlaws. It is suggested that programs of intervention for patients with Alzheimer's and other chronic diseases should focus on the multigeneration family as the context for care, rather than only on the primary caregiver.
**Record 3**

**Title:**
Dementia in the family: the caring experiences of grandchild.

**Authors:**
Philipp-Metzen, Elisabeth

**Source:**
Journal of Dementia Care (J DEMENT CARE), 2012 Jan-Feb; 20 (1): 35-7. (10 ref)

**Publication Type:**
journal article - research

**Language:**
English

**Major Subjects:**
Caregivers -- In Infancy and Childhood -- Germany
Dementia -- Diagnosis
Family Characteristics
Grandchildren

**Minor Subjects:**
Age Factors ; Child ; Coping ; Disruptive Behavior ; Female ; Funding Source ; Germany ; Human ; Information Needs ; Intergenerational Relations ; Interviews ; Knowledge ; Life Experiences ; Male ; Qualitative Studies ; Retrospective Design ; Social Responsibility ; Stress, Psychological ; Support, Psychosocial ; Young Adult

**Journal Subset:**
Biomedical; Editorial Board Reviewed; Europe; Expert Peer Reviewed; UK & Ireland

**Special Interest:**
Gerontologic Care

**ISSN:**
1351-8372

**Grant Information:**
Heinrich Boll Foundation, Germany

**Entry Date:**
20120302

**Revision Date:**
20120302

**Accession Number:**
2011427824

**Persistent link to this record (Permalink):**

**Cut and Paste:**
<A href="http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2011427824&site=ehost-live">Dementia in the family: the caring experiences of grandchild.</A>

**Database:**
CINAHL Plus with Full Text

---

**Record 4**

**Title:**
Family caregiving: the positive impact on adolescent relationships.

**Authors:**
Beach DL
Adult children are a significant contingent of elder care providers; a number of these individuals simultaneously care for children of their own while coping with caregiving commitments. Unfortunately, there is a paucity of information regarding the caregiving impact on these children and young adults. Moreover, the possible positive consequences of caring for an impaired elder are rarely mentioned. The current study was undertaken to examine the potential positive caregiving experiences of adolescents and their perceptions of relational enhancement as a result of caregiving. Twenty adolescents aged 14-18 were interviewed and asked a series of semistructured questions concerning satisfaction related to caregiving. To be included, respondents had to be a child, grandchild, or niece/nephew of an Alzheimer's (or Alzheimer's Type Dementia) patient cared for by the adolescent's immediate family. Employing features of content analysis methodology, all interviews were audiotaped and transcribed verbatim. The results merged into four primary categories: 1) increased sibling activity/sharing; 2) greater empathy for older adults; 3) significant mother-adolescent bonding and 4) peer relationship selection and maintenance. The implications for future research and practice are discussed.
Spousal dementia caregiving in the context of late-life remarriage.

Sherman CW ; Boss P

University of Michigan, USA

Dementia (14713012) (DEMENTIA), 2007 May; 6 (2): 245-70. (102 ref 2 bib)

Journal article - research

English

Caregiver Burden
Caregivers -- Psychosocial Factors
Dementia -- Psychosocial Factors
Family Relations
Marriage
Stepfamilies -- Psychosocial Factors

Adult ; Aged ; Decision Making, Family ; Female ; Funding Source ; Grounded Theory ; Intergenerational Relations ; Interviews ; Male ; Spouses ; Human

Increasing numbers of older couples entering late-life remarriage will face dementia and spousal caregiving. This qualitative study, informed by grounded theory methods, is a first to explore spousal caregiving in the late-life remarried context. Interviews with nine late-life remarried wife caregivers identified complex intergenerational stepfamily dynamics that appear to amplify isolation and stress for this group of caregivers. Most women reported experiencing rejection of remarriage by adult children, minimal family involvement in caregiving, and intergenerational conflict regarding decision making. Nonetheless, caregivers described proactive, strategic approaches toward caregiving. This study examines the construct of boundary ambiguity as it relates to late-life remarriage and dementia caregiving, thus merging the unique challenges of caregiver and stepfamily dynamics. Findings are discussed in light of the potential risks highlighted for remarried couples facing chronic health issues. Future dementia research that accounts for diverse marital and family histories is suggested.

Biomedical; Blind Peer Reviewed; Europe; Online/Print; Peer Reviewed; UK & Ireland

1471-3012

101128698

National Institute of Aging Pre-doctoral Fellowship program

20080411

20091218

2009718724

Persistent link to this record (Permalink):
Increasing numbers of older couples entering late-life remarriage will face dementia and spousal caregiving. This qualitative study, informed by grounded theory methods, is a first to explore spousal caregiving in the late-life remarried context. Interviews with nine late-life remarried wife caregivers identified complex intergenerational stepfamily dynamics that appear to amplify isolation and stress for this group of caregivers. Most women reported experiencing rejection of remarriage by adult children, minimal family involvement in caregiving, and intergenerational conflict regarding decision making. Nonetheless, caregivers described proactive, strategic approaches toward caregiving. This study examines the construct of boundary ambiguity as it relates to late-life remarriage and dementia caregiving, thus merging the unique challenges of caregiver and stepfamily dynamics. Findings are discussed in light of the potential risks highlighted for remarried couples facing chronic health issues. Future dementia research that accounts for diverse marital and family histories is suggested. (PsycINFO Database Record (c) 2012 APA, all rights reserved)
Keywords:
adult offspring/in-law gender & patient dementia severity & offspring caregiver stress & family characteristics, in-law marital strain, 3-generation families of Alzheimer's patients

Abstract:
Studied how the stresses of caring for an elder with dementia spread through the family system to affect nondisease-related family role functioning, and identified family system characteristics that affected this process. Participants were 78 3-generation families of patients (mean age 70 yrs) with probable or possible Alzheimer's disease (AD). Results were based on associations of 3 domains of family variables (worldview, structure/organization, emotion management) with marital strain reported by the spouses of the patient's adult offspring (in-laws), after controlling for offspring/in-law gender, severity of patient illness, and offspring's caregiver strain. Each control variable was significantly associated with in-law marital strain, with male in-laws reporting more marital strain than female in-laws. Strong support for cross-generational boundaries, good family organization, and conflict avoidance served as protective effects, containing the stresses of caregiving from affecting other role behaviors, whereas family life engagement and emotional distance were risk factors. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

Subjects:
*Caregiver Burden; *Dementia; *Family; *Inlaws; *Intergenerational Relations; Adult Offspring; Alzheimer's Disease; Caregivers; Human Sex Differences; Marital Relations; Psychological Stress; Severity (Disorders)

Classification:
Home Care & Hospice (3375)

Population:
Human (10)
Male (30)
Female (40)

Location:
US

Age Group:
Adulthood (18 yrs & older) (300)
Middle Age (40-64 yrs) (360)
Aged (65 yrs & older) (380)

Methodology:
Empirical Study

Format Covered:
Print

Publication Type:
Journal; Peer Reviewed Journal

Document Type:
Journal Article

Release Date:
19991201

Accession Number:
1999-11300-001

Persistent link to this record (Permalink):

Cut and Paste:

Database:
PsycINFO

Date of older search which was performed: 30th October 2012

**ASSIA (Applied Social Sciences Index and Abstracts)** – Yielded 4 results with 0 selected.

1) Chinese
2) Intergenerational family(ies)
3) Multigenerational family(ies)
4) 2 or 3
5) Next-of-kin
6) Relative(s)
7) Family
8) 5 or 6 or 7
9) Family carer(s)
10) Family caregiver(s)
11) Informal carer(s)
12) Informal caregiver(s)
13) Wife / wives
14) Husband(s)
15) Spouse(s)
16) Spouse carer(s)
17) Spouse caregiver(s)
18) Spousal carer(s)
19) Spousal caregiver(s)
20) 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
21) Sibling
22) Brother
23) 21 or 22
24) Sister
25) 21 or 23
26) Child / Children
27) Off spring(s)
28) Son(s)
29) Daughter(s)
30) 27 or 28 or 29
31) Son-in-law(s)
32) Daughter-in-law(s)
33) 1 and 2-26
34) Live-in maid(s)
35) Live-in helper(s)
36) Domestic helper(s)
37) Foreign domestic worker(s)
38) 34 or 35 or 36 or 37
39) Altered mental status
40) Dementia
41) Alzheimer’s disease
42) Fronto-temporal lobe dementia
43) Lewey body dementia
44) Parkinson’s disease
45) Vascular dementia
46) 39 or 40 or 41 or 42 or 43 or 45
47) Care
48) Caring
49) Caregiving
50) 47 or 48 or 49
51) Qualitative
52) Grounded Theory
53) Ethnography
54) Phenomenology
55) Action research
56) Case Studies
57) Systematic review
58) Meta-analysis
59) Observation
60) Focus group
61) Interview
62) Quantitative
63) 51 or 52 or 53 or 54 or 55 or 56 or 57 or 59 or 60 or 61
64) 55 or 56 or 57 or 58 or 59 or 60 or 61
65) 1 and 4 and 46 and 50
66) 1 and 20 and 46 and 50
67) 1 and 25 and 46 and 50
68) 1 and 30 and 46 and 50
69) 1 and 33 and 46 and 50
70) 1 and 38 and 46 and 50
71) 63 and 65
72) 63 and 66
73) 63 and 67
74) 63 and 68
75) 63 and 69
76) 63 and 70
77) 64 and 65
78) 64 and 66
79) 64 and 67
80) 64 and 68
81) 64 and 69
82) 64 and 70

NOTE: Similar search strategy was performed for the following list of databases, peer review journals, hand searched articles and reference list

- CINAHL – Yielded 15 results with 0 selected.
- BNI – Yielded 78 results with 0 selected.
• PsychInfo - Yielded 0 results.
• The Cochrane Library – Yielded 11 results from 680109 records identified. 0 selected.
• TRIP – Yielded 4 results with 0 selected.
• National Research Register Archive – Yielded 200 results with 0 selected.
• Web of Science – Yielded 0 results.
• System for Information on Grey Literature in Europe (SIGLE) – Yielded 0 results.
• Peer Reviewed Journals
  o Aging and Society – Yielded 0 results.
  o Alzheimer's and Dementia – Yielded 0 results.
  o American Journal of Alzheimer's Disease and other Dementias – Yielded 0 results.
  o Dementia – Yielded 0 results.
  o International Journal of Alzheimer's Disease – Yielded 0 results.
  o The Gerontologist – Yielded 63 results with 3 selected.
• Hand search – 10 local & regional studies. 8 selected.
• End reference list – 1 selected as 3 others were duplicates.
APPENDIX 4: DETAILED LIST OF STUDIES WITH EXTRACTED DATA – AN EXAMPLE

Data Extraction - Description and quality assessment of a qualitative study

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<thead>
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<th>No</th>
<th>Author, Year, Journal, Country, Source</th>
<th>Design and setting</th>
<th>Sample</th>
<th>Findings</th>
<th>Analysis</th>
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<td></td>
<td><strong>Qualitative Studies</strong></td>
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</table>
**Gender** - Female (n=11), Male (n=9)  
**Relation to Person with dementia** - Offspring (n=4), Niece / Nephew (n=4), Grandchildren (n=12)  
Age and generation of family caregivers - No data on the age of parent caregivers. Adolescent caregiver (n=12): Age range 14 to 18 years. 2 generations of caregivers - 3rd generation caregiver (n=12), 2nd generation caregivers (n=8).  
Marital status of adult caregivers - Data not provided.  
Ethnicity and Culture - 13 Caucasian White, 3 African American, 2 Native American, 2 Pacific Islander.  
Educational status - 64% of adolescents completed 12th grade. Data not provided for adult caregivers.  
Employment / Financial status - Data not provided.  
Type of care - Physical and emotional care  
**Impact of caregiving – Care Gains** | Limited scope due to small sample size. Data were gathered from retrospectively reported narratives by adolescents. Future studies should address both the adolescent's and the primary caregiver's perceptions of the caregiving environment. Mostly Caucasian with an average age of 18. Majority of respondents identified the primary caregiver as a mother. There is a need to assess adolescent caregivers of diverse ethnic backgrounds, different relationships to the primary caregiver, and various age groups. Perceptions of positive caregiving outcomes may possibly be influenced by ethnicity, the relationship to the primary caregiver, and age.  
5 adolescents were asked to read a portion of their transcribed interviews and comment on the accuracy of their reported thoughts. Non-participating caregiving adolescents were asked to verify the experiences described by the study participants with their own. Colleagues who were not involved with the
| immediate family. | Increased Sibling Activity/Sharing - positive influence on family relationships; closer family bonding as a result of coping with patients' aberrant (yet expected) behaviours; positive changes in historically distant sibling relationships. Greater Empathy for Older Adults - more understanding of older people; compassion regarding private behaviours in public settings; need to cultivate patience. Significant Mother / Adolescent Bonding - greater intimacy within the mother / adolescent relationship; positive reinforcement accorded to adolescent by mother; adolescent feeling more trusted; offering help and reassurance when mother is experiencing emotional outbursts and burnout; genuine desire to spend time with their mothers; greater appreciation and respect for their caregiving mothers. Peer Relationship Selection and Maintenance - having friends at the house (where the patient resided) necessitated the selection of empathetic peers; learned how to openly discuss the situation with their friends to prepare them for visitations; friends were more objective regarding caregiving challenges. | study were asked to comment on the participant's reported circumstances (as related to their own support group members' experiences).

**Participant selection:**
Non participation – Not mentioned. However, participants suit the inclusion criteria.

**Data collection:**
Duration of data collection – Not mentioned

**Data analysis:**
Number of data coders and software – Not mentioned
APPENDIX 5: CHECKLISTS AND APPRAISAL OF THE 19 ARTICLES

Consolidated criteria for reporting qualitative research (COREQ) 32-item checklist (Tong et al 2007) – Quality assessment of identified qualitative studies

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**Reference list of articles assessed for quality:**


## STROBE Statement 22-Item Checklist (Stroup et al 2000) - Quality assessment of identified quantitative / cross-sectional studies

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### PRISMA Statement 27-item checklist (Liberati et al 2009) – Quality assessment of identified systematic review

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## APPENDIX 6: SUMMARY AND TEXTUAL DESCRIPTION OF SELECTED STUDIES

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|                  |                   |                 |                                          |
| Beach (1997); United States | Family Caregiving: The Positive Impact on Adolescent Relationships. | Content analysis methodology. 20 Caucasian, African American, Native American and Pacific Islander adolescents [Offspring (n=4); Niece / Nephew (n=4); Grandchildren (n=12)] aged between 14 to 18 years were recruited via the local chapter of the Alzheimer's Association. They were interviewed and asked a series of semi-structured questions concerning satisfaction related to caregiving. All interviews were audiotaped and transcribed verbatim. | Four primary categories emerged - increased sibling activity / sharing, greater empathy for older adults, significant mother-adolescent bonding, and peer relationship selection and maintenance. Limitations: Data were gathered from narratives and retrospectively reported by adolescents without input from other intergenerational family members. Their perceptions on the relational outcomes from caregiving may not be similarly perceived by their other siblings, mothers or peers. Furthermore, recruitment from one setting alone – the local chapter of the Alzheimer's Association- may not necessarily reflect the perception and views of other adolescents. Besides, the fact that these adolescents have agreed to participate in the study implies their more forthcoming attitude. Generally, its only weakness is the absence of description with regard to the relationship of the study’s researchers with participants, how participants were selected, number of people who refused to participate or dropped out, the duration of data collection, number of data coders and any software used to assist in data analysis. |

| Boughtwood et al (2011); Australia | Experiences and Perceptions of Culturally and Linguistically Diverse (CALD) Family Carers of | Modified grounded theory approach. In-depth focus group interview of 121 (19 Arabic, 37 Chinese, 40 Italian, and 25 Spanish speaking) family carers [Spouses (n=25); Adult children / spouse of the adult child | Analysis revealed significant similarities in the experiences and perceptions of family carers from all four Culturally and Linguistically Diverse communities. All were heavily involved in caring for the person with dementia. Unlike the Italian-speaking and Spanish-speaking carers, Arabic-speaking and Chinese-speaking carers did not take on an active advocacy role in hospitals. They also reported less conflict with other family members |

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<td>People With Dementia.</td>
<td>To examine the experiences and perceptions of these family carers with regard to their caregiving for a person living with dementia.</td>
<td>(n=93); Grandchildren (n=3) between 17 to 90 years; with an average of 8 participants per group. Digitally recorded and lasted between 1 to 2¾ hours in duration. All fieldwork digital recordings were transcribed to word file and thematic analyses were undertaken without the aid of a qualitative analysis computer package.</td>
<td>about caregiving decisions as compared with the Italian-speaking and Spanish-speaking carers. Gender was described as having more impact on care decisions in the Italian-speaking and Spanish-speaking carers. Arabic-speaking carers were more inclined to be emotional and aggrieved about the condition of the person with dementia. They worry about the future and the impact of caring on themselves but were less concerned about dementia-related behaviours than the other 3 groups. Unlike carers from the other Culturally and Linguistically Diverse communities, Chinese-speaking carers were not so worried about the safety of the person with dementia. Limitations: Although the study included more than one family member in the focus group, not the entire family unit was involved. There is a need to look at the wider family structure and examine how the carers’ experiences and perceptions in relation to family disagreements and difficulties around decision making, compare and contrast with that of other family members. Generally, its only weakness is the absence of description with regard to how participants were selected, the number of people who refused to participate or dropped out, repeat interviews if any, setting of data collection, presence of non-participants, return of transcripts to participants for comment and/or correction, number of data coders, the coding tree, and whether participant provided feedback on the finding.</td>
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<td>Lived Experience of Caregivers of Persons with Dementia in Hong Kong: a Qualitative Study.</td>
<td>Qualitative study. 27 Chinese spouses and children [Wives (n=5); Husbands (n=5); Daughters (n=16); Son (n=1)] were recruited from the Community Rehabilitation Network of the Hong Kong Society for</td>
<td>From the analysis, themes such as ‘confusion regarding diagnosis’, ‘emotional impact’, ‘difficulty in coping with the care recipients’ behaviours, ‘provision of care recipient’s daily care needs is demanding’, and ‘conflicts among social roles’ were found to be pervasive across every focus group. It was revealed that carers’ needs changed as care recipients’ condition progressed.</td>
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<td>Ho et al (2003); Canada</td>
<td>Caregiving for relatives with Alzheimer’s disease: feelings of Chinese-Canadian women. To explore the feelings of Chinese-Canadian female caregivers when providing care for relatives</td>
<td>Qualitative study. Semi-structured, in-depth interview of 12 Chinese-Canadian female family caregivers [Wives (n=2); Daughters (n=8); Daughters in-law (n=2)]. The family caregivers were recruited from the community facilities in the Greater Toronto area. They were interviewed in Cantonese using semi-structured, in-depth interviews which were guided by an adapted version of the conceptual model of Alzheimer’s caregivers’ stress by Pearlin et al</td>
<td>Despite anticipating and accepting their caregiving role as a cultural obligation, caregivers felt overwhelmed, anxious and fearful of the future. All caregivers had made applications to nursing homes despite conflicts with cultural and personal values. Six were even ready to institutionalize their relatives upon availability. Even though coping mechanisms and social support appeared to alleviate their stress, caregivers’ concerns about Western influence on Chinese traditional values – particularly, intergenerational issues on caregiving - was an extra burden. Limitations: Only 1 interview was conducted over 1½ hours with brief rest periods. This alone, may not allow data saturation to be reached. Thirdly, all participants lived within a ‘service-rich’ environment. Hence, their caregiving...</td>
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<td>To report the lived experience of caregivers of persons with dementia in Hong Kong and to explore their service needs.</td>
<td>Rehabilitation which provides psychosocial support for care recipients and their family carers. 4 focus group interviews, each group comprising 6 to 7 informal caregivers, were conducted. Interviews were audiotaped and transcribed verbatim. Colaizzi’s methods for phenomenological analysis were used.</td>
<td>Limitations: Some of the study’s researchers were active participants in the voluntary services of Community Rehabilitation Network. Bias was only partially overcome by selecting the researcher who was the least familiar with the participants to be the moderator for the focus group. This process of translation may compromise the original semantic richness. Family carers were only recruited from the Community Rehabilitation Network which may typically reflect carers from a particular demographic profile. Generally, its only weakness is the absence of description with regard to the relationship of the study’s researchers with participants, how participants were selected, number of people who refused to participate or dropped out, presence of non-participants, repeat interviews if any, utilization of field notes, attainment of data saturation, number of data coders, coding tree, software to assist in data analysis, and minor themes.</td>
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<td>Innes et al (2011); Malta</td>
<td>The organisation of dementia care by families in Malta: The experiences of family caregivers. To discuss the experiences of dementia family caregivers in Malta.</td>
<td>Exploratory study. In-depth semi-structured interviews were conducted with 17 family caregivers [Husbands (n=2); Wives (n=2); Daughters (n=8); Son (n=1); Daughters-in-law (n=3)]. Caregivers were recruited through their relatives’ attendance at a hospital-based out-patient memory clinic. Interviews were recorded, transcribed and when required, phrases were translated from Maltese to English. The thematic analysis was guided by the questions: What are the experiences of family caregiving in Malta? And what impact does caregiving have for individual/family life?</td>
<td>There were three key findings: the organization of family care in Malta; the use of formal services; and the dislocation of dementia caregiving experiences from wider community life. Organization of family care was centred upon the notion of shared filial responsibility and obligation, gender expectations and individual responsibility. With regard to formal services, family carers highlighted the limited availability of suitable services, lack of respite care, difficulty in finding someone to provide personal care, limited knowledge on alternative services, lack of information and informal support, and financial burden as key concerns. The dislocation of dementia caregiving experiences from wider community life came about from having to juggle multiple roles. This actually created a dislocation from previous pursuits and roles. Some carers have resorted to separating caregiving days or weeks from normal family and work life by coordinating the care with other family members. On the other hand, the female carers shared that the men managed to maintain previous interests by dislocating their caregiving role from their desire and need to maintain social lives. Limitations: The translation of Maltese to English during analysis may compromise the original semantic richness. Gender expectation is from the perspectives of</td>
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The interview duration was 1½ hours with brief rest periods. Interviews were audio taped and transcribed. Thematic analysis was done manually. This was in English and based on the Chinese version of the analysis.

Experiences may differ from that of others. Generally, its only weakness is the absence of description with regard to the relationship of the study’s researchers with participants, how participants were selected, number of people who refused to participate or dropped out, repeat interviews if any, attainment of data saturation, and return of transcripts to participants for comment and/or correction, number of data coders, coding tree, and participants’ feedback on the findings.
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<td>Netto et al (2009); Singapore</td>
<td>Growing and gaining through caring for a loved one with dementia.</td>
<td>A qualitative design, guided by the grounded theory approach was adopted. 12 family caregivers [Daughters (n = 8); Sons (n=2); Wife (n=1); Niece (n=1). NOTE: 2 of the respondents were adopted] were recruited using purposive sampling from three institutions in Singapore. Semi-structured, in-depth, face-to-face interviews were conducted. The interviews were recorded, transcribed and analysed using open, axial and selective coding.</td>
<td>All caregivers reported having gained from caregiving. The most common gain was that of ‘personal growth’ which comprised being more patient/understanding, becoming stronger/more resilient, having increased self-awareness and being more knowledgeable. Another theme that emerged was ‘gains in relationships’ whereby caregivers experienced an improvement in their relationship with the care recipient, with others in the family or in their ability to interact with other older persons. The third gain experienced was that of ‘higher-level gains’ which encompassed gains in spirituality, deepened relations with God, and a more enlightened perspective in life. Limitations: The researcher as instrument in data collection during interviews may possibly lead to interview bias. In this case, the study’s findings may likely be influenced by the researchers’ effect on the family carers’ responses. Generally, its only weakness is the absence of description with regard to the relationship of the study’s researchers with participants, how participants were selected, the number of people who refused to participate or dropped out, the setting of data collection, presence of non-participants, use of interview guide, repeat interviews if any, duration of data collection, attainment of data saturation, return of transcripts to participants for comments and/or correction, number of data coders, coding tree, and participants’ feedback on the finding.</td>
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<td>Roach et al 2013</td>
<td>‘We can’t keep going on like this’: Identifying family storylines in young onset dementia. To gain an in-depth Understanding about the day-to-day experience of young onset dementia in a family-centred context.</td>
<td>Longitudinal, narrative case study design. Five intergenerational families including the person with dementia [Caregivers: Family 1 – wife; Family 2 – Wife; Family 3 – Husband &amp; daughter; Family 4 – Husband, brother, uncle; Family 5 - Husband]. Family members were nominated by the person with dementia from services in the North West of England, including old-age psychiatrists, community mental health teams, specialist young onset dementia services, a memory clinic, a dementia treatment clinic and mental health team operational managers. Data collection: co-construction of a ‘family biography’ (written and non-textual data, such as photographs), semi-structured interview and guided categories of discussion. Total of 126 visits over 12 to 15 months between 2009 and 2010. Ongoing narrative analysis. Qualitative data were transcribed verbatim and entered into NVivo</td>
<td>Emergence of five family storyline types: agreeing; colluding; conflicting; fabricating; and protecting. Findings indicated that families were likely to use each of these storylines at different points and at different times in their exposure to young onset dementia. Families that adopted a predominantly ‘agreeing’ storyline were more likely to find ways of positively overcoming challenges in their everyday lives. Families who adopted predominantly ‘conflicting’ and ‘colluding’ storylines were more likely to require help to understand family positions and promote change. The findings suggest that the identification of the most dominant and frequently occurring storylines used by families may help to further understand family experience in young onset dementia and assist in planning supportive services.</td>
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<td>Szinovacz (2003); United States</td>
<td>Caring for a demented relative at home: Effects on parent–adolescent relationships and family dynamics. To identify changes in parent–adolescent relationships and in family dynamics when a family member with Alzheimer’s or similar dementia moves into the household.</td>
<td>Grounded theory approach. 15 adult family caregivers and 17 adolescent from 15 families [Parent caregiver (n=15): Daughters / daughters in-law (n=13), Husband (n=1), Son / sons in-law (n=1). Adolescents (n=17) from 15 families: Granddaughters (n=13), Grandsons (n=4). NOTE: 2 adolescents were from the same family] of African and Caucasian descent were recruited. Semi-structured interviews with interview guide were conducted at the families’ homes and lasted about an hour each. Computer-aided qualitative analysis and supplemental quantitative analyses of the interview data were performed.</td>
<td>The analyses revealed that the care situation induces both positive and negative changes in family relationships. Adolescents showed considerable empathy and respect for the parent who is the primary caregiver and reported that joint involvement in caregiving enhances adolescent–parent bonds. But, the adolescents lamented restrictions on their own and the family unit’s activities due to the care situation. They also complained about spill over of caregiver stress on other family relationships and about the parent-caregivers’ focus of attention to the care recipient. These negative features strongly influenced adolescents’ adaptation to the care situation. Limitations: Only one interview is unable to gain in-depth insights into the consequences of caregiving environments on children. Data saturation may not be reached either. Generally, its only weakness is the absence of description with regard to the relationship of the study’s researchers with participants, how participants were recruited, number of people who refused to participate or dropped out, presence of non-participants, repeat interviews if any, attainment of data saturation, return of transcripts to participants for comments and/or checking, number of data coders, and whether participants provided feedback on the finding.</td>
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<td>Ward-Griffin et al (2007); Canada</td>
<td>Mother-Adult Daughter Relationships Within Dementia Care A Critical Analysis.</td>
<td>Interpretive descriptive study. 15 Canadian mother-adult daughter dyads [Daughters (n=15). NOTE: 2 or more daughters from 3 families] participated were recruited. In-depth interviews and participant</td>
<td>4 dynamic types of mother-daughter relationships - custodial, combative, cooperative, and cohesive – were identified. Custodial and cooperative relationships mainly focused on the provision of and receipt of tasks, whereas combative and cohesive are emotion focused. Custodial and combative relationships are based on deficits compared with the strength-based cohesive and cooperative relationships. Certain contextual factors,</td>
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To know about the specific relationships between adult daughters and their mothers with dementia.

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<td>observation which was guided by socialist-feminist theory and a life-course perspective were conducted on the mother-adult daughter dyads. Two individual semi-structured interviews lasting about 1 hour at intervals between 6 to 9 months were conducted. Interviews were audio-taped and field notes of each interview were taken. These were transcribed verbatim. Member checking and sharing preliminary findings with the participants, peer debriefing were performed. The multiple sources of data (interview and observation were analysed using NUD*IST qualitative software programme.</td>
<td>such as expectations of care and levels of support, shaped the development of these relationships. Limitations: This study has restricted participation to persons in the earlier stages of dementia only. The mother-daughter relationship may likely differ in the other stages of dementia. Generally, its only weakness is the absence of description with regard to the relationship of the study’s researchers with participants, how participants were recruited, presence of non-participants, attainment of data saturation, number of data coders, the coding tree, and derivation of themes.</td>
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<td>Quantitative Studies</td>
<td>A Longitudinal Study of Predictors of Nursing Home Placement for Patients With Dementia: The Contribution of Longitudinal study. Mailed questionnaire Tape-recorded telephone interview. 164 family caregivers [Spouses (n=92); Offsprings (n=40)] of elderly patients with dementia were followed for 2 years. Clinical assessment occurred at baseline, and caregivers were</td>
<td>No patient demographic, severity, or caregiver characteristic significantly predicted NHP. Families scoring high on emotional closeness, high on negative family feelings, and low on family efficiency institutionalized their ill elders at a significantly higher rate than other families, especially at low levels of patient severity. Limitations:</td>
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<td>Fisher &amp; Lieberman (1999); United States</td>
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<td>Hamill (2012); United States</td>
<td>Caring for Grandparents With Alzheimer’s Disease: Help From the “Forgotten” Generation. To examine adolescent grandchildren’s contributions to</td>
<td>Cross-sectional study. Structured telephone interviews. 29 adolescents and their parents [Parent caregiver: Daughter / daughter-in-law (n=29); Son / son-in-law (n=24); Adolescents: Granddaughters (n=21); Grandson (n=8)] were recruited through the University of California State Department’s Shiley-Marcos Alzheimer’s Disease Research Center, the Alzheimer’s</td>
<td>Participants were mostly European American, with a small number of ethnic minorities. Ethnicity often influences disease management behaviour (Fisher &amp; Lieberman 1999). Thus, findings may not be generalizable to other ethnic groups. Possible factors such as living arrangements, social class, and gender were not explored. Variations among the associations based on the timing of NHP within the 2-year period should look at the care recipient’s disease progression over time. This is likely to be quite variable and could have affected at least some of the relationships. Lastly, this study only looked at the primary carer and not the entire family system. In essence, it is important to go beyond understanding the primary carer to the relevant family system involved in the care. The study did not describe any efforts to address potential sources of bias.</td>
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Participants were mostly European American, with a small number of ethnic minorities. Ethnicity often influences disease management behaviour (Fisher & Lieberman 1999). Thus, findings may not be generalizable to other ethnic groups. Possible factors such as living arrangements, social class, and gender were not explored. Variations among the associations based on the timing of NHP within the 2-year period should look at the care recipient’s disease progression over time. This is likely to be quite variable and could have affected at least some of the relationships. Lastly, this study only looked at the primary carer and not the entire family system. In essence, it is important to go beyond understanding the primary carer to the relevant family system involved in the care. The study did not describe any efforts to address potential sources of bias. |
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<td>Kua &amp; Tan (1997); Singapore</td>
<td>caregiving for grandparents with Alzheimer’s disease.</td>
<td>Association, newspaper announcements, health fairs, assisted living facilities, and word of mouth. Mothers, fathers, and adolescents each had separate ½ hour structured telephone interviews. Adolescents rated the amount of care they provided to grandparents, relationship quality with grandparents and parents, social responsibility, and attitudes toward the provision of long term care. Parents reported levels of caregiver burden. Bivariate analyses of study variables were used to examine relationships between caregiving indices, adolescent development, and attitudes toward long term care. To reduce Type I error due to multiple comparisons, a Bonferroni correction was used. Subsequently, only results with associations at p \leq 0.03 were considered significant.</td>
<td>over time. The title, abstract and potential sources of bias were partially described.</td>
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28 (56%) scored 5 points or more on the 28-item General Health Questionnaire (GHQ). The GHQ scores correlated significantly with duration of care; presence of delusion, hallucination, depression, insomnia, incontinence and agitation; and the total score of the Behavioural Pathology in Alzheimer's Disease Rating Scale. On multiple regression analysis, the...
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<td>To investigate the behavioural problems of the dementia patients and factors associated with the emotional well-being of the caregivers.</td>
<td>Chinese patients with dementia in Singapore were required to self-rate using a structured questionnaire - the 28-item General Health Questionnaire while patients were rated on the Behavioural Pathology in Alzheimer's Disease Rating Scale. Data was entered into SPSS and GMS computerized programme AGECAT. X² test, p-value and multiple regression equation analysis were used to analyse data.</td>
<td>only variables to achieve a significant relationship with the GHQ scores were duration of care, depression and the total behavioural score. 56% of caregivers had high GHQ scores. Limitations: The sample size of caregivers is relatively small for a quantitative study. There is a selection bias in using hospital patients because the milder cases do not seek medical advice. Therefore, results cannot be generalized to all Singaporean Chinese families caring for an older person with dementia.</td>
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<td>Lieberman &amp; Fisher (1999); United States</td>
<td>The Effects of Family Conflict Resolution and Decision Making on the Provision of Help for an Elder With Alzheimer's Disease.</td>
<td>Longitudinal, cross-sectional study. 211 patients and their families [Spouse (n=99); Spouse &amp; offspring (n=17); Offspring (n=49); Non-relatives (n=8)] were recruited from the California Alzheimer's and Memory Disorders Clinics located in San Francisco, Davis, Fresno, Palo Alto, Los Angeles, San Diego, and Irvine. 197-item questionnaire and a 45-minute tape-recorded telephone interview were conducted. 211 adult off springs and in-laws who were most involved in ADLs / IADLs care were recruited. The 211 families were eventually reduced by 10 deaths</td>
<td>Above and beyond control variables, families who used a focused decision making style and positive conflict resolution methods provided more help than families who did not use these styles and methods. Limitations: Findings were based on cross-sectional, retrospective data from family members. Predictive linkages among these variables were not assessed. Appraisals by members of the same family were not determined. Thus, findings may be biased as data is only from the offspring most involved in the care. The sample was mostly Caucasian White. Because family structures, beliefs, and styles of management vary by culture and ethnicity, these findings cannot be directly translated to other ethnic groups (Lieberman &amp; Fisher 1999).</td>
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<td>Liew et al (2010); Singapore</td>
<td>Predicting Gains in Dementia Caregiving. To explore factors associated with the experience of gains in dementia caregiving.</td>
<td>Cross-sectional study. 442 family caregivers - Husband (n=23); Wife (n=22); Son (n=78); Daughter (n=169); Son-in-law (n=2); Daughter-in-law (n=25); Grandson (n=2); Granddaughter (n=2); Other (n=10) - were recruited from a tertiary hospital dementia clinic and the local Alzheimer’s Association in Singapore. 340 responded but only 334 responses were valid. Caregivers completed a questionnaire containing the following scales: gain in Alzheimer’s care Instrument (GAIN), General Health Questionnaire (GHQ-28), Dementia</td>
<td>Mean GAIN score was 30 (SD = 6.6, range = 7–40). Regression analysis identified 3 factors significantly associated with gains (adjusted R² 32.3%): mental well-being of the caregiver, use of active management as a caregiving strategy, and participation in caregiver educational and support group programmes. Limitations: The study sample was from 2 different settings. But, they were similar in the type and range of support. The findings may not be extrapolated to the larger community as the positive caregivers’ gain could be due to the provision of carer support services in both settings. Differences between respondents and non-respondents could not be examined. The cross-sectional nature of the study limits interpretation on causality of identified factors associated with caregivers’ gain. The study sample was self-selecting and educated caregivers. Caregivers who were less educated or with poor eye-sight, such as spousal caregivers, may have been under-represented. Thus, external</td>
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| Lim et al (1999); Singapore. | Burden of Caregiving in Mild to Moderate Dementia: An Asian Experience. To determine (a) the prevalence of carer stress in patients with mild to moderate dementia, (b) whether caregiver quantification was conducted. Primary caregivers - Sons 19%, and daughters 37%, husbands 14%, wives 18%, daughters-in-law, granddaughters, sisters, and friends (12%) - of 93 patients with mild to moderate dementia attending an outpatient cognitive assessment clinic in Singapore were interviewed via a structured questionnaire that focused upon (a) patient-related variables such as their behavioural and functional abnormalities; and (b) 49% of caregivers reported problems in looking after the patients, and their perception of difficulties was significantly associated with institutionalization plans for the patients. Logistic regression analysis using a forward variable selection procedure showed 2 of the patients’ behavioural abnormalities (repetition, agitation) and 1 of their functional impairments (urinary incontinence) and the carers’ depressed feelings to be predictive of the carers’ problematic status, explaining 40% of the variance. Limitations: The measurement ‘scale’ has not been validated. The study’s researchers claim that the individual variables studied were similar to items found in other validated scales, and the careful definition of the study variables and keeping the responses from the caregivers to a simple (yes / no) format, the measurement ‘scale’ has not been validated. The study’s researchers claim that the individual variables studied were similar to items found in other validated scales, and the careful definition of the study variables and keeping the responses from the caregivers to a simple (yes / no) format, the measurement ‘scale’ has not been validated. The study’s researchers claim that the individual variables studied were similar to items found in other validated scales, and the careful definition of the study variables and keeping the responses from the caregivers to a simple (yes / no) format,
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<td>Lin et al (2012); Taiwan</td>
<td>Comparison of the burdens of family caregivers and foreign paid caregivers (FPC) of the individuals with dementia. To identify predictors and differences in caregiver burden between FPCs and family caregivers who provided care.</td>
<td>Cross-sectional study – Spouse (n=112); Adult children (n=306); Daughters-in-law (n=41); Other relatives (n=30); Live-in maid (n=42). Structured questionnaires. 489 patients with dementia (diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition) and the Neuropsychiatric Inventory (NPI) and Clinical Dementia Rating (CDR) Scale to assess their neuropsychiatric behavioural problems and severity of dementia were recruited. All caregivers [FPCs (n=42) and family caregivers with NPI and CDR scores were higher among patients assisted by FPCs than among those whose families did not employ FPCs. Burdens were greater among family caregivers assisted by FPCs than among FPCs and family caregivers who were not assisted by FPCs. Family caregivers had greater knowledge of dementia than did FPCs. For family caregivers, CES-D scores (Spearman’s r=0.650; p&lt;0.01) and patients’ NPI scores (Spearman’s r=0.471; p&lt;0.01) were correlated with caregiver burden. For FPCs, only CES-D scores (Spearman’s r=0.511; p&lt;0.01) were correlated with caregiver burden. A linear regression model showed that CES-D scores contributed most to caregiver burden in all groups [β =0.560 (family caregivers without FPCs), 0.546 (family caregivers with FPCs), and 0.583 (FPCs); p&lt;0.005]. Limitations: The reliability and validity of the questionnaires have been confirmed in Taiwan but not for the Indonesian version. Measurement of patients’ symptoms was based on caregivers’ reports. Caregivers’ ratings may have...</td>
<td>caregiver-related variables such as whether they were having problems looking after the patients, the duration of their caregiving, their associated feelings of anger and/or depression, and their financial status and intentions to institutionalize patients. Data was entered into the SPSS version 7.5. X² or the Mann-Whitney U test, logistic regression analysis and goodness-of-fit test were performed during data analysis.</td>
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<td>Tew et al (2010); Singapore</td>
<td>Why Family Caregivers Choose to Institutionalize a Loved One with Dementia: A Singapore Perspective.</td>
<td>Cross-sectional study. 266 family caregivers - Spouse (n=48); Adult children (n=183); Others (n=34) - were recruited from a tertiary hospital dementia clinic and the local Alzheimer’s Association in Singapore. Caregivers completed a questionnaire containing demographics of the person with dementia and caregiver, their choice of care setting and the following</td>
<td>Most caregivers (85.7%) preferred caring for the person with dementia at home with only 38 (14.3%) choosing institutionalization. Four factors were associated with choice of nursing home: caregiver who is working (OR = 6.363, 2.120–19.086), no domestic maid (OR = 3.27, 1.458–7.331), lower caregiver gain (OR = 0.935, 0.882–0.992) and behavioural problems in the person with dementia (OR = 1.011, 1.005–1.018). Limitations: It is not possible to determine if the caregiver’s preference at the point of study will translate into the eventual outcome. External validity and generalizability of the result may be limited due to sample characteristics,</td>
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for patients with dementia. (n=42) and without (n=447) FPCs] completed 3 questionnaires: the Zarit Burden Interview (ZBI), the Center for Epidemiological Studies–Depression Scale (CES-D), and caregivers’ knowledge of dementia. The questionnaires were translated from English to Chinese and Bahasa Indonesia as the majority of FPCs in Taiwan are Indonesian citizens. Data were analysed using the SPSS software version 18.0. The correlations between ZBI and other variables were analysed. The differences between family caregivers and FPCs were investigated. | an element of subjectivity as these may be affected to some extent by their mood status. The FPCs were not asked to rate patients’ neuropsychiatric symptoms, which may have resulted in some bias in the correlational analysis of FPC burden and the severity of patients’ symptoms. Generalizability (external validity) of the study results was not discussed. |
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<td>choice of care setting (own home versus nursing home) for their relatives with dementia.</td>
<td>scales: Gain in Alzheimer Care Instrument, General Health Questionnaire, Short Sense of Competence Questionnaire, Revised Memory and Behavioural Problems Checklist and Zarit Burden Interview. Multiple logistic regressions were performed to identify significant variables associated with the outcome of interest.</td>
<td>that is, the self-selected population of caregivers who are educated and able to complete the questionnaires independently. There is a likely-hood that these were motivated caregivers who had been bringing the person with dementia for regular doctors’ consults in the ambulatory dementia clinic or are active participants of the local Alzheimer’s association who had received the appropriate education and support. As such, the proportion of caregivers who preferred in-home care may have been falsely inflated. The title and abstract were partially described whereas potential sources of bias were not described.</td>
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**Reviews**

<p>| Reviews | The Influence of Ethnicity and Culture on Dementia Caregiving: A Review of Empirical Studies on Chinese Americans. | Narrative review of qualitative and quantitative studies. 18 publications on Chinese American dementia caregivers published in peer-reviewed journals between 1990 and early 2011 were identified. This was based on a systematic database search and review process to pinpoint the cultural and ethnic influences on dementia caregiving in Chinese American families through a systemic review and analysis of published research findings. | Caregivers’ beliefs regarding dementia and the concept of family harmony through the practice of filial piety are pervasive cultural values. In combination, they affect caregivers’ attitudes toward research and help-seeking behaviours (that is, seeking information on diagnosis and using formal services). These cultural beliefs also impinge on key elements of the caregiving process, including caregivers’ appraisal of stress, coping strategies, and informal and formal support. Limitations: Only a small number of articles were identified. Secondly, studies were of a wide-ranging nature. Reviewed studies varied in research design, variable levels of rigour, sample and study sites. Generally, its only weakness is the absence of a full electronic search strategy for at least one database. The authors did not discuss how studies were appraised for quality and how data from selected studies were extracted. Synthesis of results was also not described. Flow diagram was not used to depict study selection. |</p>
<table>
<thead>
<tr>
<th>Author, Year, Country</th>
<th>Title, Objectives</th>
<th>Design, Sampling</th>
<th>Findings, limitations, risk of bias if any</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wang (2012); United States</td>
<td>Caregiving for Dementia in Asian Communities: Implications for Practice. To review the literature on the perceptions and knowledge of dementia in Asian communities, discuss the consequences of caregiving, and discuss implications for practice and research.</td>
<td>Narrative review of qualitative and quantitative studies. Keywords such as “Asian,” “Alzheimer’s,” “dementia,” and “caregiving” were searched. The search was conducted from April 2011 through March 2012 and each abstract was screened and determined for eligibility for full text review. Approximately 95 abstracts and full-text articles were reviewed, resulting in a total of 20 articles that met the inclusion criteria.</td>
<td>Although dementia can be a debilitating condition for both older adults and their caregivers, strategically examining culture, context, and individual perceptions can increase the quality of life for those affected. By understanding the perceived causes, the reasons for these perceptions, and effective strategies to combat these perceptions, a shared understanding of how to best meet the needs of Asians with dementia and their caregivers, and how to facilitate better relationships through the various generations can be achieved. Limitations: Only articles written in English were reviewed due to the review author’s language literacy. Thus, articles in Asian languages which could likely add to the richness in data were omitted. Resources were limited to those within the United States. This may contribute to unidentified literature. Due to the multitude of Asian groups, specific searches were not conducted at subgroup level. Therefore, there is a high likelihood that more obscure articles were not located. Generally, its only weakness is the absence of a full electronic search strategy for at least one database. The authors also did not discuss how studies were appraised for quality and how data from selected studies were extracted. Synthesis of results was also not described. Flow diagram was not used to depict study selection. Furthermore, there was no declaration pertaining to funding.</td>
</tr>
</tbody>
</table>
APPENDIX 7: SYNTHESIS OF RESULTS

Textual Narrative Synthesis: (1) Characteristics of the intergenerational family caregivers and persons with dementia

Textual Narrative Synthesis: (1) What are the characteristics of the intergenerational family caregivers?

Gender of Family Caregivers

<table>
<thead>
<tr>
<th>Source</th>
<th>Study characteristics</th>
<th>Study Design</th>
<th>Findings</th>
<th>Conclusion (Scope, differences and similarities among studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Beach (1997); USA</td>
<td>Female (n=11), Male (n=9)</td>
<td>Content analysis methodology. Semi-structured interviews</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>2. Boughtwood et al (2011); Australia</td>
<td>Female (n=88), Male (n=33)</td>
<td>Modified grounded theory approach. Focus group.</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>3. Chan et al (2010); Hong Kong</td>
<td>Female (n=21), Male (n=6)</td>
<td>Qualitative study; Focus group interviews</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>4. Ho et al (2003); Canada</td>
<td>Female (n=12)</td>
<td>Qualitative study</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>5. Innes et al (2011); Malta</td>
<td>Female (n=13); Male (n=3)</td>
<td>Exploratory study using semi-structured interview</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>6. Netto et al (2009); Singapore</td>
<td>Females (n=10); Males (n=2)</td>
<td>Grounded theory approach using Semi-structured, in-depth, face-to-face interviews</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>7. Roach et al 2013; UK</td>
<td>Females (n=3); Males (n=5)</td>
<td>Longitudinal, narrative case study design</td>
<td>Male &gt; Female</td>
<td><em>The only exception.</em></td>
</tr>
<tr>
<td>8. Szinovacz (2003); USA</td>
<td>Parent caregiver: Female (n=13), Male (n=2) Adolescents: Female (n=13), Male (n=4)</td>
<td>Grounded theory approach using semi-structured interviews</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>Source</td>
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<td>Study Design</td>
<td>Findings</td>
<td>Conclusion (Scope, differences and similarities among studies)</td>
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<tr>
<td>9. Ward-Griffin et al (2007); Canada</td>
<td>Female (n=15)</td>
<td>Interpretive descriptive study using in-depth interviews</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>10. Fisher &amp; Lieberman (1999); USA</td>
<td>Female (n=101), Male (n=63)</td>
<td>Longitudinal study</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>11. Hamill (2012); USA</td>
<td>Parent caregiver: Female (n=29), Male (n=24) Adolescents: Female (n=21), Male (n=8)</td>
<td>Cross-sectional study</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>12. Lieberman &amp; Fisher (1999); USA</td>
<td>Female (n=131), Male (n=80)</td>
<td>Longitudinal, cross-sectional study</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>13. Liew et al (2010); Singapore</td>
<td>Female (n=237), Male (n=97)</td>
<td>Cross-sectional Study</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>14. Lin et al (2012); Taiwan</td>
<td>Family caregivers: Female (n=320), Male (n=169) Lived-in maid (Female) (n=42)</td>
<td>Cross-sectional study</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>15. Tew et al (2010); Singapore</td>
<td>Female (n=195), Male (n=70)</td>
<td>Cross-sectional study</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>16. Kua &amp; Tan (1997); Singapore</td>
<td>Female (n=34), Male (n=16)</td>
<td>Quantitative survey</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
<tr>
<td>17. Lim et al (1999); Singapore</td>
<td>68% female, 32% male</td>
<td>Quantitative survey</td>
<td>Female &gt; male</td>
<td>Similar to the other 14 studies.</td>
</tr>
</tbody>
</table>

Commentary based on the synthesis:
The predominant number of female caregivers is similar across 16 studies (Beach 1997; Boughtwood et al 2011; Chan et al 2010; Fisher & Lieberman 1999; Ho et al 2003; Hamill 2012; Innes et al 2011; Kua & Tan 1997; Lieberman & Fisher 1999; Liew et al 2010; Lim et al 1999; Lin et al 2012; Netto et
al 2009; Szinovacz 2003; Tew et al 2010; Ward-Griffin et al 2007) regardless of geographical location – Singapore, Australia, Canada, H.K., Malta, Taiwan and U.S.A. except for Roach et al (2013) from the UK. The trend has not changed from 1997 until current. With the increasing number of women joining and remaining actively employed in the work force to keep up with the standards of living, the implications would be the fine balance between family caregiving and career needs.

### Relation of Family Caregiver to Care Recipient

<table>
<thead>
<tr>
<th>Source</th>
<th>Study characteristics</th>
<th>Study Design</th>
<th>Findings</th>
<th>Conclusion (Scope, differences and similarities among studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender of Family Caregivers</strong></td>
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<td><strong>Religion of Family Caregivers to Care Recipient</strong></td>
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</tr>
<tr>
<td>1. Beach (1997); USA.</td>
<td>Offspring (n=4), Niece / Nephew (n=4), Grandchildren (n=12)</td>
<td>Content analysis methodology. Semi-structured interviews</td>
<td>Grandchildren &gt; Offspring, niece / nephew. No breakdown in numbers according to granddaughters, grandsons, sons or daughters.</td>
<td>Findings are different compared to the other studies because of the study’s focus.</td>
</tr>
<tr>
<td>2. Boughtwood et al (2011); Australia.</td>
<td>Spouses (n=25), Adult children (or the spouse of the adult child) (n=93), Grandchildren (n=3)</td>
<td>Modified grounded theory approach. Focus group.</td>
<td>Adult children &gt; Spouse &gt; grandchildren. No breakdown in numbers according to</td>
<td>Most caregivers are adult children followed by spouses.</td>
</tr>
<tr>
<td>Source</td>
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<td>Study Design</td>
<td>Findings</td>
<td>Conclusion (Scope, differences and similarities among studies)</td>
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<td>Relation of Family Caregivers to Care Recipient</td>
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<tr>
<td>3. Chan et al (2010); Hong Kong.</td>
<td>Wives (n=5), Husbands (n=5), Daughters (n=16), Son (n=1)</td>
<td>Qualitative study; Focus group interviews</td>
<td>Daughters &gt; Spouses (wives, husbands) &gt; Sons</td>
<td>Most caregivers are adult children followed by spouses. Daughters form the bulk of the caregivers.</td>
</tr>
<tr>
<td>4. Ho et al (2003); Canada.</td>
<td>Wives (n=2), Daughters (n=8), Daughters in-law (n=2)</td>
<td>Qualitative study</td>
<td>Daughters &gt; Wives, Daughters in-law</td>
<td>Study’s focus is on women caregivers. However, daughters form the bulk of the caregivers.</td>
</tr>
<tr>
<td>5. Innes et al (2011); Malta</td>
<td>Husbands (n=2), Wives (n=2), Daughters (n=8), Son (n=1), Daughters-in-law (n=3)</td>
<td>Exploratory study using semi-structured interview</td>
<td>Daughters &gt; Daughters in-law &gt; Wives, Husbands &gt; Son</td>
<td>Most caregivers are adult children followed by spouses. Daughters form the bulk of the caregivers.</td>
</tr>
<tr>
<td>6. Netto et al (2009); Singapore</td>
<td>Daughters (n = 8), Sons (n=2), Wife n=1), Niece (n=1). <strong>NOTE:</strong> 1 of the daughters and sons is adopted.</td>
<td>Grounded theory approach using Semi-structured, in-depth, face-to-face interviews</td>
<td>Daughters &gt; Sons &gt; Wife &gt; Niece</td>
<td>Most caregivers are adult children followed by spouses. Daughters form the bulk of the caregivers.</td>
</tr>
<tr>
<td>7. Roach et al 2013; UK</td>
<td>Family 1 – wife; Family 2 – Wife (n=1); Family 3 – Husband &amp; daughter (n=2);</td>
<td>Longitudinal, narrative case study design.</td>
<td>Husbands &gt; Wives &gt; Brother / Daughter / Uncle</td>
<td>Most caregivers are spouses.</td>
</tr>
<tr>
<td>Source</td>
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<td>Findings</td>
<td>Conclusion (Scope, differences and similarities among studies)</td>
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<tr>
<td><strong>Relation of Family Caregivers to Care Recipient</strong></td>
<td>Family 4 – Husband (n=1), brother (n=1), uncle (n=1); Family 5 – Husband (n=1)</td>
<td></td>
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<tr>
<td>8. Szinovacz (2003); USA.</td>
<td>Parent caregiver: Daughters / daughters in-law (n=13), Husband (n=1), Son / sons in-law (1). Adolescents: Granddaughters (n=13), Grandsons (n=4)</td>
<td>Grounded theory approach using semi-structured interviews</td>
<td>Parent caregiver: Daughters / daughters in-law &gt; Husband, Son / sons in-law. Adolescents: Granddaughters &gt; Grandsons. For the parent caregiver, no breakdown in numbers to differentiate the number of daughters, daughters in-law, son, sons in-law.</td>
<td>Most parent caregivers are daughters / daughters-in-law. Most adolescent caregivers are granddaughters.</td>
</tr>
<tr>
<td>9. Ward-Griffin et al (2007); Canada.</td>
<td>Daughters (n=15)</td>
<td>Interpretive descriptive study using in-depth interviews</td>
<td>Daughters only. Study looks at adult daughters.</td>
<td>Findings are different compared to the other studies because of the study’s focus. Therefore, not included in synthesis.</td>
</tr>
<tr>
<td>10. Fisher &amp; Lieberman (1999); USA.</td>
<td>Spouses (n=92), Off springs (n=40)</td>
<td>Longitudinal study</td>
<td>Spouses &gt; Off springs.</td>
<td>Most caregivers are spouses followed by off springs.</td>
</tr>
<tr>
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<tr>
<td>Relation of Family Caregivers to Care Recipient</td>
<td></td>
<td></td>
<td>No breakdown in numbers according to wives, husbands, daughters, sons.</td>
<td></td>
</tr>
<tr>
<td>12. Lieberman &amp; Fisher (1999); USA.</td>
<td>Spouse (n=99), Spouse &amp; offspring (n=17), Offspring (n=49), Non-relatives (n=8)</td>
<td>Longitudinal, cross-sectional study</td>
<td>Spouse &gt; Offspring &gt; Spouse &amp; offspring &gt; Non-relatives. No breakdown in numbers according to wives, husbands, daughter, son. No details on whom the non-relatives are.</td>
<td>Most caregivers are spouses followed by offsprings.</td>
</tr>
<tr>
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<td>Conclusion (Scope, differences and similarities among studies)</td>
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<tr>
<td>13. Liew et al (2010); Singapore.</td>
<td>Relation of Family Caregivers to Care Recipient: Husband (n=23; 6.9%), Wife (n=22; 6.6%), Son (n=78; 23.4%), Daughter (n=169; 50.8%), Son-in-law (n=2; 0.6%), Daughter-in-law (n=25; 7.5%), Grandson (n=2; 0.6%), Granddaughter (n=2; 0.6%), Other (n=10; 3.0%)</td>
<td>Cross-sectional Study</td>
<td>Daughter &gt; Son &gt; Daughter-in-law &gt; Husband, Wife &gt; Other &gt; Son-in-law, Grandson, Granddaughter. No details on who the other is.</td>
<td>Most caregivers are adult children. Daughters form the bulk of the caregivers.</td>
</tr>
<tr>
<td>14. Lin et al (2012); Taiwan</td>
<td>Spouse (n=112), Adult child (n= 306) Daughter-in-law (n=41), Other relatives (n=30), Lived-in maid (n=42)</td>
<td>Cross-sectional study</td>
<td>Adult child &gt; Spouse &gt; Lived-in maid &gt; Daughter-in-law &gt; Other relatives. No breakdown in numbers according to daughters, sons for the adult child, wives, husbands for the spouse. No details on whom the other relatives are.</td>
<td>Most caregivers are adult children followed by spouses.</td>
</tr>
<tr>
<td>15. Tew et al (2010); Singapore.</td>
<td>Spouse (n=48; 18%), Children (n=183; 69.2%), Others (n=34; 12.8%)</td>
<td>Cross-sectional study</td>
<td>Children &gt; Spouse &gt; Others.</td>
<td>Most caregivers are adult children followed by spouses.</td>
</tr>
<tr>
<td>Source</td>
<td>Study characteristics</td>
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<td>Conclusion (Scope, differences and similarities among studies)</td>
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<tr>
<td>Relation of Family Caregivers to Care Recipient</td>
<td></td>
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<td>No breakdown in numbers according to daughters, sons for the children, wives, husbands for the spouse. No details on whom the others are.</td>
<td></td>
</tr>
<tr>
<td>16. Kua &amp; Tan (1997); Singapore.</td>
<td>Wives (n=9), Husband (n=6), Daughters (n=16), daughters-in-law (n=9), Sons (n=10)</td>
<td>Quantitative survey</td>
<td>Daughters &gt; Sons &gt; Wives, daughters-in-law &gt; Husband.</td>
<td>Most caregivers are adult children. Daughters form the bulk of the caregivers.</td>
</tr>
<tr>
<td>17. Lim et al (1999); Singapore.</td>
<td>Sons 19%, and daughters 37%, husbands 14%, wives 18%, daughters-in-law, granddaughters, sisters, and friends of the patients (12%)</td>
<td>Quantitative survey</td>
<td>Daughters &gt; Sons &gt; Wives &gt; daughters-in-law, granddaughters, sisters, and friends of the patients. No breakdown in numbers according to daughters-in-law, granddaughters, sisters, and friends of the patients.</td>
<td>Most caregivers are adult children. Daughters form the bulk of the caregivers.</td>
</tr>
</tbody>
</table>

Commentary based on the synthesis:
Studies done in the U.S.A., in the late 1990s found that most caregivers are spouses followed by off springs (Fisher & Lieberman 1999; Lieberman & Fisher 1999). Likewise, a recent one in the U.K. (Roach et al 2013). In contrast, studies from 1997 until 2012 in Singapore (Kua & Tan 1997; Liew et al 2010;
Netto et al, 2009; Tew et al, 2010; Australia (Boughtwood et al, 2011), Canada (Ho et al, 2003), H.K. (Chan et al, 2010), Malta (Innes et al, 2011) and Taiwan (Lin et al, 2012) have found that most caregivers are adult children followed by spouses. Of these adult caregivers, most are daughters (Chan et al, 2010; Ho et al, 2003; Innes et al, 2011; Kua & Tan, 1997; Liew et al, 2010; Lim et al, 1999; Netto et al, 2009). In studies on adolescent caregivers, most parent caregivers are daughters or daughters-in-law and most adolescent caregivers are granddaughters (Hamill, 2012; Szinovacz, 2003). In fact, the involvement of grandchildren (Boughtwood et al, 2011; Hamill, 2012; Liew et al, 2010; Lim et al, 1999; Szinovacz, 2003; Hamill, 2012; Kua & Tan, 1997; Liew et al, 2010; Lim et al, 1999; Lin et al, 2012) has been frequently cited. Infrequently mentioned caregivers are other relatives such as nieces or nephews (Beach, 1997; Netto et al, 2009), sisters (Lin et al, 2012), sons-in-law (Szinovacz, 2003; Hamill, 2012; Liew et al, 2010), lived-in maid (Lim et al, 1999) and friends of the care recipient (Lin et al, 2012). A Singapore study (Netto et al, 2009) in particular mentioned that 2 of the caregivers were the adopted son and daughter.

Several studies (Beach, 1997; Boughtwood et al, 2011; Fisher & Lieberman, 1999; Hamill, 2012; Lieberman & Fisher, 1999; Lim et al, 1999; Lin et al, 2012; Szinovacz, 2003; Tew et al, 2010) did not provide the specific detailed relation of family caregivers to the care recipients, for example, instead of wives, husbands, daughters or sons, family caregivers were broadly labelled as spouse, children or offspring. Lieberman and Fisher (1999, Liew et al, 2010, Lin et al, 2012) and Tew et al (2010)’s studies have also labelled a proportion of their caregivers as others. This lack of break down in details did not allow more in-depth analysis in relation to the hierarchical order of caregivers and their specific roles. Thus far, based on the available data from the included studies, specific to spousal involvement, only 5 studies could be analysed and synthesized. 2 Singapore studies in the late 1990s (Kua & Tan, 1997; Lim et al, 1999) noted that there were more wives than husbands providing spousal caregiving. Recent studies from H.K. (Chan et al, 2010), Malta (Innes et al, 2011) and Singapore (Liew et al, 2010) seemed to shed a different finding. The number of wives and husbands involved in spousal caregiving was found to be similar. But, interpretation must be done with caution particularly for the Hong Kong (Chan et al, 2010), and Malta (Innes et al, 2011) studies as the sample size for the wives (between n=2 to n=5) and husbands (between n=2 to n=5) is relatively small to make any generalization.
### Age and Generation of Family Caregivers

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>1. Beach (1997); USA</td>
<td>Parent caregiver: Age not provided. Adolescent caregiver: Age range 14 to 18 years</td>
<td>Content analysis methodology.</td>
<td>No data on the age of parent caregivers. 2 generations of caregivers.</td>
<td>Unable to determine age of parent caregivers. Adolescent caregivers’ age is similar to studies no. 7, 9, 11. The finding of 2 generations of caregivers is similar to studies no. 3-6, 10-12, 16. The only study where there are more 3rd than 2nd generation caregivers. Likely due to more than 1 grandchildren representing per family.</td>
</tr>
<tr>
<td></td>
<td>Offspring (n=4), Niece / Nephew (n=4), Grandchildren (n=12)</td>
<td>Semi-structured interviews</td>
<td>3rd generation caregivers (n= 12) &gt; 2nd generation caregivers (n= 8). More 3rd than 2nd generation caregivers.</td>
<td></td>
</tr>
<tr>
<td>2. Boughtwood et al (2011); Australia</td>
<td>Youngest caregiver = 17 years, Oldest caregiver = 90 years. Spouses (n=25), Adult children (or the spouse of the adult child) (n=93), Grandchildren (n=3)</td>
<td>Modified grounded theory approach. Focus group.</td>
<td>Incomplete data on the age. 3 generations of caregivers. 2nd generation caregivers (n= 93) &gt; 1st generation caregivers (n= 25) &gt; 3rd generation caregivers (n= 3). Mostly 2nd generation caregivers.</td>
<td>Unable to determine nor differentiate the ages of the intergenerational caregivers. The finding of mostly 2nd generation caregivers is similar to studies no. 3-6, 11, 13-15-17. The finding of 3 generations of caregivers is similar to studies no. 7, 13, and 17.</td>
</tr>
<tr>
<td>Source</td>
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<td>Conclusion (Scope, differences and similarities among studies)</td>
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<tr>
<td>Age and generation of</td>
<td></td>
<td>Qualitative study; Focus</td>
<td>Older group of caregivers &gt; 65 years. 2 generations of caregivers.</td>
<td>The finding of 2 generations of caregivers is similar to studies no. 1, 4-6, 10-12, 16.</td>
</tr>
<tr>
<td>family caregivers</td>
<td></td>
<td>group interviews</td>
<td>2nd generation caregivers (n=17) &gt; 1st generation caregivers (n= 10). Mostly 2nd generation caregivers.</td>
<td>The finding of mostly 2nd generation caregivers is similar to studies no. 2, 4-6, 11, 13-17.</td>
</tr>
<tr>
<td>3. Chan et al (2010);</td>
<td>Age range 66 to 98</td>
<td>Qualitative study; Focus</td>
<td></td>
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<tr>
<td>Hong Kong</td>
<td>years (Median 78</td>
<td>group interviews</td>
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<td>years)</td>
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<td></td>
<td>Wives (n=5), Husbands</td>
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<tr>
<td></td>
<td>(n=5), Daughters</td>
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<td></td>
<td>(n=16), Son</td>
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<td></td>
<td>(n=1)</td>
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<td></td>
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<tr>
<td>4. Ho et al (2003);</td>
<td>Wives (n=2) – 75 to</td>
<td>Qualitative study</td>
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<tr>
<td>Canada</td>
<td>80 years. Daughters</td>
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<td></td>
<td>(n=8), Daughters in-</td>
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<td>law (n=2) - Age range</td>
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<td></td>
<td>30 to 67 years.</td>
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<tr>
<td>5. Innes et al (2011);</td>
<td>Age not provided.</td>
<td>Exploratory study using semi-</td>
<td>No data on age. 2 generations of caregivers. 2nd generation caregivers</td>
<td>Unable to determine nor differentiate the ages of caregivers. The finding of 2 generations of caregivers is similar to studies no. 1, 3-4, 6, 10-12, 16.</td>
</tr>
<tr>
<td>Malta</td>
<td>Husbands (n=2),</td>
<td>structured interview</td>
<td>(n= 12) &gt; 1st generation caregivers (n= 4). Mostly 2nd generation</td>
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<tr>
<td></td>
<td>Wives (n=2),</td>
<td></td>
<td>caregivers.</td>
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<td></td>
<td>Daughters (n=8),</td>
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<td></td>
<td>Son (n=1), Daughters-</td>
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<td></td>
<td>in-law (n=3)</td>
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</table>

No data on age. 2 generations of caregivers. 2nd generation caregivers (n= 12) > 1st generation caregivers (n= 4). Mostly 2nd generation caregivers.

Unable to determine nor differentiate the ages of caregivers. The finding of 2 generations of caregivers is similar to studies no. 1, 3-4, 6, 10-12, 16. The finding of mostly 2nd generation caregivers is similar to studies no. 2-3, 5-6, 11, 13-17.
<table>
<thead>
<tr>
<th>Source</th>
<th>Study characteristics</th>
<th>Study Design</th>
<th>Findings</th>
<th>Conclusion (Scope, differences and similarities among studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age and generation of family caregivers</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>6.Netto et al (2009); Singapore</td>
<td>30s (n=2), 40s (n=1), 50s (n=8), 70s (n=1). Daughters (n = 8), Sons (n=2), Wife (n=1), Niece (n=1)</td>
<td>Grounded theory approach using Semi-structured, in-depth, face-to-face interviews</td>
<td>50s &gt; 30s &gt; 40s &amp; 70s. Most caregivers are in their 50s. <strong>2 generations of caregivers.</strong> 2nd generation caregiver (n= 11) &gt; 1st generation caregiver (n= 1). Mostly 2nd generation caregivers.</td>
<td>The finding of <strong>2 generations of caregivers</strong> is similar to studies no. 1, 3-5, 10-12, 16. The finding of mostly 2nd generation caregivers is similar to studies no. 2-5, 11, 13-17.</td>
</tr>
<tr>
<td>7.Roach et al 2013; UK</td>
<td>30s (n=1), 40s (n=1), 50s (n=3), 70s (n=3)</td>
<td>Longitudinal, narrative case study design.</td>
<td>50s, 70s &gt; 30s, 40s <strong>3 generations of caregivers.</strong> 1st generation caregiver (n=3) 2nd generation caregiver (n=5)</td>
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<tr>
<td>8.Szinovacz (2003); USA</td>
<td>Parent caregiver: Mean age = 46 years. Adolescent caregiver: Age range 12 to19 years. Parent caregiver (n=15): Daughters / daughters in-law (n=13), Husband (n=1), Son / sons in-law (1). Adolescents (n=17) from 15 families: Granddaughters (n=13),</td>
<td>Grounded theory approach using semi-structured interviews</td>
<td>Incomplete data on age. <strong>3 generations of caregivers.</strong> 3rd generation caregivers (n= 17) &gt; 2nd generation caregivers (n= 14) &gt; 1st generation caregivers (n= 1). Mostly 2nd and 3rd generation caregivers. 2 3rd generation caregivers were from the same family.</td>
<td>Adolescent caregivers’ age is similar to studies no.1, 9, 11. The finding of 3 generations of caregivers is similar to studies no. 2, 13, and 17.</td>
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<td>Grandsons (n=4). NOTE: 2 from the same family.</td>
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<tr>
<td>9. Ward-Griffin et al (2007); Canada</td>
<td>Age range 35 to 63 years. Daughters (n=15). NOTE: 2 or more daughters from 3 families participated.</td>
<td>Interpretive descriptive study using in-depth interviews</td>
<td>Most 2nd generation caregivers are in their 30s to 60s. 1 generation of caregivers, 2nd generation caregivers (n= 15). Only 2nd generation caregivers.</td>
<td>The finding of 1 generation of caregivers is similar to studies no. 9. Only 2nd generation caregivers due to study’s focus.</td>
</tr>
<tr>
<td>10. Fisher &amp; Lieberman (1999); USA</td>
<td>Mean age = 45 years. Spouses (n=92), Off springs (n=40)</td>
<td>Longitudinal study</td>
<td>Insufficient data on age specific to the 2 generation of caregivers. 2 generations of caregivers. 1st generation caregivers (n= 92) &gt; 2nd generation caregivers (n= 40). Mostly 1st generation caregivers.</td>
<td>Unable to determine specific caregiver age group. The finding of 2 generations of caregivers is similar to studies no. 1, 3-6, 11-12, 16. The finding of mostly 1st generation caregivers is similar to study no. 12.</td>
</tr>
<tr>
<td>11. Hamill (2012); USA</td>
<td>Parent caregiver (Mother): Age range 30 to 56 years. Parent caregiver (Father): Age range 35 to 67 years. Adolescent caregiver: Age range 11 to 21 years. Parent caregiver: Daughter / daughter-in-law (n=29), Son / son-in-law (n=24).</td>
<td>Cross-sectional study</td>
<td>Most 2nd generation caregivers are in their 30s to 60s. 2 generations of caregivers. 2nd generation caregivers (n= 53) &gt; 3rd generation caregivers (n= 29). Mostly 2nd generation caregivers.</td>
<td>The 3rd generation caregivers / Adolescent caregivers age is similar to studies no. 1, 7, 9. The finding of 2 generations of caregivers is similar to studies no. 1, 3-6, 10,12, 16. The finding of mostly 2nd generation caregivers is</td>
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<td></td>
<td>Adolescents: Granddaughters (n=21), Grandson (n=8)</td>
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<tr>
<td>12. Lieberman &amp; Fisher (1999); USA</td>
<td>Age was not provided. Spouse (n=99), Spouse &amp; offspring (n=17), Offspring (n=49), Non-relatives (n=8)</td>
<td>Longitudinal, cross-sectional study</td>
<td>No data on the caregivers’ age. 2 generations of caregivers; 1st generation caregivers &gt; 2nd generation caregivers &gt; Non relatives. Mostly 1st generation caregivers.</td>
<td>Unable to determine caregivers’ age – no data. The finding of 2 generations of caregivers is similar to studies no. 1, 3-6, 10-11, 16. The finding of mostly 1st generation caregivers is similar to study no. 10.</td>
</tr>
<tr>
<td>13. Liew et al (2010); Singapore</td>
<td>Age range 22 to 85 years. Husband (n=23), Wife (n=22), Son (n=78), Daughter (n=169), Son-in-law (n=2), Daughter-in-law (n=25), Grandson (n=2), Granddaughter (n=2), Other (n=10).</td>
<td>Cross-sectional Study</td>
<td>Age is not differentiated by generations. 3 generations of caregivers; 2nd generation caregivers (n= 274) &gt; 1st generation caregivers (n= 45) &gt; 3rd generation caregivers (n= 2). Mostly 2nd generation caregivers.</td>
<td>Data on age was not differentiated by generations. Unable to determine specific intergenerational caregivers’ age group. The finding of 3 generations of caregivers is similar to studies no. 2, 7, and 17. The finding of mostly 2nd generation caregivers is similar to studies no. 2-6, 11, 14-17.</td>
</tr>
<tr>
<td>14. Lin et al (2012); Taiwan</td>
<td>Lived-in maids’ age range 23 to 45 years. Age of family caregivers with lived-in maid</td>
<td>Cross-sectional study</td>
<td>Age is not differentiated by generations except for the lived-in maid. Unable to</td>
<td>Unable to determine specific intergenerational caregivers’ age group except for the</td>
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<tr>
<td>Age and generation of family caregivers</td>
<td>- 35 to 87 years. Age of family caregivers without lived-in maid – 23 to 45 years. Spouse (n=112), Adult child (n= 306) Daughter-in-law (n=41), Other relatives (n=30); Lived-in maid (n=42).</td>
<td>Cross-sectional study</td>
<td>determine the generations of caregivers due to ambiguity of description, ‘other relatives’.  2nd generation caregivers &gt; 1st generation caregivers &gt; Lived-in maid &gt; others relatives. But, mostly 2nd generation caregivers. Unique as caregiver also includes lived-in maid.</td>
<td>lived-in maid. The finding of mostly 2nd generation caregivers is similar to studies no. 2-6, 11, 13, 15-17. Similar to study no.15, unable to determine the generations of caregivers due to ambiguity of description, ‘other relatives’.</td>
</tr>
<tr>
<td>15.Tew et al (2010); Singapore</td>
<td>Age range 22 to 85 years. Spouse (n=48), Children (n=183), Others (n=34).</td>
<td>Cross-sectional study</td>
<td>Age is not differentiated by generations. Unable to determine the generations of caregivers due to ambiguity of description, ‘others’. 2nd generation caregivers &gt; 1st generation caregivers &gt; others. Mostly 2nd generation caregivers.</td>
<td>Unable to determine specific intergenerational caregivers’ age group. Similar to study no. 14, unable to determine the generations of caregivers due to ambiguity of description, ‘others’. The finding of mostly 2nd generation caregivers is similar to studies no. 2-6, 11, 13-14, 16-17.</td>
</tr>
<tr>
<td>16.Kua &amp; Tan (1997); Singapore</td>
<td>Age range 42 to 79 years. Wives (n=9), Husband (n=6),</td>
<td>Quantitative survey</td>
<td>Age is not differentiated by generations. 2 generations of</td>
<td>Unable to determine specific intergenerational caregivers’</td>
</tr>
<tr>
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<td>Study Design</td>
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<td>Conclusion (Scope, differences and similarities among studies)</td>
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<td>Age and generation of family caregivers</td>
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<td></td>
<td>Daughters (n=16), daughters-in-law (n=9), Sons (n=10)</td>
<td></td>
<td>2nd generation caregivers (n= 35) &gt; 1st generation caregivers (n= 15). Mostly 2nd generation caregivers.</td>
<td>age group. The finding of 2 generations of caregivers is similar to studies no. 1, 3-6, 10-12. The finding of mostly 2nd generation caregivers is similar to studies no. 2-6, 11, 13-14, 15, 17.</td>
</tr>
<tr>
<td>17.Lim et al (1999); Singapore</td>
<td>Age was not provided. Sons 19%, and daughters, 37%, husbands 14%, wives 18%, daughters-in-law, granddaughters, sisters, and friends of the patients (12%)</td>
<td>Quantitative survey</td>
<td>No data on age. 3 generations of caregivers. Unable to provide breakdown in actual sample size for the different generations of caregivers. However, 2nd generation caregivers &gt; 1st generation caregivers &gt; 3rd generation caregivers / friends. But, mostly 2nd generation caregivers.</td>
<td>Unable to determine specific intergenerational caregivers’ age group – no data. The finding of 3 generations of caregivers is similar to studies no. 2, 7, and 13. The finding of mostly 2nd generation caregivers is similar to studies no. 2-6, 11, 13-16.</td>
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</table>

Commentary based on the synthesis:
For this review, spouses / siblings, children / children-in-law / nephews / nieces and grandchildren of care recipients are referred to as first, second and third generation caregivers respectively. As many as 10 studies (Beach 1997; Chan et al (2010; Hamill 2012; Ho et al 2003; Innes et al 2011; Kua & Tan 1997; Netto et al 2009; Fisher & Lieberman 1999; Lieberman & Fisher 1999); Roach et al 2013) had 2 generations of caregivers. Of these, only 2 studies conducted in the late 1990s in U.S.A. noted that most were first generation caregivers (Fisher & Lieberman 1999; Lieberman & Fisher 1999). The other 7 studies had mostly second generation caregivers (Chan et al (2010; Hamill 2012; Ho et al 2003; Innes et al 2011; Kua & Tan 1997; Netto et al 2009; Roach et al 2013).
### Age and generation of family caregivers

1 study (Beach 1997), in particular, had more third generation caregivers. This is likely due to the study’s focus on adolescent caregiving experiences and more than one grandchild from a family participating. A few studies managed to recruit 3 generations of caregivers (Boughtwood et al 2011; Liew et al 2010; Lim et al 1999; Szinovacz 2003). However, a similar pattern is observed. Most caregivers were second generation caregivers (Boughtwood et al 2011; Liew et al 2010; Lim et al 1999). Only had 1 generation of caregivers (Ward-Griffin et al 2007) because of the specific focus which was looking at either the second or third generation caregivers. Only 5 studies, 3 from the U.S.A. (Beach 1997; Hamill 2012; Szinovacz 2003), 1 from Australia (Boughtwood et al 2011) included third generation or adolescent caregivers with ages ranging between 11 to 21 years old.

It was difficult to analyse and synthesize the ages of the caregivers specific to the 3 different generations as age was not differentiated according to the generations of caregivers for a majority of the studies. The process was further complicated when several studies did not even provide data on the caregivers’ age (Beach 199; Innes et al 2011; Lieberman & Fisher (1999). Some provided minimal data – such as age of the youngest (17 years) and oldest caregivers (90 years) (Boughtwood et al 2011), age range between 2 or 3 generations (Chan et al 2010; Kua & Tan 1997; Liew et al 2010; Lin et al 2012; Tew et al 2010) and the mean age of 2 generations (Fisher & Lieberman 1999). The only ones which permitted meaningful interpretation and correspondence to the specific intergenerational caregivers’ age were studies by Hamill (2012), Ho et al (2003), Netto et al (2009), Szinovacz (2003), Ward-Griffin et al (2007) which indicated that first, second and third generation caregivers tend to be in their 70s and 80s, 30s to 60s, and 11 to 21 years old respectively. On the other hand, live-in maids’ age range tend to be from 23 to 45 years old as reflected in Lin et al (2012)’s study.

### Marital status of family caregiver

<table>
<thead>
<tr>
<th>Source</th>
<th>Study characteristics</th>
<th>Study Design</th>
<th>Conclusion (Scope, differences and similarities among studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Marital status of family caregiver</strong></td>
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<tr>
<td>Qualitative</td>
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<tr>
<td>1. Beach (1997); USA</td>
<td>Data not provided.</td>
<td>Content analysis methodology. Semi-structured interviews</td>
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1. Beach (1997); USA

Data not provided.
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<thead>
<tr>
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<th>Study Design</th>
<th>Conclusion (Scope, differences and similarities among studies)</th>
</tr>
</thead>
<tbody>
<tr>
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<td></td>
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<tr>
<td>2. Boughtwood et al (2011); Australia</td>
<td>Data not provided.</td>
<td>Modified grounded theory approach. Focus group.</td>
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<tr>
<td>3. Chan et al (2010); Hong Kong</td>
<td>Data not provided.</td>
<td>Qualitative study; Focus group interviews</td>
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</tr>
<tr>
<td>4. Ho et al (2003); Canada</td>
<td>Married (n=11), Divorced / widowed (n=1).</td>
<td>Qualitative study.</td>
<td>Similar</td>
</tr>
<tr>
<td>5. Innes et al (2011); Malta</td>
<td>Not provided.</td>
<td>Exploratory study using semi-structured interview.</td>
<td></td>
</tr>
<tr>
<td>6. Netto et al (2009); Singapore</td>
<td>Married (n = 8), Singles (n=3), Widowed (n=1).</td>
<td>Grounded theory approach using Semi-structured, in-depth, face-to-face interviews</td>
<td>Similar</td>
</tr>
<tr>
<td>7. Roach et al 2013; UK</td>
<td>Married (n=5), Possibly single (n=3)</td>
<td>Longitudinal, narrative case study design.</td>
<td></td>
</tr>
<tr>
<td>8. Szinovacz (2003); USA</td>
<td>Adult caregivers: Married (n = 11), Divorced (n=2), Widowed (n=1). Never married (n=1). Adolescent caregivers: Never married (n=17).</td>
<td>Grounded theory approach using semi-structured interviews</td>
<td>Similar</td>
</tr>
<tr>
<td>9. Ward-Griffin et al (2007); Canada</td>
<td>Married (n=10), *Single (n=5)</td>
<td>Interpretive descriptive study using in-depth interviews</td>
<td>Similar</td>
</tr>
<tr>
<td><strong>Quantitative</strong></td>
<td></td>
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<tr>
<td>10. Fisher &amp; Lieberman (1999); USA</td>
<td>Data not provided.</td>
<td>Longitudinal study</td>
<td></td>
</tr>
<tr>
<td>11. Hamill (2012); USA</td>
<td>Not provided.</td>
<td>Cross-sectional study</td>
<td></td>
</tr>
<tr>
<td>12. Lieberman &amp; Fisher (1999); USA</td>
<td>Married (n=153), Single (n=32), Divorced / Separated (n=23), Widowed (n=3)</td>
<td>Longitudinal, cross-sectional study</td>
<td>Similar</td>
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<tr>
<td>13. Liew et al (2010); Singapore</td>
<td>Married (n=212), Single (n=100), Widowed / Divorced / Separated (n=21)</td>
<td>Cross-sectional Study</td>
<td>Similar</td>
</tr>
<tr>
<td>14. Lin et al (2012); Taiwan</td>
<td>Data not provided.</td>
<td>Cross-sectional study</td>
<td></td>
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<tr>
<td>15. Tew et al (2010); Singapore</td>
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<td></td>
</tr>
<tr>
<td>16. Kua &amp; Tan (1997); Singapore</td>
<td>Data not provided.</td>
<td>Quantitative survey</td>
<td></td>
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<tr>
<td>17. Lim et al (1999); Singapore</td>
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<tr>
<td>19. Wang (2012); USA</td>
<td>Data not provided.</td>
<td>Narrative Review</td>
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Commentary based on the synthesis:
Only 5 out of 9 qualitative (Ho et al 2003; Netto et al 2009; Roach et al 2013; Szinovacz 2003; Ward-Griffin et al 2007) and 2 out of 8 quantitative studies (Lieberman & Fisher 1999; Liew et al 2010) provided data on caregivers’ marital status. The family caregivers from these studies were mostly married. Single caregivers whether divorced or never married formed the second largest group of caregivers.

### Ethnicity and Culture of Family Caregivers

<table>
<thead>
<tr>
<th>Source</th>
<th>Study characteristics</th>
<th>Study Design</th>
<th>Findings</th>
<th>Conclusion (Scope, differences and similarities among studies)</th>
</tr>
</thead>
<tbody>
<tr>
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<tr>
<td>Qualitative</td>
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</table>

325
<table>
<thead>
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<th>Conclusion (Scope, differences and similarities among studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Innes et al (2011); Malta</td>
<td>17 family caregivers from Malta – Maltese.</td>
<td>Exploratory study using semi-structured interview.</td>
<td>Maltese only.</td>
<td>Maltese only.</td>
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<tr>
<td>9. Ward-Griffin et al (2007); Canada</td>
<td>*15 caregivers from Canada – no breakdown according to ethnicity.</td>
<td>Interpretive descriptive study using in-depth interviews</td>
<td>*No breakdown according to ethnicity.</td>
<td>*No breakdown according to ethnicity. Similar to Fisher &amp; Lieberman (1999).</td>
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<tr>
<td><strong>Quantitative</strong></td>
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<tr>
<td>10. Fisher &amp; Lieberman (1999); USA</td>
<td>*164 mostly European descent and a small number of ethnic minority caregivers from the USA – no breakdown according to ethnicity.</td>
<td>Longitudinal study</td>
<td>*No breakdown according to ethnicity.</td>
<td>*No breakdown according to ethnicity. Similar to Ward-Griffin et al (2007).</td>
</tr>
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<td>Study Design</td>
<td>Findings</td>
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<tr>
<td><strong>Ethnicity and culture of family caregivers</strong></td>
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<tr>
<td>169 Non-Hispanic White.</td>
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<tr>
<td><strong>Review</strong></td>
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</tbody>
</table>
| **Ethnicity and culture of family caregivers** |  |  |  | the PICo criteria of the current review. **Chinese only.** Similar to Chan et al (2010), Ho et al (2003), Kua 
& Tan (1997). |
<p>| Hicks &amp; Lam (1999)             | 3 Chinese American medical professional and 7 Chinese American caregivers.            |  |  |  |
| 19. Wang (2012); USA           | Braun, Takamura, &amp;                                                                     | Narrative Review | • Vietnamese in USA.     | 10/20 of Wang (2010)’s reviewed studies on Asian |</p>
<table>
<thead>
<tr>
<th>Source</th>
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<th>Conclusion (Scope, differences and similarities among studies)</th>
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<td></td>
<td><strong>Ethnicity and culture of family caregivers</strong></td>
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<tr>
<td>Mougeot (1996) - Vietnamese in USA. South Asians in the U.K. Chan et al. (2010) - Chinese in Hong Kong. Ho, Friedland, Rappolt, &amp; Noh (2003) - Chinese in Canada. Ikels (1998) - Chinese in China. Lim, Griva, Goh, Chionh, &amp; Yap (2011) - Asians (primarily Chinese, Indians, Eurasians, Malays) in Singapore. Lim, Sahadevan, Choo, &amp; Anthony (1999) - Asians (primarily Chinese, followed by Eurasians, Malays, South Indian). Country not specified. Liu, Hinton, Tran, Hinton, &amp; Barker (2008) - Chinese and Vietnamese in the USA.</td>
<td></td>
<td>Caregivers fitted the PICO criteria of the current review based on objectives and findings. 5 were Chinese only studies – H.K (x1), Canada (x1), China (x1), USA (x2). 2 were South Asians in U.K. 1 was a study on Vietnamese in USA. The other 3 studies were on Chinese with other ethnic groups (Vietnamese in USA; Indians, Eurasians, Malays in Singapore; Eurasians, Malays, South Indian in unspecified locality).</td>
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</table>

- Chinese and Vietnamese in the USA.
- Chinese in Hong Kong.
- Chinese in Canada.
- Chinese in China.
- Chinese in the U.S.A. x2
- Chinese, Indians, Eurasians, Malays in Singapore.
- Chinese, Eurasians, Malays, South Indian (Country not specified).
- South Asians in U.K. x2
<table>
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</table>

Commentary based on the synthesis:
1 qualitative study (Netto et al (2009) and 4 quantitative studies (Liew et al 2010; Lin et al 2012; Tew et al 2010; Lim et al 1999) included caregivers who were **predominantly Chinese**. 3 qualitative (Beach 1997; Roach et al 2013; Szinovacz 2003) and 2 quantitative studies (Hamill 2012; Lieberman & Fisher 1999) had mostly Caucasian White caregivers. 2 Qualitative studies from H.K. and Canada, 1 quantitative study from Singapore and 1 narrative review from U.S.A. had **Chinese caregivers only**. 7 out of 25 of Sun et al (2012)’s reviewed studies were on Chinese American caregivers and these studies fitted the PICo criteria of the current review. Additionally, 3 of their other studies on Chinese only caregivers were from H.K. and Singapore. 10 out of 20 of Wang (2010)’s reviewed studies on Asian caregivers fitted the PICo criteria of the current review based on objectives and findings. 5 were Chinese only studies – 1 from H.K., Canada and China respectively and 2 from the U.S.A. 2 were on South Asians in U.K. and 1 was on Vietnamese in the U.S.A. The other 3 studies were on Chinese with other ethnic groups (Vietnamese in USA; Indians, Eurasians, Malays in Singapore; Eurasians, Malays, South Indian in unspecified locality).

**Educational status of family caregiver**

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<tbody>
<tr>
<td>Educational status of family caregiver</td>
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<tr>
<td>Qualitative</td>
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331
<table>
<thead>
<tr>
<th>Source</th>
<th>Study characteristics</th>
<th>Study Design</th>
<th>Conclusion (Scope, differences and similarities among studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Beach (1997); USA</td>
<td>64% of adolescents completed 12th grade. Data not provided for parent caregivers.</td>
<td>Content analysis methodology. Semi-structured interviews</td>
<td>Data is incomplete for educational status.</td>
</tr>
<tr>
<td>2. Boughtwood et al (2011);</td>
<td>Data not provided.</td>
<td>Modified grounded theory approach. Focus group.</td>
<td>Data not provided.</td>
</tr>
<tr>
<td>Australia</td>
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<tr>
<td>3. Chan et al (2010); Hong</td>
<td>3 (11%) no formal education, 10 (37%) primary school, 12 (44%) secondary school; 2 (7%)</td>
<td>Qualitative study; Focus group interviews</td>
<td>Hong Kong Population By-census (ref), population ≥ 15 years who had received primary, secondary and tertiary education = 18%, 52%, and 15%. *Educational attainment of caregivers was &lt; HK national average.</td>
</tr>
<tr>
<td>Kong</td>
<td>tertiary education.</td>
<td></td>
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</tr>
<tr>
<td>4. Ho et al (2003); Canada</td>
<td>Data not provided.</td>
<td>Qualitative study.</td>
<td>Data not provided.</td>
</tr>
<tr>
<td>5. Innes et al (2011); Malta</td>
<td>Data not provided.</td>
<td>Exploratory study using semi-structured interview.</td>
<td>Data not provided.</td>
</tr>
<tr>
<td>6. Netto et al (2009);</td>
<td>O-levels (secondary school equivalent) (n = 4), A-levels (pre-university equivalent)</td>
<td>Grounded theory approach using Semi-structured,</td>
<td></td>
</tr>
<tr>
<td>Singapore</td>
<td>(n = 1), diplomas (n = 5), university degrees (n = 2).</td>
<td>in-depth, face-to-face interviews</td>
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</tr>
<tr>
<td>7. Roach et al 2013; UK</td>
<td>Data not provided.</td>
<td>Longitudinal, narrative case study design.</td>
<td></td>
</tr>
<tr>
<td>8. Szinovacz (2003); USA</td>
<td>Less than high school, 6.7%, High school (including vocational training) 6.7%, some</td>
<td>Grounded theory approach using semi-structured</td>
<td></td>
</tr>
<tr>
<td></td>
<td>college (no degree) 26.7%, Bachelor’s degree 46.7%, Graduate education 13.4%.</td>
<td>interviews</td>
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<tr>
<td><strong>Educational status of family caregiver</strong></td>
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<tr>
<td>9. Ward-Griffin et al (2007); Canada</td>
<td>Post-secondary education (50%).</td>
<td>Interpretive descriptive study using in-depth interviews</td>
<td></td>
</tr>
<tr>
<td>10. Fisher &amp; Lieberman (1999); USA</td>
<td>Data not provided.</td>
<td>Longitudinal study</td>
<td>Data not provided.</td>
</tr>
<tr>
<td>11. Hamill (2012); USA</td>
<td>Data not provided.</td>
<td>Cross-sectional study</td>
<td>Data not provided.</td>
</tr>
<tr>
<td>12. Lieberman &amp; Fisher (1999); USA</td>
<td>&gt;11 years (n=44), High school (n=21), Some college (n=41), University / College graduate (n=73), Post-college (n=32)</td>
<td>Longitudinal, cross-sectional study</td>
<td></td>
</tr>
<tr>
<td>13. Liew et al (2010); Singapore</td>
<td>Primary or below 22 (9.0), Secondary/high school 107 (32.1), Tertiary 193 (57.9).</td>
<td>Cross-sectional Study</td>
<td></td>
</tr>
<tr>
<td>14. Lin et al (2012); Taiwan</td>
<td>Family caregiver without maid (9.5 to 17.1 years of education) (Lower secondary to university / post graduate). Family caregiver with maid (9.7 to 18.1 years of education) (Lower secondary to university / post graduate). Lived-in maid: 7.7 to 12.5 years of education (Primary to high school) (n=42).</td>
<td>Cross-sectional study</td>
<td></td>
</tr>
<tr>
<td>15. Tew et al (2010); Singapore</td>
<td>No education / primary (n=30, 11.3%), Pre-university / diploma (n=166, 62.4%), Tertiary (n=70, 26.3%).</td>
<td>Cross-sectional study</td>
<td></td>
</tr>
<tr>
<td>16. Kua &amp; Tan (1997); Singapore</td>
<td>Data not provided.</td>
<td>Quantitative survey</td>
<td>Data not provided.</td>
</tr>
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<tr>
<td>17. Lim et al (1999); Singapore</td>
<td>Data not provided.</td>
<td>Quantitative survey</td>
<td>Data not provided.</td>
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<tr>
<td><strong>Review</strong></td>
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<tr>
<td>19. Wang (2012); USA</td>
<td>Data not provided.</td>
<td>Narrative Review</td>
<td>Data not provided.</td>
</tr>
</tbody>
</table>

Commentary based on the synthesis:
Conclusion: Most of the caregivers in the Asian region are not equipped with a degree and above as compared to their counterparts from the U.S.A. Only 8 out of 17 qualitative and quantitative studies provided data on family caregivers’ educational status. 2 studies from the USA reported family caregivers being equipped with mostly pre-university, degree and above (Lieberman & Fisher 1999; Szinovacz 2003). The only Canadian study reported that 50% of the family caregivers have post-secondary education (Ward-Griffin et al 2007). For the 3 Singapore studies, family caregivers are mostly equipped with secondary school, pre-university equivalent and above education (Liew et al 2010; Netto et al 2009; Tew et al 2010). Family caregivers from Taiwan are quite similar to Singapore caregivers in terms of educational qualification. They are also equipped with lower secondary to university or post graduate education (Lin et al 2012). For the H.K. study, most family caregivers’ educational qualification is below the H.K. national average (Chan et al 2010).
### Employment / Financial status of family caregiver

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<td><strong>Qualitative</strong></td>
<td><strong>Content analysis methodology. Semi-structured interviews</strong></td>
<td><strong>Data not provided.</strong></td>
</tr>
<tr>
<td>1. Beach (1997); USA</td>
<td>Data not provided.</td>
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<tr>
<td>2. Boughtwood et al (2011);</td>
<td>Data not provided.</td>
<td><strong>Modified grounded theory approach. Focus group.</strong></td>
<td><strong>Data not provided.</strong></td>
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<tr>
<td>Australia</td>
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<tr>
<td>3. Chan et al (2010); Hong Kong</td>
<td>9 caregivers did not disclose their incomes. 18 disclosed information on income. 9/18 received Comprehensive Social Security Assistance Scheme. Majority of the 18 earned ≤ HK$10,000/month per household, which was lower than the median household income for HK families (HK$15,500 in the 2004). *No data on employment status.</td>
<td><strong>Qualitative study; Focus group interviews</strong></td>
<td>*No data on employment status. Poorer income group.</td>
</tr>
<tr>
<td>4. Ho et al (2003); Canada</td>
<td>Employed: Daughter (n=4). Unemployed: Wife (n=2), Daughter (n=4), Daughter-in-law (n=2). *Data did not include part-time or full-time job. Financial status not provided.</td>
<td><strong>Qualitative study.</strong></td>
<td>*Data did not include part-time or full-time job. Financial status not provided. “Caregivers varied in financial status; however, none of the participants indicated or were observed to be experiencing financial difficulties” (p. 305).</td>
</tr>
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<tr>
<td>5. Innes et al (2011); Malta</td>
<td>Data not provided.</td>
<td>Exploratory study using semi-structured interview.</td>
<td>Data not provided.</td>
</tr>
<tr>
<td>6. Netto et al (2009); Singapore</td>
<td>Employment status not provided. Monthly income ranged from nothing (living on savings) to about S$12,000. Monthly income comprised entire household income and contributions received from other relatives or sources.</td>
<td>Grounded theory approach using Semi-structured, in-depth, face-to-face interviews</td>
<td><em>Data should include number of members in the household and type of expenditure.</em></td>
</tr>
<tr>
<td>7. Roach et al 2013; UK</td>
<td>No data provided.</td>
<td>Longitudinal, narrative case study design.</td>
<td></td>
</tr>
<tr>
<td>8. Szinovacz (2003); USA</td>
<td>Employed (n= 6; 40%). *Data did not include complete detail of part-time or full-time job. *Family income (&lt; US$10,000) (n=1); &gt; US$500,000) (n=15).</td>
<td>Grounded theory approach using semi-structured interviews</td>
<td>N=15 adult caregivers but income showed N=16 in total. Is income monthly or yearly? Data did not include complete detail of part-time or full-time job.</td>
</tr>
<tr>
<td>9. Ward-Griffin et al (2007); Canada</td>
<td>Full-time (50%) or part-time (14%) in various sectors, such as education, business, or retail. Average household income: $0 to $19,999 (8% of daughters); $20,000 to $39,999 (23% of daughters); $40,000 to $59,999 (39% of daughters); $60,000 to $79,000 (23% of daughters); and more than $80,000 (8% of daughters). 71 % care recipient receives income &lt; $20,000.</td>
<td>Interpretive descriptive study using in-depth interviews</td>
<td>No financial concerns. Is income monthly or yearly?</td>
</tr>
<tr>
<td><strong>Quantitative</strong></td>
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336
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<td>10. Fisher &amp; Lieberman (1999); USA</td>
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<td>Data not provided.</td>
</tr>
<tr>
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<td>Data not provided.</td>
<td>Cross-sectional study</td>
<td>Data not provided.</td>
</tr>
<tr>
<td>12. Lieberman &amp; Fisher (1999); USA</td>
<td>Working part-time: &gt;50% (n=173), &lt; 50% time (n=38). *Did not include data on financial status.</td>
<td>Longitudinal, cross-sectional study</td>
<td>Ambiguous data on employment status. Did not include data on financial status.</td>
</tr>
<tr>
<td>13. Liew et al (2010); Singapore</td>
<td>Working (n=214; 64.3%), Homemaker/housewife/other (n=92; 27.6%), Retired (n=27; 8.1%). *Data did not include part-time or full-time job. Self-reported financial problems: No/minimal (n=165), Some (n=62), A lot (n=21)</td>
<td>Cross-sectional Study</td>
<td>*Data did not include part-time or full-time job. Self-reported financial problems: No/minimal (n=165), Some (n=62), A lot (n=21)</td>
</tr>
<tr>
<td>14. Lin et al (2012); Taiwan</td>
<td>Data not provided.</td>
<td>Cross-sectional study</td>
<td>Data not provided.</td>
</tr>
<tr>
<td>15. Tew et al (2010); Singapore</td>
<td>Working (holding a job): Yes (n=163; 61.3%), No (n=103; 38.7%). *Data did not include part-time or full-time job. *Financial status not provided.</td>
<td>Cross-sectional study</td>
<td>Data did not include part-time or full-time job. Financial status not provided.</td>
</tr>
<tr>
<td>16. Kua &amp; Tan (1997); Singapore</td>
<td>Working full-time (n=11), part-time (n=13), unemployed (n=26). *Financial status not provided.</td>
<td>Quantitative survey</td>
<td>Financial status not provided.</td>
</tr>
<tr>
<td>17. Lim et al (1999); Singapore</td>
<td>Data not provided.</td>
<td>Quantitative survey</td>
<td>Data not provided.</td>
</tr>
<tr>
<td><strong>Review</strong></td>
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</table>
Commentary based on the synthesis:
Chan et al (2010)’s study revealed that 9 out of 18 caregivers were on comprehensive social security assistance scheme. Most of the 18 caregivers earn a monthly income equal to or less than HK$10,000 (approximately US$1,200) per household. *No employment data.
Ho et al (2003) – Working (1/3 of the caregivers). Varied financial status and were not in financial difficulties. *Financial status was not provided. *No data on whether employment is part-time or full-time.
Netto et al (2009) - Monthly household income ranged from nothing (living on savings) to about S$12,000 (~US$9700). Monthly income comprised the entire household income and contributions received from other relatives or sources. *No employment data.
Szinovacz (2003) - Working (n= 6; 40%). *Household income (< US$10,000) (n=1); > US$500,000) (n=15). N=15 adult caregivers but income showed N=16 in total. *No data on whether employment is part-time or full-time.
Ward-Griffin et al (2007) – Working full-time (50%) or part-time (14%) in various sectors, such as education, business, or retail. Average household income: $0 to $19,999 (8% of daughters); $20,000 to $39,999 (23% of daughters); $40,000 to $59,999 (39% of daughters); $60,000 to $79,000 (23% of daughters); and more than $80,000 (8% of daughters). 71% care recipient receives income < $20,000. No financial concerns.
Liew et al (2010); Working (n=214; 64.3%), Homemaker/housewife/other (n=92; 27.6%), Retired (n=27; 8.1%). *Data did not include part-time or full-time job. Self-reported financial problems: No/minimal (n=165), Some (n=62), A lot (n=21).
Tew et al (2010) - Working (Yes =163; 61.3%; No =103; 38.7%). *No data on whether employment is part-time or full-time. *Financial status not provided.
Kua & Tan (1997); Working full-time (n=11), part-time (n=13), unemployed (n=26). *Financial status not provided.

NOTE:
No data on caregivers’ employment and financial status were provided in several of the studies and reviews (Beach 1997; Boughtwood et al 2011; Innes et al 2011; Fisher & Lieberman 1999; Hamill 2012; Lin et al 2012; Lim et al 1999; Roach et al 2013; Sun et al 2012; Wang 2012). 5 studies did not provide any data on financial status (Ho et al 2003; Kua & Tan 1997; Lieberman & Fisher 1999; Roach et al 2013; Tew et al 2010). 3 studies did not provide employment data (Chan et al 2010; Netto et al 2009; Roach et al 2013) and another 5 did not specify if caregivers were employed full-time or part-time (Ho et al 2003; Liew et al; Roach et al 2013; Szinovacz 2003; Tew et al 2010). Studies reporting caregivers’ employment status revealed that most of them are working in addition to providing care (Kua & Tan 1997; Szinovacz 2003; Ward-Griffin et al 2007; Lieberman & Fisher 1999; Liew et al 2010; Tew et
Employment / Financial status of family caregiver

al 2010). At this juncture, it is difficult to draw further conclusions from the existing data. For example, unemployment may not be a clear cut indicator of financial status as demonstrated in Ho et al (2003) and Ward-Griffin et al (2007)’s findings which revealed that eventhough 33% to 64% of the caregivers were employed with varied financial status, the unemployed caregivers did not express any financial difficulties. Even caregivers who are not financially well off did not report financial concerns (Chan et al 2010). The likely reason could be the comprehensive social security assistance scheme which caregivers are provided with in the H.K. study (Chan et al 2010). In contrast, Liew et al (2010)’s sample of about 64% working caregivers noted some degree of self-reported financial problems. Additionally, caregivers from the Maltese study (Innes et al (2011) also reported financial burden but no information on the caregivers’ financial and employment status is provided in the study’s article to facilitate the analysis.

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<tr>
<td>Conclusion</td>
<td>(Scope, differences</td>
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<td></td>
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<td>among studies)</td>
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Caregiver’s role

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<td>Study Design</td>
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<tr>
<td>Conclusion</td>
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<td>among studies)</td>
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</table>

| Qualitative                   |                       |                                   |                                                               |
| 1. Beach (1997); USA         | Adolescents’ mothers were identified as the primary / main caregiver (82%) and adolescents as the auxiliary caregivers. | Content analysis methodology. Semi-structured interviews       |                                                               |
| Australia                     |                       |                                   |                                                               |
| 3. Chan et al (2010); Hong    | No data on caregivers’ role. | Qualitative study; Focus group interviews                        |                                                               |
| Kong                          |                       |                                   |                                                               |
| 4. Ho et al (2003); Canada    | No data on caregivers’ role. | Qualitative study.                                                      |                                                               |
### Source & Study characteristics

<table>
<thead>
<tr>
<th>Source</th>
<th>Study characteristics</th>
<th>Study Design</th>
<th>Conclusion (Scope, differences and similarities among studies)</th>
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<tbody>
<tr>
<td><strong>Caregiver’s role</strong></td>
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<tr>
<td>5. Innes et al (2011); Malta</td>
<td>No data on caregivers’ role.</td>
<td>Exploratory study using semi-structured interview.</td>
<td></td>
</tr>
<tr>
<td>6. Netto et al (2009); Singapore</td>
<td>All are primary / <strong>main caregivers</strong> i.e. the off-springs who are mainly the daughters followed by spouses.</td>
<td>Grounded theory approach using Semi-structured, in-depth, face-to-face interviews</td>
<td></td>
</tr>
<tr>
<td>7. Roach et al 2013; UK</td>
<td>No data on caregivers’ role.</td>
<td>Longitudinal, narrative case study design.</td>
<td></td>
</tr>
<tr>
<td>8. Szinovacz (2003); USA</td>
<td>No data on caregivers’ role.</td>
<td>Grounded theory approach using semi-structured interviews</td>
<td></td>
</tr>
<tr>
<td>9. Ward-Griffin et al (2007); Canada</td>
<td>No data on caregivers’ role.</td>
<td>Interpretive descriptive study using in-depth interviews</td>
<td></td>
</tr>
<tr>
<td><strong>Quantitative</strong></td>
<td></td>
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</tr>
<tr>
<td>10. Fisher &amp; Lieberman (1999); USA</td>
<td>Spouses (mostly wives) followed by off spring most involved with ADL/IADL were the primary / <strong>main caregivers</strong>.</td>
<td>Longitudinal study</td>
<td></td>
</tr>
<tr>
<td>11. Hamill (2012); USA</td>
<td>No data on caregivers’ role except for adolescents who provided auxiliary roles.</td>
<td>Cross-sectional study</td>
<td></td>
</tr>
<tr>
<td>12. Lieberman &amp; Fisher (1999); USA</td>
<td><strong>Primary</strong> and <strong>secondary</strong> caregivers but no breakdown in data.</td>
<td>Longitudinal, cross-sectional study</td>
<td></td>
</tr>
<tr>
<td>13. Liew et al (2010); Singapore</td>
<td>269 main and 65 primary / <strong>main caregivers</strong>. Mostly daughters.</td>
<td>Cross-sectional Study</td>
<td></td>
</tr>
</tbody>
</table>
### Study characteristics

<table>
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<td><strong>Caregiver’s role</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>14. Lin et al (2012); Taiwan</td>
<td>No data on family caregivers’ role. Lived-in maid provides <strong>auxiliary</strong> roles.</td>
<td>Cross-sectional study</td>
<td></td>
</tr>
<tr>
<td>15. Tew et al (2010); Singapore</td>
<td>No specific data on caregivers’ role except that 140 (52.8%) family caregivers employed lived-in maid to provide <strong>auxiliary</strong> roles.</td>
<td>Cross-sectional study</td>
<td></td>
</tr>
<tr>
<td>16. Kua &amp; Tan (1997); Singapore</td>
<td><strong>Primary</strong> caregivers. Mostly daughters.</td>
<td>Quantitative survey</td>
<td></td>
</tr>
<tr>
<td>17. Lim et al (1999); Singapore</td>
<td>No data on caregivers’ role.</td>
<td>Quantitative survey</td>
<td></td>
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<tr>
<td><strong>Review</strong></td>
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</table>

Commentary based on the synthesis:
The role of each family member involved in intergenerational caregiving is important to facilitate a clearer understanding of what goes on within the family; be it the role as primary / main or secondary / auxiliary caregiver. The current review has noted that most of the studies either do not provide such details or have only provided partial details. 7 out of 9 qualitative studies (Boughtwood et al 2011; Chan et al 2010; Ho et al 2003; Innes et al 2011; Roach et al 2013; Szinovacz 2003; Ward-Griffin et al 2007), 1 out of the 9 quantitative studies (Lim et al 1999) and the 2 reviews (Sun et al 2012; Wang 2012) did not include data on the role of caregivers. Meanwhile, those studies with interpretable data seem to highlight the primary / main caregiver and adolescent who provide the auxiliary role, and live-in maid providing the supportive role. For instance, in studies involving adolescents, the primary / main caregiver tended to be mothers or healthy grandparent / grandmothers whilst auxiliary caregivers tended to be the adolescents (Beach 1997). Some study mainly focuses on the adolescent’s auxiliary role (Hamill 2012) only. On the other hand, adult studies have mainly emphasised on primary or main caregivers who are daughters, followed by spouses (Kua & Tan 1997; Liew et al 2010; Netto et al 2009) and, in some cases, spouses followed by off springs (Fisher & Lieberman 1999). Others have mentioned the inclusion of primary and secondary caregivers but with no breakdown of details (Lieberman & Fisher 1999). Those studies involving live-in maids as supportive caregivers chose not to provide data on family caregivers’ role (Lin et al 2012; Tew et al 2010). All the reviewed
Caregiver’s role

studies did not focus on exact details of other family members’ roles and what they do exactly. Future data will require the specific role description of each family member and what they do.

<table>
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<td>Caregiver’s role</td>
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</table>

Care recipients’ gender, age, living arrangement and care duration

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<th>Study characteristics</th>
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<th>Conclusion (Scope, differences and similarities among studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Beach (1997); USA</td>
<td>Mean age 69 years. No data on gender, living arrangement and care duration.</td>
<td>Content analysis methodology. Semi-structured interviews</td>
<td>Age mentioned.</td>
</tr>
<tr>
<td>2. Boughtwood et al (2011); Australia</td>
<td>No data provided.</td>
<td>Modified grounded theory approach. Focus group.</td>
<td></td>
</tr>
<tr>
<td>3. Chan et al (2010); Hong Kong</td>
<td>Predominantly female. 66 to 98 (median, 78) years. &gt; 1/2 were residing with their caregiver and the remainder received frequent visits. Mean (range) duration of 64 (12-168) months.</td>
<td>Qualitative study; Focus group interviews</td>
<td>Age mentioned.</td>
</tr>
<tr>
<td>4. Ho et al (2003); Canada</td>
<td>7 lived with the caregiver and 5 were not. 3 were &lt; 1 year or equal, 3 were 1.5 years, 6 between 3 to 7 years. *No data on gender and age.</td>
<td>Qualitative study.</td>
<td></td>
</tr>
<tr>
<td>Source</td>
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<td>Study Design</td>
<td>Conclusion (Scope, differences and similarities among studies)</td>
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</tr>
<tr>
<td>5. Innes et al (2011); Malta</td>
<td>Care recipients’ gender, age, living arrangement and care duration Over 65 years of age. * No data on gender, living arrangement and duration of care.</td>
<td>Exploratory study using semi-structured interview.</td>
<td>Age mentioned.</td>
</tr>
<tr>
<td>7. Roach et al 2013; UK</td>
<td>Predominantly female (n=3) with age 60-64 years. Male (n=2) with age 49 &amp; 61 years. Care duration &lt; 1 to 3 years. Residing in own home with caregiver.</td>
<td>Longitudinal, narrative case study design.</td>
<td></td>
</tr>
<tr>
<td>8. Szinovacz (2003); USA</td>
<td>Predominantly female (73%). Elderly (mean age 76). Care duration on average = 35 months (S.D. = 31.79). *No data on living arrangement.</td>
<td>Grounded theory approach using semi-structured interviews</td>
<td>Age mentioned.</td>
</tr>
<tr>
<td>9. Ward-Griffin et al (2007); Canada</td>
<td>All female. 75 to 98 years (mean age = 84.6 years). 4 mothers lived in their own homes, 4 lived in their daughters’ homes, and 2 resided in retirement homes.</td>
<td>Interpretive descriptive study using in-depth interviews</td>
<td>Age mentioned.</td>
</tr>
<tr>
<td>Quantitative</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Fisher &amp; Lieberman (1999); USA</td>
<td>88 females, 76 males, Mean age 76-78 years. Living with Spouse (n=92), Offspring (n=40), Alone (n=32). *No data on duration of care.</td>
<td>Longitudinal study</td>
<td>Age mentioned.</td>
</tr>
<tr>
<td>11. Hamill (2012); USA</td>
<td>Maternal grandmother (58.6%) and the paternal grandmother (20.7%) were the most common grandparents to receive care. The rest were grandfathers (maternal = 10.3%, paternal = 3.4%) or some other older family member (e.g., aunt or uncle, 6.9%. Mean age</td>
<td>Cross-sectional study</td>
<td>Age mentioned.</td>
</tr>
<tr>
<td>Source</td>
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<td>Study Design</td>
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<tr>
<td></td>
<td><strong>Care recipients’ gender, age, living arrangement and care duration</strong></td>
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</tr>
<tr>
<td>79.29 years (SD = 8.28), 20% of the grandparents lived with the adolescent’s family, 44.8% lived in their own home, 24.1% lived in a nursing home, and 10.3% lived in some other residence. *No data on duration of care.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Lieberman &amp; Fisher (1999); USA</td>
<td>133 Male and 78 Female. Living arrangements – 38 Alone, 99 With spouse only, 17 With spouse &amp; offspring, 49 With offspring, 8 With non-relatives. *No data on age and duration of care.</td>
<td>Longitudinal, cross-sectional study</td>
<td>Exception in gender of care recipient.</td>
</tr>
<tr>
<td>13. Liew et al (2010); Singapore</td>
<td>Females (64.9%). Mean age was 79.1 years (SD = 8.4, range = 53 – 99). Living with caregiver (Yes = 227, 68.6%), (No=104, 31.4%). Duration of care &lt; 6 months (n=15, 4.5%), 6 months to 1 year (n=35, 10.5%), &gt;1 – 3 years (n=119, 35.7%), &gt;3 years (n=164, 49.3%).</td>
<td>Cross-sectional Study</td>
<td>Age mentioned.</td>
</tr>
<tr>
<td>14. Lin et al (2012); Taiwan</td>
<td>Female. 70-90 years old. All living with caregivers. Duration of care: Family caregivers = 4.5 years and lived-in maids = 1.2 years.</td>
<td>Cross-sectional study</td>
<td>Age mentioned.</td>
</tr>
<tr>
<td>15. Tew et al (2010); Singapore</td>
<td>Living with caregiver (Yes = 210, 79.2%; No = 55, 20.8%). Duration of care of 0.5 – 3 years (n=120, 45.5%), &gt;3 years (n=144, 54.5%). * No data on gender and age.</td>
<td>Cross-sectional study</td>
<td></td>
</tr>
<tr>
<td>16. Kua &amp; Tan (1997); Singapore</td>
<td>Mean duration of care was 2.3 years (range 1±6 years). * No data on gender, age and living arrangement.</td>
<td>Quantitative survey</td>
<td></td>
</tr>
<tr>
<td>17. Lim et al (1999); Singapore</td>
<td>Female (66%). 60-74 years and 75 years and above. *No data on living arrangement and care duration.</td>
<td>Quantitative survey</td>
<td>Duration of care rendered did not correlate significantly with caregiver stress (p = .75, .92, and .28, respectively). Duration of care was also not</td>
</tr>
</tbody>
</table>
### Commentary based on the synthesis:
Most care recipients in the review studies are female with a mean age of more than 65 years old. The living arrangement for care recipients seems to differ between Eastern and Western countries. In particular, most care recipients are still cared for at home by family caregivers in H.K., Singapore and Taiwan (Chan et al 2010; Liew et al 2010; Lin et al 2012; Tew et al 2010). Notably, the correlation to Asian culture cannot be denied as the similarity in living arrangement pattern appears to transcend across geographical boundaries. Such is the case of Ho et al (2003)’s qualitative study on Chinese-Canadian women family caregivers in Canada which noted a higher number of care recipients being cared for at home. This pattern of care is less prominent in other cultures in Canada and USA where care recipients usually reside with their spouses, are staying alone or residing in nursing homes (Fisher & Lieberman 1999; Hamill 2012; Lieberman & Fisher 1999; Ward-Griffin et al 2007).

NOTE: Why are care recipients mostly female? - Females live longer. As they live longer, risk for Alzheimer’s Disease increases.

<table>
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<th>Conclusion (Scope, differences and similarities among studies)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>19. Wang (2012); USA No data.</td>
<td>Narrative Review</td>
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</tbody>
</table>

### Care recipients’ type of dementia and stage or severity of dementia

<table>
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<tr>
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<th>Conclusion (Scope, differences and similarities among studies)</th>
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<tbody>
<tr>
<td></td>
<td>Care recipients’ type of dementia and stage or severity of dementia</td>
<td>Qualitative</td>
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<tr>
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<td>Conclusion (Scope, differences and similarities among studies)</td>
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</tr>
<tr>
<td>1. Beach (1997); USA</td>
<td>Alzheimer's or Alzheimer's Type Dementia (ATD) patient. No data on stage or severity of dementia.</td>
<td>Content analysis methodology. Semi-structured interviews</td>
<td>Dementia type mentioned.</td>
</tr>
<tr>
<td>2. Boughtwood et al (2011); Australia</td>
<td>Patients diagnosed with dementia. No data on type and stage or severity of dementia.</td>
<td>Modified grounded theory approach. Focus group.</td>
<td>No differentiation between the types of dementia.</td>
</tr>
<tr>
<td>3. Chan et al (2010); Hong Kong</td>
<td>No data on type of dementia. Mild to severe dementia.</td>
<td>Qualitative study; Focus group interviews</td>
<td>No differentiation between the types of dementia. Data on stage and severity mentioned.</td>
</tr>
<tr>
<td>5. Innes et al (2011); Malta</td>
<td>Formal diagnosis of dementia. No data on type and stage or severity of dementia.</td>
<td>Exploratory study using semi-structured interview.</td>
<td>No differentiation between the types of dementia.</td>
</tr>
<tr>
<td>6. Netto et al (2009); Singapore</td>
<td>Clinician diagnosed dementia. No data on type and stage or severity of dementia.</td>
<td>Grounded theory approach using Semi-structured, in-depth, face-to-face interviews</td>
<td>No differentiation between the types of dementia.</td>
</tr>
<tr>
<td>7. Roach et al 2013; UK</td>
<td>Alzheimer's Disease (n=4); Fronto-temporal dementia (n=1)</td>
<td>Longitudinal, narrative case study design.</td>
<td>No data on stage or severity of dementia.</td>
</tr>
<tr>
<td>8. Szinovacz (2003); USA</td>
<td>Alzheimer's dementia. Moderate to advanced stages of dementia.</td>
<td>Grounded theory approach using semi-structured interviews</td>
<td>Dementia type mentioned. Data on stage and severity mentioned.</td>
</tr>
<tr>
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</tr>
<tr>
<td><strong>Quantitative</strong></td>
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</tr>
<tr>
<td>9. Ward-Griffin et al (2007);</td>
<td>Care recipients’ type of dementia and stage or severity of dementia</td>
<td>Interpretive descriptive study</td>
<td>No differentiation between the types of dementia.</td>
</tr>
<tr>
<td>Canada</td>
<td>No data on type of dementia. Standardized mini-mental state examination (SMMSE) score</td>
<td>using in-depth interviews</td>
<td>Data on stage and severity mentioned.</td>
</tr>
<tr>
<td></td>
<td>of the mother participants ranged from 18 to 28 indicated early to advanced stage dementia.</td>
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</tr>
<tr>
<td>10. Fisher &amp; Lieberman (1999);</td>
<td>Alzheimer’s disease. No data on stage or severity of dementia.</td>
<td>Longitudinal study</td>
<td>Dementia type mentioned.</td>
</tr>
<tr>
<td>USA</td>
<td>The patient met National Institute of Neurological and Communicative Disorders and Stroke diagnostic criteria for probable or possible Alzheimer’s disease. No data on stage or severity of dementia.</td>
<td></td>
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</tr>
<tr>
<td>11. Hamill (2012); USA</td>
<td>Alzheimer’s disease. No data on stage or severity of dementia.</td>
<td>Cross-sectional study</td>
<td>Dementia type mentioned.</td>
</tr>
<tr>
<td>12. Lieberman &amp; Fisher (1999);</td>
<td>Probable or possible Alzheimer’s dementia. Blessed Roth Dementia Rating Scale (Mean 4.87, SD 5.6).</td>
<td>Longitudinal, cross-sectional study</td>
<td>Data on stage and severity mentioned.</td>
</tr>
<tr>
<td>USA</td>
<td>Diagnosed as suffering from dementia by clinicians using established clinical criteria such as Diagnostic Manual of Mental Disorders, ed. 4 (DSM IV). Mild to severe dementia with most at moderate stage.</td>
<td></td>
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</tr>
<tr>
<td>13. Liew et al (2010); Singapore</td>
<td>Diagnoses of dementia were based on the criteria of the Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision (American Psychiatric Association, 1994), and diagnoses of Alzheimer’s dementia (AD) was based on the criteria of the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer’s Disease and Related Disorders Association. Mild to severe dementia.</td>
<td>Cross-sectional study</td>
<td>No differentiation between the types of dementia.</td>
</tr>
<tr>
<td>Taiwan</td>
<td></td>
<td></td>
<td>Data on stage and severity mentioned.</td>
</tr>
<tr>
<td>14. Lin et al (2012); Taiwan</td>
<td></td>
<td>Cross-sectional study</td>
<td>No differentiation between the types of dementia.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Data on stage and severity mentioned.</td>
</tr>
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</tr>
<tr>
<td>15. Tew et al (2010); Singapore</td>
<td>Diagnosed as suffering from dementia by clinicians with established clinical criteria, such as the Diagnostic Manual of Mental Disorders, 4th edition. Mild to severe dementia. No data on type of dementia.</td>
<td>Cross-sectional study</td>
<td>No differentiation between the types of dementia.</td>
</tr>
<tr>
<td>16. Kua &amp; Tan (1997); Singapore</td>
<td>50 patients fulfilled Diagnostic and Statistical Manual of Mental Disorders, Third Edition Revised, or DMS-III-R: 21 patients had Alzheimer's disease and 29 multi-infarct dementia; 15 were rated mild, 27 moderate and eight severe according to DSM-III-R criteria.</td>
<td>Quantitative survey</td>
<td>Dementia type mentioned. Data on stage and severity mentioned.</td>
</tr>
<tr>
<td>17. Lim et al (1999); Singapore</td>
<td>Proportional number of patients with Alzheimer’s disease and vascular dementia. Mild to moderate stage.</td>
<td>Quantitative survey</td>
<td>Dementia type mentioned. Data on stage and severity mentioned.</td>
</tr>
<tr>
<td><strong>Review</strong></td>
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<td></td>
</tr>
<tr>
<td>18. Sun et al (2012); U.S.A</td>
<td>Type of dementia was mentioned as Alzheimer’s disease in 2 of the studies. No data on stage or severity of dementia.</td>
<td>Narrative Review</td>
<td>Only 2 studies mentioned type of dementia. Data on stage and severity mentioned.</td>
</tr>
<tr>
<td>19. Wang (2012); USA</td>
<td>Type of dementia was mentioned as Alzheimer’s disease in 1 of the studies. Stage or severity was mentioned as mild to moderate in 1 of the studies.</td>
<td>Narrative Review</td>
<td>Only 1 study mentioned type of dementia. Only 1 study mentioned stage and severity mentioned.</td>
</tr>
</tbody>
</table>

Commentary based on the synthesis:
Global differences in the type of dementia diagnostic tool used are noted - Standardized mini-mental state examination (SMMSE) score in Canada (Ward-Griffin et al 2007), Global Deterioration Scale in Spain (Celdrán et al 2012), National Institute of Neurological and Communicative Disorders and Stroke diagnostic criteria in the USA (Fisher & Lieberman 1999), Blessed Roth Dementia Rating Scale in the USA (Lieberman & Fisher 1999), Diagnostic Manual of Mental Disorders 3rd ed. revised (Kua & Tan (1997), 4th ed. (DSM IV) in Singapore (Liew et al 2010; Tew et al (2010). Diagnostic and Statistical Manual
of Mental Disorders, 4th edition, text revision (American Psychiatric Association, 1994), and the criteria of the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer’s Disease and Related Disorders Association in Taiwan (Lin et al 2012). Less than half of the studies specified the specific dementia subtypes. 7 studies (Beach 1997; Fisher & Lieberman 1999; Hamill 2012; Ho et al 2003; Kua & Tan 1997; Lieberman & Fisher 1999; Lim et al 1999; Roach et al 2013; Szinovacz 2003) and 2 reviews (Sun et al 2012; Wang 2012) were targeted towards Alzheimer’s disease with only 1 pinpointing the specific type, that is, Alzheimer’s disease and vascular dementia. Only 9 studies (Chan et al 2010; Kua & Tan 1997; Lieberman & Fisher 1999; Liew et al 2010; Lim et al 1999; Lin et al 2012; Roach et al 2013; Szinovacz 2003; Ward-Griffin et al 2007) and 2 reviews (Sun et al 2012; Wang 2012) reported the stages or severity of dementia. Care recipients were diagnosed with mild to severe dementia in 4 studies (Chan et al 2010; Ward-Griffin et al 2007; Liew et al 2010) with 1 study reporting most care recipients to be at moderate stage dementia (Lin et al 2012). Care recipients in Lim et al (1999)’s study and 1 of the studies in the review (Wang 2012) had mild to moderate stage dementia. 1 study had care recipients with moderate to advanced stage dementia (Szinovacz 2003). 1 study only had care recipients with moderate stage dementia (Kua & Tan 1997).

### Textual Narrative Synthesis: (2) What care do the intergenerational family caregivers provide for the care recipient?

#### Type of care – ADL or IADL care or both

<table>
<thead>
<tr>
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<th>Study characteristics</th>
<th>Study Design</th>
<th>Conclusion (Scope, differences and similarities among studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Beach (1997); USA</td>
<td>Going out to dinner with grandma Respondent #3,</td>
<td>Content analysis methodology.</td>
<td>IADL care</td>
</tr>
<tr>
<td>Source</td>
<td>Study characteristics</td>
<td>Study Design</td>
<td>Conclusion (Scope, differences and similarities among studies)</td>
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<tr>
<td><strong>Type of care</strong></td>
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<tr>
<td>2. Boughtwood et al (2011); Australia</td>
<td>Physical Care of the PWD (bathing, dressing, and eating) – all caregivers Emotional Care of the PWD – all caregivers Assistance Seeing Doctors (assisting the person with dementia to visit and consult with doctors, by offering a transport option, interpreting for them, or advocating on their behalf or a combination of all 3) – all caregivers Advocacy in Hospital – Italian &amp; Spanish caregivers only</td>
<td>Modified grounded theory approach. Focus group.</td>
<td>IADL and ADL care</td>
</tr>
<tr>
<td>3. Chan et al (2010); Hong Kong</td>
<td>Provided “substantial amount of care for older persons with dementia” (n=27). *Ambiguous data.</td>
<td>Qualitative study; Focus group interviews</td>
<td>*Ambiguous data.</td>
</tr>
<tr>
<td>4. Ho et al (2003); Canada</td>
<td>Most activities (n=4) Some activities (n=5) Independent (n=3) *Ambiguous data.</td>
<td>Qualitative study.</td>
<td>*Ambiguous data.</td>
</tr>
<tr>
<td>5. Innes et al (2011); Malta</td>
<td>“…my children [relative’s grandchildren] to stay with her [so the daughter can shop and take care of bills]… we helped her even if the bathroom…”</td>
<td>Exploratory study using semi-structured interview.</td>
<td>ADL and IADL care</td>
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<td><strong>Type of care</strong></td>
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<tr>
<td>7. Roach et al 2013; UK</td>
<td>Data not provided.</td>
<td>Longitudinal, narrative case study design.</td>
<td>IADL and ADL care</td>
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<td>8. Szinovacz (2003); USA</td>
<td>Needs personal care (1 = not, 2 = a little, 3 = a lot) 2.40 Needs help walking inside home (1 = not, 2 = a little, 3 = a lot) 1.80 Needs help walking on street (1 = not, 2 = a little, 3 = a lot) 2.33</td>
<td>Grounded theory approach using semi-structured interviews</td>
<td>IADL and ADL care</td>
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<td>9. Ward-Griffin et al (2007); Canada</td>
<td>Caregiver’s quotes: “I usually take care of what needs to be done . . . it’s just to make sure she’s eating and getting her medicine, but other than that. . . To sit and talk . . .”. Doctor’s appointment . . . “eye doctor’s office”. “It depends what she needs. But I am there when she needs me”. “I’d do anything for mom.” . . . “My mom just loves to get out on her own and she is the one who directs the day.” “. . . sit and have a discussion with my mother . . .” Care recipient’s quote: “She brings me little dinners and stuff like that. . . She does anything I want, and when she can’t, I then have to depend on my other children [another daughter and two sons].” “. . . she was able to talk with the doctors and the nurses. . . . She also goes to the doctor’s [office] with me. She listens. She keeps it all straightened in my mind”</td>
<td>Interpretive descriptive study using in-depth interviews</td>
<td>IADL and ADL care</td>
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<tr>
<td>10. Fisher &amp; Lieberman (1999); USA</td>
<td>On-going ADL or IADL care. *No breakdown of the data.</td>
<td>Longitudinal study</td>
<td>ADL and IADL care</td>
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<td>11. Hamill (2012); USA</td>
<td><strong>Type of care</strong>&lt;br&gt;Instrumental activities of daily living (IADL)&lt;br&gt;Shopping (27.6%), Meal preparation (34.5%), Housework (48.3%), Managing money (13.8%), Using the telephone (27.6%), Getting to places beyond walking distance (31.0%), Taking medications (20.7%). <strong>Activities of daily living (ADL)</strong>&lt;br&gt;Eating (44.8%), Dressing (20.7%), Grooming (31.0%), Walking (37.9%), Getting in and out of bed (3.4%), Bathing (3.4%), Toileting (3.4%)</td>
<td>Cross-sectional study</td>
<td>ADL and IADL care</td>
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<tr>
<td>12. Lieberman &amp; Fisher (1999); USA</td>
<td>Providing ADLs / IADLs care</td>
<td>Longitudinal, cross-sectional study</td>
<td>ADL or IADL care</td>
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<tr>
<td>13. Liew et al (2010); Singapore</td>
<td>Helping him take medication, helping with housework or cooking, helping him bathe or dress, providing emotional support, spending time talking to him, bringing him for outings and the like.</td>
<td>Cross-sectional study</td>
<td>ADL or IADL care</td>
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<td>14. Lin et al (2012); Taiwan</td>
<td>Data not provided.</td>
<td>Cross-sectional study</td>
<td>Data not provided.</td>
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<td>15. Tew et al (2010); Singapore</td>
<td>Data not provided.</td>
<td>Cross-sectional study</td>
<td>Data not provided.</td>
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<td><strong>Type of care</strong></td>
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<td>17. Lim et al (1999); Singapore</td>
<td>Urinary incontinence** (n=13), Dependence in ADL: Dressing** (n=13), Bathing (n=13), Toileting (n=8), Eating (n=4), Dependence in mobility* (n=10), Bowel incontinence (n=13).</td>
<td>Quantitative survey</td>
<td>ADL care</td>
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Commentary based on the synthesis:
- **IADL** care - Beach (1997)
- **ADL** care - Lim et al (1999)
- **Ambiguous** data - Chan et al (2010); Ho et al (2003); Kua & Tan (1997)

Conclusion - Most caregivers provide both IADL and ADL care.
What are the caregiving experiences of the intergenerational family caregivers? What is the impact of caregiving on the intergenerational family caregivers?

Caregiving experiences and impact of caregiving

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| Beach (1997); USA | **Positive impact:**  
1) Increased Sibling Activity/Sharing - positive influence on family relationships; closer family bonding as a result of coping with patients' aberrant (yet expected) behaviours; positive changes in historically distant sibling relationships  
2) Greater Empathy for Older Adults - more understanding of older people; compassion regarding private behaviours in public settings; need to cultivate patience  
3) Significant Mother / Adolescent Bonding - greater intimacy within the mother / adolescent relationship; positive reinforcement accorded to adolescent by mother; adolescent feeling more trusted; offering help and reassurance when mother is experiencing emotional outbursts and burnout; genuine desire to spend time with their mothers; greater appreciation and respect for their caregiving mothers  
4) Peer Relationship - Selection and Maintenance - having friends at the house (where the patient resided) necessitated the selection of empathetic peers; learned how to openly discuss the situation with their friends to prepare them for visitations; friends were more objective regarding caregiving challenges | Content analysis methodology | Study examining adolescent grandchildren. Theme 2 and 3 are similar to Celdrán (2012) and Hamil (2012) |
| Boughtwood et al (2011); Australia | **Negative experiences:**  
Emotional and Personal Concerns: | Modified grounded theory | Multicultural study |
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<td><strong>Caregiving experiences and impact of caregiving</strong></td>
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<td></td>
<td>- Grief and Loss for the person with dementia (could not “cure” the person with dementia; not being recognized by the person with dementia; person with dementia’s loss of dignity) – all caregivers</td>
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<td>- No Time for Self (lack of time to focus on other aspects of their lives, including personal and professional; mixed emotions pertaining to love for the person with dementia, ‘role’ as family members, cultural obligations, strain as caregivers) – except the Italian caregivers</td>
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<td>- Worry About the Future (concern about the progression of dementia, in terms of the person with dementia’s condition and the level of assistance the caregivers would need to provide) – except Arabic speaking caregivers.</td>
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<td>- Deterioration in Caregivers’ Health (Physical and mental health; dementia was a particularly stressful and constant burden) – all caregivers</td>
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<td><strong>Dementia-Related Concerns:</strong></td>
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<td>- Behaviour of a person with dementia’s antisocial behaviour leading to isolation of person with dementia and other family. E.g. embarrassed when person with dementia was rude to service providers, including accusations of stealing. On-going struggle to understand and accept the changed relationship with the person with dementia. Previously close and loving, now prone to volatility, disruption, and conflict.) – except the Arabic caregivers</td>
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<td>- Safety Issues (great concern about the safety of the person with dementia at home. Emotional and physical burden of attempting to provide constant presence and support to the person with dementia) – except Chinese caregivers</td>
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<td>3. Chan et al (2010); Hong Kong</td>
<td><strong>Positive experience:</strong></td>
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<td></td>
<td>- Companionship</td>
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<td>- Adding meaning to life</td>
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<td>- Opportunities to care for close ones.</td>
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| Caregiving experiences and impact of caregiving | - **Less personal burden and role acceptance** – as dementia worsens, family support increases and lesser complaints from others about the caregivers or the care recipients.  
**Negative experience:**  
**Emotional burden**  
70% reported psychological distress, 56% reported disturbed mood. Range of negative emotional responses - grief, sadness, anxiety, anger, guilt, blame, fear, and embarrassment, exhausting, depressing. Psychosocial distress - caregivers of PWD with mild-to-moderate dementia compared with more severe disease.  
**Role Conflict.** Unable to have regular work because of the need to attend to the care recipients almost round the clock.  
Strained relationships with other family members.  
Higher levels of concern towards care recipients. Female compared with male caregivers had high expectations of themselves to be competent, significantly more stress than males. *Difference could be due to a self-reporting gender bias.*  
**Difficulty in Coping with the Care Recipient’s Behaviours**  
-behavioural and psychological symptoms such as agitation, irritability, aggression, obstinacy, withdrawal, insomnia and abnormal perception.  
**Provision of Care Recipient’s Daily Care Needs is Demanding**  
Functional deficits increased as the illness progressed. Very demanding to help with activities of daily living. Provision of care **24 hours a day all year round** - major sources of burden.  
**Perspectives on Caregiving and Services.** Caregivers of those with mild-to moderate dementia had more psychosocial distress than those of persons with more severe disease; attributed their burden to the behavioural and psychological symptoms of dementia (BPSD) exhibited by the care recipients. BPSD had a significant deleterious effect on caregivers’ quality of life. As the disease progresses. | | |
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<td><strong>Caregiving experiences and impact of caregiving</strong></td>
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|            | progressed, care focus shifted to more basic daily care. Personal care to relatives was both labour-intensive and time-consuming, but caregivers of persons with severe dementia accepted their role better. Increasing severity also resulted in less personal burden due to increased family support and fewer complaints from others about the caregivers or the care recipients. Perceptions about the usefulness of social services also differed across the spectrum of dementia: Caregivers of persons with milder dementia  
- Mutual support groups were helpful to cope with distress.  
- Day care facilities preferred to other support services, such as home care and respite services. Caregivers of persons with late-stage dementia  
- generally benefited from community-based services but most regarded residential services as the best long-term care arrangement.  
Information leaflets, audio visual materials, and problem oriented skills training programmes were very practical. Should be expanded in scope and frequency. Availability of an accessible ‘resource person’ (nurse, social worker, occupational therapist, or doctor) is helpful for obtaining information and advice about specific aspects of caregiving. Useful for the resource person to play a direct service provider role, and when the need arose, makes referrals to appropriate agencies. ->‘One-stop’ service with the resource person as the contact point. |              |                                                                  |
| 4. Ho et al (2003); Canada | **Positive experiences:**  
Mediators: Approaches to coping  
- **acceptance** of the need to fulfill duty due to *sense of obligation* / part of responsibilities leading to positive feeling when fulfilled.  
- **positive attitude** – relaxed approach, focus on the tasks at hand, humour, understanding the recipient | Qualitative study. |                                                                  |
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<td><strong>Caregiving experiences and impact of caregiving</strong></td>
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<td></td>
<td>- <strong>Informal social support</strong> (family and friends) – social support from friends, emotional support from family;</td>
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<td>- <strong>Formal social support</strong> - government-supported home-care programs, Informational support.</td>
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<td>Formal emotional support from professional counselling and support groups, hiring of helpers.</td>
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<td><strong>Sense of obligation and anticipation of role</strong></td>
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<td>- <strong>Relationships in accordance with Chinese tradition</strong>. 1 wife-caregiver stated: “The responsibility is mine. I can take care of him like this only because I am his wife. If it was the daughter or the daughter-in-law, it will be different. They are not as close, so they cannot take care of him like this. The relationship between husband and wife is the most important. I am the closest to him; I ought to take care of him.”</td>
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<td>- <strong>Filial obligation</strong>. 1 daughter-in-law caregiver said: “I think this change is only a short period in my life. I have to face it. I have my father-in-law, my mother-in-law, and my own children, so I have to go through a period of time when I cannot go out or have other social life. It is something I have to face.”</td>
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<td><strong>Differences between Chinese and western culture</strong></td>
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<td>– “Chinese people truly feel that they have the responsibility to take care of their parents, this is different from the western family values.” 1 daughter said: “I think the part of our Chinese culture [where] one has to take care of and respect elderly people, is right. Conversely, I do not know how western countries justify this, explain this [not taking care]. I think it really is culture. . .being filial to our parents is right; take care of them is what we ought to do. We ought to live with them and hope that we can give even more than what they are getting now.”</td>
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<td><strong>Family values</strong> – obliged to provide care simply because they belonged to the same family. 1 daughter-in-law caregiver said, “We are a family, of course I have to do it. My husband has to go to work, so I feel that I ought to do it.” This desire for a sense of unity also contributed to</td>
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Caregiving experiences and impact of caregiving

caregivers’ efforts to keep the family together. 6 caregivers said that being members of a family meant they should try to overcome difficulties and not avoid responsibilities—for the sake of the family as a whole and also for themselves.

Strong negative feelings against institutionalization – institutionalization was inappropriate as it did not conform with their traditional cultural or personal family values and would therefore be against care recipients’ wishes. 1 daughter caregiver said: ‘‘I still have some old Chinese mentality for sure I want to be together with my parents. I will not worry as much.’’ Six of the eight caregivers who expressed strong negative feelings thought that residents of nursing homes were treated badly. 1 daughter caregiver said, ‘‘Chinese people always think that when elderly persons are being sent away from their families, they will be treated like nothing.’’ Just as they perceived institutions negatively, so did they believe that the family’s act of sending a relative to a nursing home would be labelled negatively within their culture. ‘‘I am a traditional person. I very much dislike those people who leave the elderly people alone. Let them live on their own, cook and eat by themselves, live and die on their own, and visit them only when they have time. I do not like those people. I am very traditional.’’

Negative experiences:
Primary stressors: demands of caregiving and appraisal of stress
Secondary stressors: role strains - Family conflict resulting from lack of support from family, regarding care provision and disagreement on care; different levels of adherence to traditional culture; Seniority and status in the family
-Role conflict - caregiver roles interfered with their worker roles; Roles within the caregivers’ extended families were affected - little time left to spend with other members of their families; reduced social roles - difficult to socialize with friends or engage in other activities.
Secondary stressors: intra-psychic strains
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<th>Source</th>
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| Innes et al (2011); Malta | **Shared filial obligation**  
Shared filial responsibility and obligation. 3 daughters (D) rotating care of their mother in their homes on a week-by-week basis: “... and the thing is, we are her family we are the ones who should be taking care of her... she brought us up... we share.” | Exploratory study using semi- | Not clear if it’s a positive or negative experience. |

**Caregiving experiences and impact of caregiving**

- **Loss of self** - from lifestyle changes related to caregiving role, “role captivity; feeling of being trapped and being unable to lead own life. Resentfulness towards the caregiver role.
- **Anxiety and fatigue** - unable to relax psychologically due to constant care and supervision required. Continuous nature of caregiving depleted energy. Feeling despondent not knowing when the situation would end.
- **Intergenerational issues** where children no longer retained traditional values and caregivers could not expect their children to behave similarly. Conflict between Western and Chinese value systems. Importance of family education in maintaining traditionalism
- **Readiness to institutionalize care recipients** – all were on nursing home wait-lists as advised by the social worker - in case caregivers are unable to cope with care demands. 6 caregivers providing care for an average of 4.0 years as compared to those providing care for an average of 1.8 years were ready to institutionalize care recipients. Reasons were cited as recipients’ behavioural and functional problems and caregiver’s advanced age.

Assistance required with activities - Most activities (n=4), Some activities (n=5), Independent (n=3); Behavioural problems - frequent physical aggression (n=3), occasional physical aggression (n=1), occasional verbal abuse (n=2), occasional agitation (n=1), no (n=5). Plan to institutionalize was due to recipients requiring assistance with most activities, having more behavioural problems, problems with continence, and some having problems with mobility. 1 caregiver had no choice due to advancing age even when the care recipient did not have functional dependence or behavioural issues.
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<td><strong>Caregiving experiences and impact of caregiving</strong></td>
<td>structured interview.</td>
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<td></td>
<td><strong>Negative experiences:</strong></td>
<td>No data provided on employment and financial status.</td>
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<td><em>Family organization of care</em></td>
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<td><strong>Gendered expectations</strong></td>
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<td>- Physical care imposed on daughters and daughters-in-law while the men make the decision.</td>
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<td>Daughter (D) caring for her mother with no input from her three brothers. D: “I want that we all look after her, but it is not going to happen because my brothers don’t want to . . . they are saying that I am <strong>obliged to do it because I am the girl</strong>, and this is the ‘illness’ of the family that says that the girl (cares) and the boys follow this understanding [tradition].”</td>
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<td>Three daughters-in-law (DL) expected to care for their mother by their husbands (mother-in-law spends a week in each house on a rotating basis). They wish to change the care arrangements: DL1: “Don’t you know how they are? Three professors, am I going to speak to them?” DL2: “I tell him ‘go and watch you, see what she is saying’.” DL3: “We will tell them what is happening and there will be a lot of mmm and as usual we will get nowhere.”</td>
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<td><strong>- Notions of individual responsibility</strong> - based on the previous relationship e.g. spousal devotion; need to change and readapt personal lifestyles.</td>
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<td>Husband: “It is my cross and I have to carry it.” Wife: “We are sort of devoting ourselves to one another really. You did it for me . . . Now it’s my turn, isn’t it?” Daughter: “I feel obliged. I feel so guilty. I can’t get away from that. It’s terrible. I can’t even live my own life . . . I really wish I can run away but I can’t. I can’t even leave. She has <strong>trapped</strong> me really.”</td>
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<td><strong>Lack of formal support</strong></td>
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<td><strong>- Limited availability of suitable services</strong> – not meeting individual needs of caregivers</td>
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<td><strong>- Lack of respite care</strong> - to enable caregivers to continue with their working or personal lives</td>
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<td><strong>- Difficulty in finding someone to provide personal care</strong></td>
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| **Caregiving experiences and impact of caregiving** | - Limited knowledge on alternative services  
- Lack of information – about dementia, caregiver’s role, community resources, care services, medical information  
- Lack of informal support – lack understanding and support from neighbours, social stigma and isolation  
- **Financial burden** - financial costs involved in accessing services that would be appropriate, financial costs involved in the purchase of the anti-dementia drugs.  
- Juggling **multiple roles**  
| **Role conflict**  
- Dislocation of dementia caregiving from and in the community - dislocation from previous pursuits and roles.  
- Separation of caregiving days or weeks from normal family and work life  
Daughter 1: “She [D2] use to look after her most of the time because I used to work . . . she would come for the day only and go back in the evening [to D2’s home].”  
Daughter 1: “I work part-time, we have a family business and I have a part-time job as well which is not very regular, but I manage to, either I don’t or else my sisters help out . . . or I take her with me.” “I daughter gave up her work resulting in a much diminished social circle and her life revolving around maintaining the home, meeting the demands of her roles as wife and mother and doing so while acting as the sole caregiver to her mother.”  
- The men maintained previous interests and dislocated their caregiving role from their desire and need to maintain social lives. | | | |  
| 6. Netto et al (2009); Singapore | **Positive experiences:**  
Personal growth  
More patient / understanding | Grounded theory approach | |
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| Caregiving experiences and impact of caregiving | - ‘learnt to be more tolerant of [the person with dementia]’  - experience taught them ‘to build up patience’ to understand the person with dementia  - learnt ‘not to be so judgmental, so quick to judge others’.  
**Stronger / more resilient**  - affirmed by relatives or friends as ‘very strong’.  - ‘able to take more hardship’  ‘take certain crisis better ... [and] cope in a better way’  
**Increased self-awareness**  - more insights on ‘strengths and weaknesses, ‘negative feelings about own parent’.  - “I need not have such high expectations of myself.’ I have to relax a bit more, not to the point of negligence but that it’s okay for me to make some mistakes.”  
**More knowledgeable**  --to make informed decisions on ‘the type of medication and treatment that [the person with dementia] went through’, tips on manoeuvering the healthcare system.  
**Gains in relationships**  
**Closer relationship with care recipient**  -“brings you closer to your [relative]”; before dementia, everyone was ‘occupied with [their] own things’. “I’m drawn closer to him. There’s that closeness ‘cause I pay so much attention to him, | using Semi-structured, in-depth, face-to-face interviews |
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<tr>
<th>Study characteristics</th>
<th>Study Design</th>
<th>Conclusion (Scope, differences and similarities among studies)</th>
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<tr>
<td><strong>Caregiving experiences and impact of caregiving</strong></td>
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<td>drawn closer to him, and understood him more, you know, his needs, all his needs, his daily needs, things like that . . . [I’m] drawn closer because of his condition and the frequent contact with him and everything. Pain, he ask me to massage, I massage. Very close contact now, so learn to love him better.”</td>
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<td>-relationship grew even closer due to the illness and the companionship - ‘go out with her [mother] and enjoy long walks in the parks and along the beach’</td>
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<td><strong>Closer as a family</strong></td>
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<td>-‘the family bond gets tighter’. “I think because of this caregiving experience, we have become closer. We realize that we treasure our loved ones more and we understand that unity is very important in the family when things happen like that. The bonding of the family, everybody has to be you know, united as well as be each other’s support. I think crisis also makes us discover our true love. Without crisis, we don’t really know how much we love each one another.”</td>
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<tr>
<td><strong>Improved interaction with older persons</strong></td>
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<td>-better able to relate to older persons and had developed skills in handling and interacting with the elderly.</td>
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<td><strong>Higher-level gains</strong></td>
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<td><strong>Positive change in philosophy</strong> – e.g. less emphasis on ‘material things and money’ and placing a higher value on ‘relationships with others’.</td>
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<td><strong>Spiritual growth</strong> – more ‘aware of God’s presence in [their] life’, deeper relationship with God, feeling peace and joy, discovering ‘some meaning in the whole experience’. “I don’t see her as a mother. In my mind, as a being, I must take care of her. It’s my chance to do a good deed for her, for another person. So we as humans, we should be kind to each other. It’s more noble that way, to give. So I find I have adopted this attitude and I would say in that sense I’ve grown spiritually.”</td>
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<td>Caregiving experiences and impact of caregiving</td>
<td>Longitudinal, narrative case study design.</td>
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<td>7. Roach et al 2013; UK</td>
<td><strong>Altruism</strong> – desire to contribute to society or help others. Started volunteering at day care centres or in church ministries related to caregiving. ‘God will use me to minister to someone who has been through a similar experience’.</td>
<td>Longitudinal, narrative case study design.</td>
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<td>An agreeing storyline refers to a family discourse presented ‘as one’ in the narratives, where role boundaries are negotiated and understood within and between family members and a strong shared narrative line of 'togetherness' is evident. Agreeing storylines were used to maintain openness in the family and to share experiences with one another. It was the most open and positive family storyline type found in the data. Colluding storylines were seen in the data when two or more family members plotted with one another in order to maintain a storyline that was important to family functioning in some way. Inherent in a colluding storyline is the notion that not all family members are working towards the same goals and that there is some divergence and dissonance between family members. A conflicting storyline represents disagreement and divergence in presentation and may represent areas of hostility. Fabricating storylines are consciously used to alter details to fit into a conceptualisation of the ‘truth’ and were often used to mislead and misinform. Protecting storylines can be used to ameliorate stress and identity within the family relationships and have the potential to be disempowering to younger people with dementia or to other family members. Protecting storylines were also seen to be used in the data as a method of adjustment to the new diagnosis and balance within the family. A protecting storyline was used in this study by a younger person with dementia and her spouse in order to protect their children from the full effects her diagnosis was having on them as a couple.</td>
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| 8. Szinovacz (2003); USA | **Positive features:**  
- Relationship with the caregiver  
  - empathy and respect for the caregiving parent - understands the caregiving stress which parents are going through  
  - bonding – sharing the experience of caregiving; brings family closer  
**Negative features:**  
- Relationship with the caregiver  
  - resentment of ‘lost time’ with the parents and of the shift in the caregiving parent’s attention to the care recipient  
  - additional constraints on them to accommodate the care recipient  
  - caregiving parents’ display of reactive behaviours  
**Family dynamics:**  
- 3 main dimensions: family adaptations (5 quotes, mentioned by 3 adolescents), family tensions (16 quotes, mentioned by 6 adolescents), and fewer family activities (12 quotes, mentioned by 5 adolescents).  
- Family dynamics and adolescents’ feelings of stress  
  Caregiver stress and family tensions resulting from the care situation impinge on adolescents’ adaptation to the care situation. Adolescents’ distress is associated with high ambivalence in family dynamics and caregiver–adolescent relations, as evidenced by simultaneous reports of positive and negative relationship features by high-problem adolescents.  
- Adolescents’ and caregivers’ perspectives:  
  - caregivers saw less change in adolescents’ relationship to themselves than the adolescents: 36% (5 of 14) of the caregivers indicated no change in the relationship versus 18% (3 of 17) of the | Study Design | Conclusion (Scope, differences and similarities among studies) |
| | Grounded theory approach using semi-structured interviews | Study examining adolescent grandchildren. |
### Study characteristics

**Caregiving experiences and impact of caregiving**

Adolescents. Adolescents were more inclined to perceive deterioration in their relationship with the caregiver (53%; 9 of 17) than the caregivers themselves (36%; 5 of 14).

Discrepancy between adolescents’ and caregivers’ perspectives. Caregivers tend to see the impact of the care situation on adolescents in a more positive light than the adolescents themselves. Although caregivers seem to be aware that their behaviours toward the adolescents are affected by their caregiving responsibilities, they do not realize that these behavioural changes also have a profound impact on adolescents’ perceptions of the entire relationship.

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<th>Source</th>
<th>Interpretive descriptive study using in-depth interviews</th>
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| Ward-Griffin et al (2007); Canada | **Cooperative mother-daughter relationship**
- reciprocity
- Cooperative, flexible and attentive to each other
- work as a team

**Cohesive relationship**
- positive, mutual emotional bond or attachment exists.

**Negative:**

**Custodial mother-daughter relationships**
- duty, familial caregiving expectations
- absence of emotional attachment
- increasing interpersonal conflict and emotional distress

**Combative mother-daughter relationship**
- emotionally charged relationship
- shaped by their previous contentious mother-daughter relationship
- conflict, tension, hostility may also lead to elder neglect and/or abuse | Interpreteive descriptive study using in-depth interviews |
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**Quantitative - Textual Narrative Synthesis** | 

10. Fisher & Lieberman (1999); USA  
**Factors determining caregiving outcome:**  
Patient demographic and severity, and caregiver characteristic variables were not significant predictors of patient nursing home placement (NHP) during the 2 years following patient evaluation at the clinics.  
The stronger the family's negative feelings, the greater the family's emotional closeness, and the lower the family's efficiency, the greater the probability that the family institutionalized their ill elder during the 2-year follow-up period.  
- Conflict, distress, and frustration amongst family members can intensify over time.  
**Emotional difficulties** led to decision on NHP – on-going, painful family interactions and emerging interpersonal difficulties when attempting to coordinate patient care.  
Families appraised as **inefficient and unorganized / not cohesive** institutionalized their ill elders more frequently than families appraised as **efficient and organized / cohesive**, but only at **low levels of patient severity**.  
Clinic recommendation for NHP - The greater the number of patient management problems and family respondent care hours, the greater the probability that the clinic recommended NHP. The clinics made their recommendations for NHP on the basis of the degree of patient functional deficit and the amount of patient care required by family members. Clinic's recommendation for NHP was unrelated to what the family eventually decided.  
**Disjunction between the reasons clinicians recommend NHP and the reasons families decide on NHP** for their elder with dementia - Clinic's recommendation is based on patient severity and management issues. Multigenerational family is based on a host of interpersonal, structural, and emotional issues that relate to the experienced inner life of the family. | Longitudinal study |
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| 11. Hamill (2012); USA | **Caregiving experiences and impact of caregiving**  
Factors influencing caregiving:  
Parents’ Caregiving Burden as Predictors of Grandchildren’s Help  
Mothers spent an average of 12.5 hours whereas fathers spent an average of 2.25 hours of help. Grandchildren assisted with a greater number of activities when their parents provided more hours of help (Spearman’s $\rho = .47$, $p = .011$ for mothers and $\rho = .49$, $p = .015$ for fathers, respectively). Parents’ subjective experience of burden was not related to grandchildren’s provision of help.  
Relationship Quality as Predictors of Grandchildren’s Help  
Adolescents’ levels of affection for mothers ($M = 4.88$, $SD = 0.84$; range = 3.25-6.0) and fathers ($M = 4.47$, $SD = 1.11$; range = 1.5-6.0) were positive. Levels of affection in their relationships with grandparents were neutral ($M = 3.56$, $SD = 1.16$; range = 1.25-5.75). Affection for parents was not related to grandchild help. Grandchildren who had greater affection for their grandparents provided more help ($r = .44$, $p = .017$).  
Impact of caregiving:  
Caregiving and Adolescents’ Sense of Social Commitment  
Results of bivariate analyses revealed that adolescents reported a lower level of social responsibility when their fathers experienced greater subjective burden in their caregiving roles ($r = −.62$, $p = .001$). There was a trend for fathers’ hours of help to contribute to lower levels of social responsibility, as well ($r = −.39$, $p = .058$).  
Predicting Attitudes Toward the Provision of Long-Term Care  
Adolescent ratings revealed generally neutral levels of commitment to long-term care ($M = 3.52$, $SD = 0.36$; range = 2.68-4.23 on a 5-point scale). The affection adolescents felt for parents and grandparents, the help parents and adolescents provided to grandparents, and adolescents’ sense of social responsibility were explored as predictors of adolescents’ general attitude toward the | Cross-sectional study | Study examining adolescent grandchildren. Similar to Celdrán (2012). Relationship: Levels of affection for parents were not predictors of grandchildren’s help but affection for grandparents was a significant predictor. |
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<td>provision of long-term care for older parents. Whereas adolescents had more positive attitudes toward long-term care when they helped with more tasks ($r = .44, p = .017$), they had more negative attitudes when their fathers experienced greater caregiver burden ($r = -.47, p = .019$; there was a trend in the same direction for mothers, $r = -.37, p = .051$).</td>
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<td>Plans to Serve as Caregiver to Parents in the Future</td>
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<td>All adolescents planned on providing care in the future. The majority (59.3%) intended to serve as primary caregivers and provide care in their own homes. An additional 22.2% intend to serve as primary caregivers and 18.5% as secondary or auxiliary caregivers to parents living elsewhere.</td>
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| 12. Lieberman & Fisher (1999); USA | **Factors influencing caregiving:**  
Provision of family help  
- Patient living with a spouse was negatively correlated with total family help ($\beta = -.17, t = -2.14, p = .03$);  
- Respondent education was positively correlated with total family help ($\beta = .16, t = 2.27, p = .02$).  
- Troubling behaviours approached statistical significance ($\beta = .13, t = 1.74, p = .08$), suggesting a positive relationship with the provision of family help.  
The greater the family's positive conflict resolution skills and the more focused their decision-making style, the more help the family provided.  
Family members who reported high levels of patient troubling behaviours more frequently institutionalized their ill elders than family members who reported low levels of patient troubling behaviours.  
Families that provided high levels of help were less likely to institutionalize their ill elders than family members who reported providing low levels of family help. | Longitudinal, cross-sectional study | Different from Chan (2010). |
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### Caregiving experiences and impact of caregiving

**NOTE:** The sample of 211 families was reduced for this analysis by 10 deaths and 25 drop-outs during the ensuing two-year period, leaving 176 families. Of these, 87 (49.4%) had been institutionalized during the two years following clinic evaluation.

#### 13. Liew et al (2010); Singapore

- **Factors associated with gains:**
  - Caregiving situation associated with gains
    - Caregiver factors significantly associated with higher gains on univariate analysis were non-working status, > 3 years of caregiving, > 60% of time spent per week on caregiving, daily contact with PWD, little or no financial problems and attendance at caregiver education or support programmes.
    - Caring for a PWD with more **advanced stages** of the dementia indicated **greater gains**.

- **Impact of caregiving – Positive experiences:**
  - Caregivers’ gain
    - Mean GAIN score was 30 (SD = 6.6, range = 7–40) and 55% of the caregivers scored above the mean. 3 factors significantly associated with gains: less mental distress and better well-being of the caregiver, use of active management, and participation in caregiver educational and support group programmes.
    - Increased caregiver gain was positively correlated with sense of **caregiver competence** (SSCQ), **Encouragement and active management** were associated with higher gain. Active management was the factor that emerged significant on regression analysis. Increased caregiver gain was positively correlated with encouragement and **active management caregiving strategies**, and inversely associated with caregiver burden (ZBI), mental health problems (GHQ-28), criticism as a care strategy and behavioural problems in the PWD (RMBPC).

- **Impact of caregiving – Negative experiences:**
  - Criticism as a caregiving strategy correlated negatively with gain.
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<td><strong>Caregiving experiences and impact of caregiving</strong>&lt;br&gt;&lt;br&gt;The regression model with all the significant factors identified in the univariate analyses entered accounted for 32.3% of the variance of the GAIN scores (F = 7.56, P = 0.0001), with active care management strategy, caregiver mental health (GHQ) and attendance at caregiver educational and support group sessions being the significant multivariate correlates. Active care management strategy carried the greatest effect with the highest standardized beta coefficient score of 3.7. Regression model explained 32.3% of gain in this study, signifying there are other factors not evaluated that can explain gain.</td>
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<td>14. Lin et al (2012); Taiwan</td>
<td>Patients who were cared for by family members and FPCs were significantly older than those with only family caregivers (82.8±7.0 vs. 79.8±7.9 years; p=0.018). Clinical Dementia Rating Scale (CDR) and Neuropsychiatric Inventory (NPI) scores were significantly higher among patients whose families employed FPCs than among those without FPCs (median CDR score: 2 vs. 1, p=0.002; median NPI score: 21 vs. 10, p&lt;0.001). <strong>Impact of caregiving – Negative</strong>&lt;br&gt;Family caregiver burden was greater and duration of care was longer than those among family caregivers with foreign paid caregivers (FPC)’ assistance than among those without such assistance. Family caregivers with foreign paid caregivers’ assistance also tended to have greater knowledge about dementia than those without such assistance, although the difference was not significant. Family caregivers with FPC assistance had longer durations of care and significantly higher scores for caregiver burden and knowledge of dementia than did their respective FPCs. Family caregivers without FPC assistance, Zarit Burden Interview (ZBI) scores showed a strong positive correlation with Center for Epidemiological Studies–Depression Scale (CES-D) scores (Spearman’s r=0.617; p&lt;0.01), a moderate positive correlation with NPI scores (Spearman’s</td>
<td>Cross-sectional study</td>
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Caregiving experiences and impact of caregiving

Caregiving experiences and impact of caregiving

r=0.492; p<0.01), and a weak positive correlation with the duration of care (Spearman’s r=0.099; p<0.05).

Similar results were found for the ZBI scores of family caregivers who had FPC assistance, except for a moderate negative correlation with the duration of care (Spearman’s r=−0.384; p<0.05). By contrast, only one strong positive correlation emerged in the FPC group: that between ZBI and CES-D scores (Spearman’s r=0.511; p<0.01).

Correlations between CES-D scores and other measures.

Family caregivers without FPC assistance, CES-D scores showed a moderate positive correlation with NPI scores (Spearman’s r=0.364; p<0.01) and weak negative correlations with Knowledge of Dementia Questionnaire (KD) scores (Spearman’s r=−0.148; p<0.01) and patients’ ages (Spearman’s r=−0.106; p<0.05). No similar findings were noted for family caregivers with FPC assistance. Age and sex of caregivers were not correlated with any assessment measure.

For family caregivers without FPC assistance, factors contributing caregiver burden were CES-D (β =0.560; p<0.005), NPI (β =0.212; p<0.005), and CDR (β =0.083; p=0.032) scores (R2 =0.490; Table 4). For family caregivers with FPC assistance, CES-D (β =0.546; p<0.005) and NPI (β =0.296; p=0.024) scores contributed to caregiver burden (R2 =0.615). For FPCs, only CES-D scores (β =0.583; p<0.005) contributed to caregiver burden (R2 =0.428).

Sources of burden differ between family caregivers and foreign paid caregivers

Behavioural problems in patients had a strong psychological effect on family caregivers and increased their burden; did not affect FPC burden. FPC perception is likely due to cultural differences, more individualistic than familistic, working obligation, different perception (task versus love), emotional detachment

Family caregivers’ mood increases burden of foreign paid caregivers.
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| Tew et al (2010); Singapore | **Caregiving experiences and impact of caregiving**  
  **Caregiving situation:**  
  Most of caregivers lived with the PWD (79.2%) and had been providing care for more than 3 years (54.5%).  
  A significant number of caregivers were working (61.3%) and received assistance in their caregiving role (52.8%) from a lived-in maid.  
  Most caregivers (85.7%) preferred to continue looking after the PWD themselves at home, with only 14.3% opting for nursing home care.  
  **Factors which impact caregiving:**  
  Uni-variate analysis of factors - non-working status, > 3 years of caregiving, > 60% of time spent per week on caregiving, daily contact with PWD, little or no financial problems and attendance at caregiver education or support programmes - indicated significant association with higher gains.  
  Caring for a PWD in the more advanced stages of the illness also conferred greater gains.  
  **Impact of caregiving:**  
  Correlational analyses indicate that increased caregiver gain was positively correlated with sense of caregiver competence (SSCQ), encouragement and active management caregiving strategies.  
  The regression model with all the significant factors identified in the univariate analyses entered accounted for 32.3% of the variance of the GAIN scores ($F = 7.56$, $p < 0.0001$), with active care management strategy, caregiver mental health (GHQ) and attendance at caregiver educational and support group sessions being the significant multivariate correlates. Active care management strategy carried the greatest effect with the highest standardized beta coefficient score of 3.7.  
  **Burden**                                                                                           | Cross-sectional study                                     |
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<td>Caregiving experiences and impact of caregiving</td>
<td>Caregiver gain is inversely associated with caregiver burden (ZBI), mental health problems (GHQ-28), criticism as a care strategy and behavioural problems in the PWD (RMBPC).</td>
<td>Quantitative survey</td>
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| 16. Kua & Tan (1997); Singapore | **Factors which impact caregiving:**  
Daughters-in-law who had relationship conflict with their mothers-in-law previously complained more about the burden of care.  
Total behavioural score and depression were significant (p < 0.001).  
No gender difference in response to caregiving. The Chinese caregivers relied more on family support and less on psychogeriatric services.  
No significant difference in GHQ scores between: male and female caregivers; age of caregivers (comparing spouses and children); employment status; types of dementia; and severity of dementia (comparing mild and moderate/severe).  
**A high GHQ score correlated significantly** with the following variables: incontinence, delusion, hallucination, agitation, sleep disturbance and depression.  
**A high GHQ score** was also associated with duration of care (X2 = 4.5, p < 0.05) and the total score on the BEHAVE-AD (F=12.2, p < 0.01).  
Multiple regression analysis to assess the relationship of depression, duration of care and total behavioural score with GHQ scores showed significance. | Quantitative survey |  |
| 17. Lim et al (1999); Singapore | **Factors which impact caregiving:**  
Five behavioural (apathy, repetition, agitation, stripping, and wandering) and three functional (dependence in dressing, mobility, and urinary incontinence) variables reported by the caregivers were significantly associated with their problematic status.  
*No noticeable difference with regard to financial difficulties* between the group of caregivers who experienced problems and those who did not (p = .39). | Quantitative survey |  |
Caregiving experiences and impact of caregiving

Caregivers’ feeling of depression was significantly correlated with their problematic status ($p < .01$), their experience of anger was not ($p = .07$). Prior knowledge of the dementing illness, the awareness of the availability of services for patients with dementia, and the duration of care rendered did not correlate significantly with caregiver stress ($p = .75, .92, \text{and } .28, \text{respectively}$).

**Duration of care** was also not associated with caregiver stress ($p = .28$).

2 patients’ *behavioural problems* (repetition and agitated behaviour), their urinary incontinence status, and caregivers’ depression were predictive of the problematic status of the caregivers.

Caregivers’ *intentions to institutionalize* was significantly associated with their problematic status ($p = .01$). Hence, caregivers who reported problems in coping were more likely to consider institutionalizing the patients.

**Impact of caregiving:**
Caregiving Stressors and Psychological Distress
- cultural regard of dementia as a stigmatized mental illness - serious stressor.
- concerned about how others in community react to diagnosis of dementia.
- stress can be amplified when social networks diminish.
- belief in Asian cultural beliefs was associated with lower levels of distress, fewer depressive symptoms, greater self-efficacy, and more positive caregiving experiences.
- Family conflict arising from the care of parents with dementia (understanding how cultural meanings affect the stress process)
- Coping and Informal Support

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### Caregiving experiences and impact of caregiving

- Dementia diagnosis is often a source of shame in Chinese American families as caregivers may not disclose or share negative emotions and experiences openly or with those they consider “outsiders leading to caregivers coping with their distress spiritually and through values of filial piety.
- Support from informal networks such as families, relatives, friends, or neighbours - sewer contact with the family of a dementia patient to avoid being stigmatized, and unwillingness to assume care responsibilities after acculturation to Western values.

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| 19. Wang (2012); USA | **Impact of caregiving:**  
  *The Burden and Consequences of Caregiving*  
  - Affect both the mental and physical health  
    - Cultural values – importance of elder care and the enactment of filial obligations may contribute to positive aspects of caregiving, or instil pride in the caregiver’s ability to carry out familial responsibilities  
  Negative aspects:  
  - Tremendous burden and lack of support from extended family  
  - Sole responsibility to the primary caregiver  
  - Families in developed countries may be geographically dispersed and not readily available to caregivers  
  - Over-involvement or family disputes  
  - Influence of Western culture and acculturation of younger family members  
  - Migration of other family members to other countries  
  **Positive aspects:**  
  - Collective caring for family members - grown family members and siblings chip in and pay for the medical treatment | Narrative Review |  |
Caregiving experiences and impact of caregiving
- duty to the greater good of the family and community may supersede individual needs and desires
- sense of responsibility to family

Commentary based on the synthesis:
*Eventual outcome of all these themes – determines whether care recipient is institutionalized or not

**Culture**
Institutionalization of a family member with dementia does not augur well with the Chinese traditional and cultural values. Caregivers in Ho et al (2003)’s study were strongly opposed to the idea of institutionalizing their family members with dementia despite recommendations by healthcare professionals. A disjunction in reasons related to institutionalization is apparent between family caregivers and healthcare professionals. Fisher and Lieberman (1999) observed that the greater the number of patient management problems and family respondent care hours, the greater the probability that the clinic recommended institutionalization. In their study, recommendations for institutionalization are usually done on the basis of the degree of patient functional deficit and the amount of patient care required by family members. In both studies (Ho et al 2003; Fisher & Lieberman 1999), the clinic’s recommendation for nursing home placement was unrelated to what the family eventually decided. The Chinese family caregivers in Ho et al (2003) study felt that this was inappropriate as it did not conform to the traditional Chinese culture or their personal family values. Also, it would be very much against the care recipients’ wishes. A majority who had expressed the strong negative feelings perceived that residents of nursing homes were treated badly and felt that the family’s act of institutionalizing a relative would be labelled negatively within their culture (Ho et al 2003). The findings from a cross-sectional study of mostly Chinese caregivers (Tew et al 2010) indicated a high preference of family caregivers to continue looking after the person with dementia themselves at home; thus, confirming this very strong objection against institutionalization. The intention to institutionalize is usually a last resort when all avenues are exhausted (Ho et al 2003). Various studies have researched the predictors of institutionalization - caregivers’ characteristics, care recipients’ characteristics and living arrangement (Ho et al 2003; Lieberman & Fisher 1999; Lim et al 1999). High levels of patient troubling behaviours and lack of support systems are usually the cited reasons or considerations for institutionalization (Chan et al 2010; Fisher & Lieberman 1999; Ho et al 2003; Kua and Tan 1997; Lieberman & Fisher 1999; Liew et al 2010; Lim et al 1999; Tew et al 2010).
Caregiving experiences and impact of caregiving

Filial and family obligation appears to be a common theme in the Chinese and Maltese cultures. In the Maltese culture (Innes et al. 2011), shared filial responsibility and obligation is a common occurrence in the family’s organization of care in which the daughters provided care on a rotational basis. Clearly, this has not been described in the other studies. Based on this current review, the filial responsibility in the Chinese family (Ho et al. 2003) appears to fall on the main caregiver alone. Somehow, the caregivers have an ingrained Chinese cultural belief that it is the children’s responsibility to take care of their parents as opposed to western family values. The caregivers also believed that it is part of the Chinese culture where one has to take care of and respect elderly people. The caregiving role is willingly accepted as part of filial obligation. This role is seen as temporary and caregivers are mentally prepared to forgo other social obligations. In line with family obligation, the Chinese caregivers were also obliged to provide care simply because of the strong desire to keep the family together. Caregivers said that being members of a family meant they should try to overcome difficulties and not avoid responsibilities. Consequently, the role acceptance leads to a positive feeling when the obligation is fulfilled. Moreover, as demonstrated in Ho et al. 2003’s study, role strain occurs when there are different levels of adherence to traditional culture such as other siblings imposing Western cultural values into the care aspect. Seniority and status in the family were described as contributors to role strain as well. This occurs when a senior and respected member of the household, example the mother-in-law to the main caregiver, interferes with the care decision.

Care provision appears to be drawn along gender lines in some cultures. In a Maltese study (Innes et al. 2011), daughters and daughters-in-law were expected to provide physical care while the men make the decision. A daughter caring for her mother shared that she was told by her brothers of her obligation as a daughter to assume the caregiving role. The same pattern is similarly experienced by Italian and Spanish caregivers (Boughtwood et al. 2011) where care provision is drawn along gender lines as well. Female caregivers in these 2 cultures often do not question nor reflect on the consequences or implications for themselves or others. Instead, they feel responsible to perform specific tasks which are seen as inappropriate for male family members to do. Due to this traditional expectation, men from certain cultures in particular, continue to maintain previous interests and dislocate their caregiving role from their desire and need to maintain social lives (Innes et al. 2011). Somehow, this traditional role expectation permeates to the next generation as demonstrated by female grandchildren’s willingness to assist older family members when compared to sons (Boughtwood et al. 2011). It is likely that the caregiving role is generally assigned to female family members resulting from the higher levels of concern which they have for the care recipient. Chan et al. (2010) identified higher levels of concern accorded to care recipients by female family caregivers in comparison to their male counterparts. The study found that female compared.
with male caregivers had higher expectations of themselves to be competent; thus, making them significantly more stressed than male caregivers (Chan et al 2010). However, this difference could be due to a self-reporting gender bias in the study.

Spousal obligation is based on the notions of individual responsibility and in accordance with cultural tradition. Previous relationship between the caregiver and care recipient, spousal devotion and responsibility, and the need to change and readapt personal lifestyles to suit the new situation seemed to resonate across several studies (Boughtwood et al 2011; Ho et al (2003; Innes et al 2011). For some, the deep sense of spousal devotion and responsibility is deeply rooted within the cultural tradition (Ho et al 2003). However, the individual devotion and responsibility have also transgressed usual cultural norms as well. For instance, some Italian and Spanish-speaking caregivers, particularly male spouses, mentioned they were doing new tasks which were normally not expected of them (Boughtwood et al 2011).

Wang (2012)’s review on the influence of Western culture and acculturation of younger family members indicated that this can lead to language barriers and differences in opinions and beliefs among family members. This very concern was brought up by caregivers in Ho et al (2003)’s study. They were concerned that their children no longer retained traditional values. In view of that, children are not expected to be similarly obliged to provide the expected filial care and responsibility. Some have even gone on to emphasise the importance of family education in maintaining traditionalism. In contrast to the perception of Chinese adult caregivers in Ho et al (2003)’s study with regard to Western culture, a majority of Caucasian adolescent caregivers shared their intention to serve as primary caregivers and provide future care to parents in their own homes (Hamill 2012). The caregiving experience can become stressful when other support systems enter the home bearing a different set of culture. This occurs when other support systems like the lived-in maid comes into the caregiving scene with a different set of culture and, possibly, value system which does not match that of the employer’s (Lin et al 2012). A Taiwan study (Lin et al 2012) found that the lived-in maid was more individualistic than familistic as the role is perceived as a working obligation. Because of the perceived role, caregiving is seen as a task rather than love. Therefore, the lived-in maid comes conditioned with emotional detachment as they attempt to acculturate into the caregiving scene. If left unaddressed, this can become a source of burden for the family caregiver and the lived-in maid as identified by Lin et al (2012).

Sun et al (2012) in their review noted that from a cultural perspective, dementia as a stigmatized mental illness can be a serious stressor for family caregivers. Often, dementia as a diagnosis becomes a source of shame in Chinese American families. This can be borne out of concern about how others in the

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Sun et al (2012) in their review noted that from a cultural perspective, dementia as a stigmatized mental illness can be a serious stressor for family caregivers. Often, dementia as a diagnosis becomes a source of shame in Chinese American families. This can be borne out of concern about how others in the
community will react to the diagnosis. Essentially, caregivers may not disclose or share negative emotions and experiences openly or with whom they consider as outsiders leading to caregivers coping with their own distress spiritually and through values of filial piety. Family caregivers in this situation experience more strain when support from informal networks such as families, relatives, friends, or neighbours sewer contact with them to avoid being stigmatized as well. The sheer lack of understanding and informal support from families, relatives, friends or neighbours from the social stigma can lead to isolation (Innes et al 2011). In this instance, stress can be amplified when social networks diminish (Sun et al 2012). In other caregiving cultures, having friends at the house (where the care recipient resides) facilitated the selection of empathetic peers who are more objective regarding caregiving challenges (Beach 1997).

**Support Network**

Generally, family caregivers seek respite from caregiving through informal and formal support systems. The reason being, the stresses from caregiving have been shown to be either mediated or influenced by these systems. Informal support is usually provided by family and friends; specifically, with friends and family providing social and emotional support respectively (Ho et al 2003). Chinese family caregivers tend to depend more on family support and less on psychogeriatric services as seen in Kua and Tan (1997)’s study. Total help and support from adult family members and siblings have been shown to bring about positive caregiving experiences (Wang 2012). Total family help or support is determined by several factors. Lieberman and Fisher (1999) found that total family help is determined by the caregiver’s educational status and care recipients’ troubling behaviours. More so, the greater the family's positive conflict resolution skills and the more focused their decision-making style, the more help the other family members provided (Lieberman & Fisher (1999). However, caregivers’ strain becomes inevitable when the family is unable to resolve conflicts (Ho et al (2003). Tremendous burden is also experienced when the sole responsibility falls on the primary caregiver and there is lack of support from the extended family (Wang 2012). Sometimes the lack of support is simply due to geographical barriers - families in developed countries being geographically dispersed and not readily available to caregivers or family members having migrated to other countries (Wang 2012). Besides, functional deficits increase with illness progression and care becomes both labour-intensive and time-consuming. This can be a major source of burden (Chan et al 2010). But, caregivers of persons with severe dementia tend to accept their role better and experience less personal burden (Chan et al 2010; Liew et al 2010; Tew et al 2010) when family support increases and fewer complaints from others about the caregivers or the care recipients are received (Chan et al 2010). The implication is such that families providing high levels of help are less likely to institutionalize the person with dementia compared to families who reported providing low levels of family help (Lieberman & Fisher (1999).

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<td>Additionally, families appraised as inefficient and unorganized / not cohesive institutionalized their ill elders more frequently than families appraised as efficient and organized / cohesive, but only at low levels of patient severity (Fisher &amp; Lieberman 1999).</td>
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<td>Live-in maid is becoming a common source of informal support in the Chinese community in South-East Asia. They are usually hired by the family caregiver whom the care recipient resides with and when the caregiver needs to work. Tew et al (2010) found that most of the caregivers in their study lived with the care recipient and a significant number of these caregivers were working and receiving assistance in their caregiving role from a live-in maid. Also, families who employ live-in maids cope better and indicated less psychological burden even when care recipients are exhibiting more psychological and behavioural problems compared to those caregivers without live-in maids (Lin et al 2012)</td>
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<td>Formal social support or services such as government-supported home-care programmes, informational support, formal emotional support from professional counselling and support groups and hired professional helpers are channels which family caregivers have sought assistance from (Chan et al 2010; Ho et al 2003; Innes et al 2011; Liew et al 2010; Tew et al 2010). Nevertheless, perceptions about the usefulness of social services differ across the spectrum of dementia (Chan et al 2010). Caregivers of persons with milder dementia have indicated a preference for mutual support groups to assist them in coping with distress (Chan et al 2010). Day care facilities are preferred to other support services, such as home care and respite services (Chan et al 2010) as these allow family caregivers to take a breather when the care recipient is attended to. On the other hand, caregivers of persons with late-stage dementia generally benefited from community-based services but most regarded residential services as the best long-term care arrangement (Chan et al 2010). Information leaflets, audio visual materials, and problem oriented skills training programmes, and an accessible ‘resource person’ were regarded as practical and helpful for obtaining information and advice about specific aspects of caregiving (Chan et al 2010). Congruent to that, Liew et al (2010) and Tew et al (2010) found the use of active management and participation in caregiver educational and support group programmes to be significantly associated with gains in family caregivers (Liew et al 2010; Tew et al 2010). Increased caregiver gain has also been positively correlated with sense of caregiver competence, encouragement and active management caregiving strategies (Liew et al 2010; Tew et al 2010). In comparison, limited availability of suitable social support or services (Innes et al 2011) and criticism as a caregiving strategy (Liew et al 2010) were identified burdens demonstrating the importance of formal support or services.</td>
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<td>Roach et al (2013)</td>
<td>Emergence of five family storyline types: agreeing; colluding; conflicting; fabricating; and protecting. Findings indicated that families were likely to use each of these storylines at different points and at different times in their exposure to young onset dementia. Families that adopted a predominantly ‘agreeing’ storyline were more likely to find ways of positively overcoming challenges in their everyday lives. Families who adopted predominantly ‘conflicting’ and ‘colluding’ storylines were more likely to require help to understand family positions and promote change. The findings suggest that the identification of the most dominant and frequently occurring storylines used by families may help to further understand family experience in young onset dementia and assist in planning supportive services.</td>
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**Togetherness**

Caregiving of the person with dementia has brought about positive changes in intergenerational family relationships and family bonding (Beach 1997; Hamill 2012; Netto 2009; Szinovacz 2003; Ward-Griffin et al 2007). Adult caregivers reported having closer relationship with the care recipient due to more frequent contact and close attention (Netto et al 2009). Parents’ influence on their children’s involvement in caregiving was not determined by the degree of affection which their children have for them (Hamill 2012). Rather, affection for grandparents living with dementia itself was the significant predictor.

Beach (1997) also noted improvement in the relationship between the parent and adolescent. Significant mother and adolescent bonding have resulted from the greater sense of intimacy within the mother / adolescent relationship (Beach 1997; Szinovacz 2003). Apparently, the greater sense of intimacy between the adolescent and parent caregiver is determined by several factors. Szinovacz (2003) found that adolescent caregivers were more empathetic and respectful of the caregiving parent when they genuinely understood the stress which their parents experienced. Positive reinforcement accorded to the adolescent by the mother and feeling more trusted to perform important caregiving tasks further reinforced this relationship (Szinovacz 2003). In fact, adolescents shared the need to offer help and reassurance when their mothers are experiencing emotional outbursts and burnout as well as a genuine desire to spend time with their mothers (Szinovacz 2003). Furthermore, positive outcomes in relationship with other members of the family have arisen. Sibling activity and sharing increased as a result of coping with the care recipient’s aberrant behaviours (Beach 1997). Previously distant sibling relationships have also undergone positive changes (Beach 1997). The family becomes closer, bonded and united (Netto et al 2009). Ward-Griffin et al (2007) in studying relationships between caregiving dyads have termed the nature of such a close and positive relationship as co-operative and cohesive relationships. They have described the
Caregiving experiences and impact of caregiving

positive relationships with similar terms used in the other studies like reciprocity, cooperativeness, flexibility and attentiveness to each other, team work where positive, and mutual emotional bond or existence of attachment. It is this deep sense of shared relational experience in caregiving where bonding develops which brings the intergenerational family closer together.

On the contrary, caregiving can consequently lead to deterioration in family relationships and poor bonding in some intergenerational families; thus, resulting in unfavourable consequences such as institutionalization of the care recipient and burden of the caregiver. Prior relational conflict between the caregiver and care recipient has a part to play. Kua and Tan (1997) found that daughters-in-law who had previous relationship conflict with their mothers-in-law complained more about the burden of care. Ward-Griffin et al (2007) negatively describes the nature of such relationship as the custodial mother-daughter relationship and combative mother-daughter relationship when studying caregiving dyads. In the custodial mother daughter relationship, the caregiver continues to provide care as part of her duty and familial caregiving expectations. However, there is an absence of emotional attachment. Overtime, increasing interpersonal conflict and emotional distress become unavoidable. In the case of the combative mother-daughter relationship, the relationship is emotionally charged; commonly shaped by their previous contentious mother-daughter relationship. Conflict, tension and hostility in the relationship may lead to elder neglect and/or abuse of the care recipient.

Strained relationships with other family members have been reported (Chan et al 2010; Szinovacz 2003); over time, leading to institutionalization of the person with dementia (Lieberman and Fisher 1999). The worsening grandparent–grandchildren relationship and parent-child relationship are related to deterioration in communication, affection and decrease in shared leisure activities (Szinovacz 2003). Some have even expressed disapproval towards the caregiving parent and grandparent’s lack of support and understanding for the care recipient (Szinovacz 2003). Adolescents’ and caregivers’ perspectives of the change in relationship do not concur (Szinovacz 2003). Caregivers tended to see the impact of the care situation on adolescents in a more positive light than the adolescents themselves. Although caregivers seem to be aware that their behaviours toward the adolescents are affected by their caregiving responsibilities, they do not realize that these behavioural changes also have a profound impact on adolescents’ perceptions of the entire relationship (Szinovacz 2003). What is noteworthy from Szinovacz (2003)’s study is the impact of the caregiver’s stress and family tensions resulting from the care situation impinging on how adolescents adapt to the care situation and correlating these to a worsening parent-child relationship. Adolescents’ distress is
Caregiving experiences and impact of caregiving

associated with high ambivalence in family dynamics and caregiver–adolescent relations, as evidenced by simultaneous reports of positive and negative relationship features by high-problem adolescents (Szinovacz 2003).

Consequently, the stronger the family's negative feelings, the greater the probability that the family institutionalized their ill elder (Lieberman and Fisher 1999). Conflict, distress, and frustration amongst family members which intensify over time are commonly cited reasons. Emotional difficulties such as ongoing, painful family interactions and emerging interpersonal difficulties when attempting to coordinate patient care have often led to decision on institutionalization. Families appraised as not cohesive institutionalized their ill elders more frequently than families appraised as cohesive (Lieberman and Fisher 1999).

Adolescent and adult caregivers have reported personal changes or gains from their involvement in caregiving. On a positive note, they expressed having developed empathy, a positive attitude, patience, understanding and improved interaction related to the elderly (Beach 1997; Ho et al 2003; Netto et al 2009). Some have even reported becoming stronger, and more resilient, self-aware, knowledgeable in care decisions, creative in problem solving, philosophical, spiritual and altruistic with a strong sense of social commitment (Netto et al 2009). For adolescents though, the sense of social commitment can be impacted by their caregiving parents. In a US study (Hamill 2012), adolescents reported a lower level of social responsibility when their fathers experienced greater subjective burden in their caregiving roles. In addition, the lesser the fathers’ hours of caregiving duration, the lower the adolescents’ levels of social responsibility. The adolescents, themselves, had more positive attitudes toward provision of long-term care when they helped with more tasks. For some, caregiving provides companionship, added meaning to life, an opportunity to care for loved ones (Chan et al 2010). Further to that, several factors have been found to be significantly associated with higher gains thereby effecting positive personal changes - non-working status, longer duration of caregiving, more time spent on caregiving, frequent contact with the care recipient, little or no financial problems and attendance at caregiver education or support programmes (Liew et al 2010; Tew et al 2010). Negative emotional responses were often described as grief, sadness, anxiety, anger, guilt, blame, fear, embarrassment, exhaustion and/or depression (Boughtwood et al 2011). These responses are usually related to caregivers’ emotional burden which eventually results in deterioration in caregivers’ physical and mental health (Boughtwood et al 2011; Kua & Tan 1997) and the care recipients’ institutionalization (Fisher & Lieberman 1999). Worry for the future, care recipients’ psychological and behavioural problems, financial issues were some of the commonly expressed concerns (Boughtwood et al 2011; Chan et al 2010; Hamill 2012; Innes et al 2011; Kua & Tan 1997).
Under One Roof; Intergenerational Care For People With Dementia In Singapore-Chinese Families - A Case Study Design

INTERVIEW GUIDE

Introduction - 5 minutes
(Aim: to explain purpose of research)
Thank interviewee for taking part in the research.

- Introduce self, interview will last 1½ hour
- Explain purpose of research: I would like to talk to you about your life in general, to get a feel of what it is like and the things of importance for you. I may discuss specific issues to get your views and opinions on intergenerational care related to your family member with dementia. This interview is an opportunity for you to have a say about how you feel about things at present.
- If at any point, you would like to take a break, just let me know.
- Reassure re: confidentiality- nothing you say will be linked to your name, recording.
- Explain importance of participants saying what they think, there are no right or wrong answers, all opinions are valid and helpful.
- Check participants is comfortable with interview format and subject matter. Any questions?

Participant’s Introduction – 10 minutes
Tell me a little about yourself and your loved one whom you are caring for….

Research topics – 1 hour 15 minutes
(Aim: to explore relevant aspects of participants’ experiences)
Researcher: identify relevant family caregiver and the person with dementia’s characteristics
Bring in the 23-item structured questionnaire here.
Family caregiver’s data should include:

- Gender, age, specific relation to the person with dementia, position in the family (example, eldest, middle, youngest), educational level, employment status, monthly salary, specific role and responsibilities, and specific type of care provided for the person with dementia.
Person with dementia’s data should include:

- Gender, age, living arrangement, type of dementia and stage, and duration of care.
Guiding questions:
- How do intergenerational Singapore-Chinese families care for a person with dementia at home? How does the intergenerational Singapore-Chinese families’ care setting operate?
- What system of beliefs, values, attitudes and coping underlie the intergenerational Singapore-Chinese families’ operation? How do they impact on the intergenerational Singapore-Chinese families’ operation?
- What is the specific role and responsibility of each member in the intergenerational Singapore-Chinese families? How is the specific role and responsibility assigned? Does hierarchical order in the intergenerational Singapore-Chinese families determine the specific
role assignment in providing care for the person with dementia? How does this impact on the intergenerational Singapore-Chinese families caring for a person with dementia at home?

• What formal and informal support services and systems do intergenerational Singapore-Chinese families rely on?
• How do the intergenerational Singapore-Chinese families transit through the caregiving experience?
• What are the short- and long-term consequences of caregiving environments on Singapore-Chinese adolescents’ well-being over time?
Name of participant:

**Family Genogram**

Legend:

- male
- female
- deceased male
- deceased female
- index person
- marriage connection
- separation
- divorce
- unmarried couple
- household

- children, with birth order left to right
- fraternal twins
- identical twins
- foster or adopted child
- informal kinship network

**Relationships**

- close
- very close or fused
- estranged or cut off
- poor or conflictual
- fused and conflicual
- distant
Family ecomap
APPENDIX 9

Under One Roof; Intergenerational Care For People With Dementia In Singapore-Chinese Families - A Case Study Design

QUESTIONNAIRE

Tick (√) the box beside the one reply that most applies to you and fill in the blank when appropriate.

Part A: Caregiver’s information

1) What is your gender? (Please tick one box only)
   □ Male 1
   □ Female 2

2) What is your age (in years)?
   ________________

3) What is your marital status? (Please tick one box only)
   □ Single 1
   □ Married 2
   □ Separated 3
   □ Divorced 4
   □ Widowed 5

4) What is your highest educational level? (Please tick one box only)
   □ Primary 1
   □ Secondary 2
   □ ITE 3
   □ Pre-university 4
   □ Polytechnic 5
   □ Degree 6
   □ Masters 7
   □ PhD 8
   □ Others. Please specify ______________________ 9
5) What is your occupation? (Please tick one box only)
   □ Student 1
   □ Housewife 2
   □ Retired 3
   □ Skilled worker. Please specify ________________ 4
   □ Professional. Please specify ________________ 5
   □ Others. Please specify ________________ 6

6) Are you working? (Please tick one box only)
   □ Self-employed 1
   □ Unemployed 2
   □ Part-time 3
   □ Full-time 4

7) What is your monthly income? (Please tick one box only)
   □ No income 1
   □ Less than S$1000 2
   □ Between S$1001 to S$2000 3
   □ Between S$2001 to S$3000 4
   □ Between S$3001 to S$4000 5
   □ Between S$4001 to S$5000 6
   □ Between S$5001 to S$6000 7
   □ Between S$6001 to S$7000 8
   □ Between S$7001 to S$8000 9
   □ Between S$8001 to S$9000 10
   □ Between S$9001 to S$10000 11
   □ Above S$10000. Please specify amount ________________ 12

8) What type of housing do you currently reside in? (Please tick one box only)
   □ 1-room housing development board flat 1
   □ 2-room housing development board flat 2
   □ 3-room housing development board flat 3
   □ 4-room housing development board flat 4
   □ 5-room housing development board flat 5
   □ Executive maisonette 6
   □ Condominium 7
   □ Landed property 8

9) How many people are staying in the same household as you? Please specify the number.
   ____________________
10) Are you staying with a person with dementia? (Please tick one box only)
- Yes 1
- No 2

11) What is your role in the care of a person with dementia? (Please tick one box only)
- Main caregiver 1
- Secondary caregiver 2
- Not involved with any care 3

12) How are you related to the care recipient (person with dementia)? (Please tick one box only)
- Wife 1
- Husband 2
- Daughter 3
- Son 4
- Daughter-in-law 5
- Son-in-law 6
- Grandson 7
- Granddaughter 8
- Others. Please specify ________________________________ 9

13) Are you the eldest, middle or youngest sibling in the family? (Please tick one box only)
- Eldest 1
- Middle 2
- Youngest 3

**Specify the type of care you provide for the person with dementia. You can select more than 1 option for questions 14 and 15.**

14) Activities of daily Living
- Bathing 1
- Dressing 2
- Toileting 3
- Transferring 4
- Continence care 5
- Feeding 6
15) Instrumental activity of daily living

- Using the telephone: 1
- Shopping: 2
- Preparing food: 3
- Housekeeping: 4
- Doing laundry: 5
- Using transportation: 6
- Handling medications: 7
- Handling finances: 8
- Others. Please specify: 9

16) How many hours a day do you spend looking after the person with dementia? Please indicate the number of hours: __________

17) Which support group or organization are you registered with? (Please tick one box only)

- None: 1
- Alzheimer’s Disease Association (ADA): 2
- Asian Women's Welfare Association (AWWA): 3
- Handicaps Welfare Association (HWA): 4
- Society for the Physically Disabled (SPD): 5
- Others. Please specify: 6

**Part B: Care recipient’s information**

18) Gender of care recipient. (Please tick one box only)

- Male: 1
- Female: 2

19) Age of care recipient in years.

- 40-49: 1
- 50-59: 2
- 60-69: 3
- 70-79: 4
- 80-89: 5
- 90-100: 6

20) Who is your relative with dementia staying with? Please specify: __________________________
21) What type of dementia is your relative diagnosed with? (Please tick one box only)
   - □ Alzheimer’s disease          1
   - □ Frontal-temporal dementia      2
   - □ Vascular dementia          3
   - □ Others. Please specify _________________________     4

22) What stage is the dementia? (Please tick one box only)
   - □ Early            1
   - □ Moderate           2
   - □ Late            3

23) How long has he / she been receiving care from you? Please specify the duration.
    _______________

Thank you for your participation
个案研究设计——同一屋檐下，在新加坡华人家庭中痴呆症患者的隔代护理

问卷

请在那项最适用于您的答复旁的方框内打勾（√），并在恰当时填写。

第一部分：看护者资料

1) 您的性别是什么？（请只在一个方框内打勾）
   □ 男性 1
   □ 女性 2

2) 您的年龄是多少（年岁）？
   ________________

3) 您的婚姻状况是什么？（请只在一个方框内打勾）
   □ 单身 1
   □ 已婚 2
   □ 分居 3
   □ 离婚 4
   □ 丧偶 5

4) 您的最高教育程度是什么？（请只在一个方框内打勾）
   □ 小学 1
   □ 中学 2
   □ 工艺教育学院 3
   □ 大学先修班 4
   □ 理工学院 5
   □ 学士学位 6
   □ 硕士学位 7
   □ 博士学位 8
   □ 其他。请注明 ____________________________
5) 您的职业是什么？（请只在一个方框内打勾）
- 学生
- 家庭主妇
- 退休人士
- 熟练工人。 请注明____________________
- 专业人士。请注明__________________
- 其他。请注明________________________

6) 您是否在工作？（请只在一个方框内打勾）
- 自雇人士
- 无业
- 兼职
- 全职

7) 您的每月收入是多少？（请只在一个方框内打勾）
- 没有收入
- S$1000 以下
- 介于 S$1001 到 S$2000 之间
- 介于 S$2001 到 S$3000 之间
- 介于 S$3001 到 S$4000 之间
- 介于 S$4001 到 S$5000 之间
- 介于 S$5001 到 S$6000 之间
- 介于 S$6001 到 S$7000 之间
- 介于 S$7001 到 S$8000 之间
- 介于 S$8001 到 S$9000 之间
- 介于 S$9001 到 S$10000 之间
- S$10000 以上。请注明金额__________________

8) 您目前居住在哪一类型的屋子？（请只在一个方框内打勾）
- 一房式政府组屋
- 二房式政府组屋
- 三房式政府组屋
- 四房式政府组屋
- 五房式政府组屋
- 公寓式政府组屋
- 共管公寓
- 有地住宅

9) 有多少人和您住在一起？请注明人数。__________________
10) 您是否和一位痴呆症患者住在一起？（请只在一个方框内打勾）
- 是 1
- 不是 2

11) 您在照顾这位痴呆症患者方面扮演什么角色？（请只在一个方框内打勾）
- 主要看护者 1
- 次要看护者 2
- 没有参与任何照顾工作 3

12) 您和被照顾者（痴呆症患者）之间是什么关系？（请只在一个方框内打勾）
- 妻子 1
- 丈夫 2
- 女儿 3
- 儿子 4
- 媳妇 5
- 女婿 6
- 孙子 7
- 孙女 8
- 其他。请注明__________________________________ 9

13) 您在兄弟姐妹之间是年龄最大、介于中间或最小的？（请只在一个方框内打勾）
- 最大 1
- 介于中间 2
- 最小 3

请注意您为痴呆症患者提供哪一方面的照顾。对于第 14 及 15 道问题，您可以选择超过一项。

14) 日常生活的活动
- 冲凉 1
- 更衣 2
- 上厕所 3
- 移动 4
- 大小便护理 5
- 喂食 6
工具性日常生活活动能力

- 使用电话 1
- 购物 2
- 准备食物 3
- 家务管理 4
- 洗衣服 5
- 使用交通工具 6
- 处理药物 7
- 处理财务 8
- 其他。请注明__________________________ 9

您一天花多少小时照顾痴呆症患者？请注明有多少小时：______________

您是在哪一间支持团体或组织之下注册的？（请只在一个方框内打勾）

- 无 1
- ADA (阿尔茨海默病协会) 2
- AWWA (亚洲女性福利协会) 3
- HWA（残疾人士福利协会） 4
- SPD (体障人士协会) 5
- 其他。请注明__________________________ 6

第二部分：被照顾者资料

被照顾者的性别（请只在一个方框内打勾）

- 男性 1
- 女性 2

被照顾者的年龄岁数。

- 40-49 1
- 50-59 2
- 60-69 3
- 70-79 4
- 80-89 5
- 90-100 6

您患痴呆症的亲人和谁住在一起？请注明_____________________________
21) 您的亲人被诊断患上哪一类型的痴呆症？（请只在一个方框内打勾）
- 阿尔茨海默病 [ ] 1
- 额颞叶痴呆 [ ] 2
- 血管性痴呆 [ ] 3
- 其他。请注明_________________________ [ ] 4

22) 痴呆症是处在哪一个阶段？（请只在一个方框内打勾）
- 早期 [ ] 1
- 中期 [ ] 2
- 晚期 [ ] 3

23) 他 / 她被您照顾了多长的时间？请注明持续时间。______________

谢谢您的参与
Ms. May Yeok Koo  
School of Nursing, Midwifery and Social Work  
7th August 2014

Dear Ms. Koo  

Research Ethics Committee 3  

Koo, Keady, Pusey: Title of the research: Under One Roof; Intergenerational Care For People With Dementia In Singapore-Chinese Families - A Case Study Design (ref 14207)  

I write to confirm that the Chair is now satisfied that you have addressed the concerns of the Ethics Committee of the 11th June 2014 and has therefore given the above research project a favourable ethical opinion.  

This approval is effective for a period of five years and if the project continues beyond that period it must be submitted for review. It is the Committee’s practice to warn investigators that they should not depart from the agreed protocol without seeking the approval of the Committee, as any significant deviation could invalidate the insurance arrangements and constitute research misconduct. We also ask that any information sheet should carry a University logo or other indication of where it came from, and that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a university computer or kept as a hard copy in a location which is accessible only to those involved with the research.  

Finally, I would be grateful if you could complete and return the attached form at the end of the project or by June 2015. 

We hope the research goes well.  

Yours sincerely  

Adrian Jarvis  

Ethics Committee 3 Secretary

NYP IRB Ref: SHS-2014-011

19 Dec 2014

Ms Koo May Yaok
School of Health Sciences
Nanyang Polytechnic

Dear Ms Koo,

NYP INSTITUTIONAL REVIEW BOARD (IRB) APPROVAL

STUDY TITLE: Under One Roof; Intergenerational Care For People With Dementia In Singapore-Chinese Families - A Case Study Design

We are pleased to inform you that the NYP Institutional Review Board has approved the application as titled above to be conducted in Nanyang Polytechnic.

The approval period is from 19 Dec 2014 to 18 Dec 2015. The NYP IRB reference number for this study is SHS-2014-011. Please use this reference number for all future correspondence.

The documents reviewed are:

1) NYP IRB Application Form: Version No. 4, dated 5 Nov 2014
4) PIS & Informed Consent Form – Appendix 5: Version No. 2, dated 5 Oct 2014
5) Parent / Guardian Informed Consent Form – Appendix 8: Version No. 4, dated 5 Nov 2014
6) PIS & Assent Form for Adolescents – Appendix 6: Version No. 2, dated 5 Oct 2014
9) Questionnaire – Appendix 4: Version No. 5, dated 18 Dec 2014
11) Cover Letter – Appendix 1: Version No. 4, dated 22 Nov 2014
12) Schedule – Appendix 2: Version No. 2, dated 5 Nov 2014
Continued approval is conditional upon your compliance with the following requirements:

1) Only the approved Informed Consent Form should be used. It must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject should be given a copy of the signed consent form.

2) No deviation from or changes to the study should be implemented without documented approval from the NYP IRB, except where necessary to eliminate apparent immediate hazard(s) to the study subjects.

3) Any deviation from or changes to the study to eliminate an immediate hazard should be promptly reported to the NYP IRB within seven calendar days.

4) Please note that for studies requiring Clinical Trial Certificate, apart from the approval from NYP IRB, no deviation from, or changes of the Research Protocol and Informed Consent Form should be implemented without documented approval from the Health Sciences Authority unless otherwise advised by the Health Sciences Authority.

Please submit the following to the NYP IRB:

1) All Unanticipated Problems Involving Risk To Subjects Or Others (UPIRTSOs) must be reported to the NYP IRB. All problems involving local deaths must be reported immediately within 24 hours after first knowledge by the Investigator, regardless of the causality and expectedness of the death. All other problems must be reported as soon as possible but not later than seven calendar days after first knowledge by the Investigator.

2) Report(s) on any new information that may adversely affect the safety of the subject or the conduct of the study.

3) NYP IRB Study Status Report Form – this is to be submitted 4 to 6 weeks prior to expiry of the approval period. The study cannot continue beyond 18 Dec 2015 until approval is renewed by the NYP IRB.

4) Study completion – this is to be submitted using the NYP IRB Study Status Report Form within 4 to 6 weeks of study completion.

Thank you.

Yours Sincerely,

[Signature]

Dr Mathew Lau
Chairperson
NYP Institutional Review Board
Dear ___________________,

I am writing to request your permission to interview some of the family caregivers in the Alzheimer’s Disease Association for my doctoral dissertation for the research entitled: **Caring for people with dementia at home by intergenerational Singapore-Chinese families – A multiple case study design.** I propose to explore the care for people with dementia at home by intergenerational Singapore-Chinese families.

In order to explore the intergenerational family system and understand how the care for the person with dementia is supported and organized at home by the families, this study employs a multiple case study research design to enable exploration of similar and contrasting case studies. The target population for this study are intergenerational Singapore-Chinese families.

I have selected the Alzheimer’s Disease Association as the initial recruitment site for this case study because it is the main organization in Singapore which provides social support services to family caregivers of persons living with dementia. For data gathering purposes, this research will employ mainly interview and observation methodologies. Specifically, I will need to recruit 12 to 15 Chinese family caregivers who meet my selection criteria to be interviewed for approximately 90 minutes for a maximum of three times.

In conclusion, I would like to seek your kind permission to study some of the Chinese family caregivers for this research. I have enclosed a copy of my Ethics Review Committee application as well as my invitation and informed consent forms for this research. Should you have any questions or concerns regarding this letter or my research, please contact me via:

Email: WAN_Koo_May_Yeok@nyp.edu.sg; Mobile number: 96245574.

Alternatively, you can contact my research supervisors:

- Professor John Keady via John.Keady@manchester.ac.uk
- Dr Helen Pusey via Helen.Pusey@manchester.ac.uk

If you wish to make a formal complaint about the conduct of the research, please contact the Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, United Kingdom.

Sincerely,

May Yeok, Koo
Under One Roof; Intergenerational Care For People With Dementia In Singapore-Chinese Families - A Case Study Design

Participant Information Sheet
You are being invited to take part in a research study [as part of a PhD coursework]. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Who will conduct the research?
May Yeok, Koo
School of Nursing, Midwifery and Social Work,
University of Manchester, University Place,
Oxford Road, Manchester, M13 9PL, United Kingdom.

Title of the Research
Under One Roof; Intergenerational Care For People With Dementia In Singapore-Chinese Families - A Case Study Design

What is the aim of the research?
I am hoping to understand how the different members of the nuclear family participate in and contribute to the care of the person with dementia.

Why have I been chosen?
You are chosen because of your potential valuable input on how the care of a loved one with dementia is organized in your family.

What would I be asked to do if I took part?
I will be interviewing you. During those times, I will be writing down notes, audio recording our conversations and taking digital photographs of items or the environment in and outside your home. Prior to utilizing these photographs, I will seek further permission from you. I will ensure that the photographs will not inadvertently reveal your identity or that of your family member with dementia. As this study does not involve any interventions, you will not experience pain or discomfort. However, some of the research questions may likely trigger sad or unhappy memories.
What happens to the data collected?
I will be analysing the data and using them for research purposes.

How is confidentiality maintained?
Audio and transcribed data, and digital photographs which are in soft copies will be stored and kept secure in the researcher’s encrypted, user ID and password protected work PC. Audio files of interview recordings will be deleted from the PC upon completion of study. Photographs which inadvertently reveal your identity or that of your family member with dementia will not be utilized. Your name will be anonymized to maintain confidentiality.

What happens if I do not want to take part or if I change my mind?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself.

Will I be paid for participating in the research?
You will not be paid monies for participating in this study.

What is the duration of the research?
A total of at least 3 interviews lasting 1½ hour each.

Where will the research be conducted?
The research will be conducted in your home if permissible by you or at your preferred location outside your home. Any research meetings outside the home will be negotiated and agreed with you and conducted in a public place, such as a café or at the ADA offices.

What can I do if I feel distressed from the interview?
You can call the Alzheimer Caregiver Support (Counselling) at 6353 8734.

Will the outcomes of the research be published?
It is anticipated that the research findings will be shared at research conferences and published in peer reviewed journals.

Criminal Records Check (if applicable)
The researcher declares that she has no prior criminal records nor has ever been convicted for any criminal offences.
Contact for further information

May Yeok, Koo
Email: WAN_Koo_May_Yeok@nyp.edu.sg
Mobile number: 96245574.

What if something goes wrong?
Please contact May Yeok, Koo via WAN_Koo_May_Yeok@nyp.edu.sg or 96245574 if you need help or advice.

Alternatively, you can contact:
Professor John Keady via John.Keady@manchester.ac.uk
Dr Helen Pusey via Helen.Pusey@manchester.ac.uk

If you wish to make a formal complaint about the conduct of the research OR If there are any issues regarding this research that you would prefer not to discuss with members of the research team, please contact the Research Governance and Integrity Team by either writing to 'The Research Governance and Integrity Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester M13 9PL’, by emailing: Research.Complaints@manchester.ac.uk, or by telephoning 0161 275 7583 or 275 8093.
个案研究设计——同一屋檐下，在新加坡华人家庭中痴呆症患者的隔代护理

参与者资料表
您受邀参与一项试验研究[作为博士学位课程作业的一部分]。在您作出决定之前，很重要的一点是，您务必要知道为什么要进行此项研究，以及它会涉及什么。请花一些时间仔细阅读以下的信息，如果您愿意，也可以和其他人讨论。如果您有任何不清楚之处或是希望能获得更多的信息，请向我们提问。您无须急于决定是否要参与。谢谢您阅读本文件。

这项研究会由谁进行？
May Yeok, Koo
School of Nursing, Midwifery and Social Work,
University of Manchester, University Place,
Oxford Road, Manchester, M13 9PL, United Kingdom.

研究名称
个案研究设计——同一屋檐下，在新加坡华人家庭中痴呆症患者的隔代护理

研究的目的是什么？
我希望能够理解一个核心家庭的不同成员如何参与及出力照顾痴呆症患者。

我为什么被选上？
您之所以会被选上，是因为您或许能够提供关于在您家中安排照顾患有痴呆症亲人方面的宝贵意见。

如果我参与，我会被要求做些什么？
我将会和您面谈。在这段时间里，我会写下笔记、将我们的谈话进行录音及拍摄数码照片。由于这项研究并不涉及任何干预措施，您将不会经历疼痛或不适。然而，一些研究问题可能会触及伤感或不愉快的记忆。

收集到的数据会如何处理？
我会分析数据，并将它们用于研究的目的。
如何保持机密性?
软拷贝里的音频及笔录数据和数码照片将会安全的储存在研究员经加密、用户名及密码保护的工作电脑。而谈录音的音频文档将会在完成研究后从电脑中删除。您的名字会是匿名的，以保持机密性。

如果我不愿意参与，或者我改变主意，那会怎么样?
参加与否完全由您自己决定。如果您决定参加，您将会拿到并保留这份信息表，并被要求签署一份同意书。如果您决定参加，您还是可以随时退出，而无须说明理由，这也不会对您有任何损害。

Will I be paid for participating in the research?
You will not be paid monies for participating in this study.
我是否会因为参与这项研究而领到钱?
您不会因为参与这项研究而领到钱。

这项研究会持续多长的时间?
总共会进行最少三次的面谈，每一次历时一个半小时。

研究会在哪里进行?
如果您允许，研究将会在您的住家进行，也可以在您所选择的地点进行。

研究的成果是否会被公布?
研究的结果预计会在科研会议中被分享，以及刊登在同行评审期刊中。

犯罪记录检查（如适用）
研究员宣称，她过去没有犯罪纪录，也不曾因任何刑事罪行被定罪。
欲知更多详情，请联系：
May Yeok, Koo
电子邮件: WAN_Koo_May_Yeok@nyp.edu.sg
手机号: 96245574.

如果发生差错要怎样做？
如果您需要帮助或意见，请通过 WAN_Koo_May_Yeok@nyp.edu.sg 或 96245574 联系 May Yeok, Koo.

此外，您也可以联系：
通过 John.Keady@manchester.ac.uk 联系 John Keady 教授
通过 Helen.Pusey@manchester.ac.uk 联系 Helen Pusey 博士

如果您对研究的进行方式要提出正式的投诉，请联系：
Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, United Kingdom。
Hi,

You are being invited to take part in a research study. It is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with your parent / guardian. Please ask me if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part.

Thank you.

Who will conduct the research?

May Yeok, Koo
School of Nursing, Midwifery and Social Work,
University of Manchester, University Place,
Oxford Road, Manchester, M13 9PL, United Kingdom.

Title of the Research

Under One Roof; Intergenerational Care For People With Dementia In Singapore-Chinese Families - A Case Study Design

What is the aim of the research?

I am hoping to understand how the different members of the nuclear family participate in and contribute to the care of the person with dementia.

Why have I been chosen?

You are chosen because of your potential valuable input on how the care of a loved one with dementia is organized in your family.
What would I be asked to do if I took part?

I will be interviewing you. During those times, I will be writing down notes, audio recording our conversations and taking digital photographs. As this study does not involve any interventions, you will not experience pain or discomfort. However, some of the research questions may likely trigger sad or unhappy memories.

You will be asked to share digital photographs which are related to your everyday experiences and interactions if permissible. You are free to select and photograph items in the home environment which are deemed as important to you. I may also be taking digital photographs of items or the environment in and outside your house if permissible.

What happens to the data collected?

I will be analysing the data and using them for research purposes.

How is confidentiality maintained?

Audio and transcribed data, and digital photographs which are in soft copies will be stored and kept secure in the researcher’s encrypted, user ID and password protected work PC. Audio files of interview recordings will be deleted from the PC upon completion of study. Your name will be anonymized to maintain confidentiality.

What happens if I do not want to take part or if I change my mind?

You can decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself.

Will I be paid for participating in the research?

You will not be paid monies for participating in this study.

What is the duration of the research?

A total of at least 3 interviews lasting 1½ hour each.

Where will the research be conducted?

The research will be conducted in your home if permissible by you or at your preferred location outside your home. Any research meetings outside the home will be negotiated and agreed with you and conducted in a public place, such as a café or at the ADA offices.

What can I do if I feel distressed from the interview?

You can call the Alzheimer Caregiver Support (Counselling) at 6353 8734.
Will the outcomes of the research be published?

*It is anticipated that the research findings will be shared at research conferences and published in peer reviewed journals.*

Criminal Records Check (if applicable)

*The researcher declares that she has no prior criminal records nor has ever been convicted for any criminal offences.*

Contact for further information

May Yeok, Koo
Email: WAN_Koo_May_Yeok@nyp.edu.sg
Mobile number: 96245574

What if something goes wrong?

Please contact May Yeok, Koo via WAN_Koo_May_Yeok@nyp.edu.sg or 96245574 if you need help or advice.

Alternatively, you can contact:
Professor John Keady via John.Keady@manchester.ac.uk
Dr Helen Pusey via Helen.Pusey@manchester.ac.uk

If you wish to make a formal complaint about the conduct of the research **OR** If there are any issues regarding this research that you would prefer not to discuss with members of the research team, please contact the Research Governance and Integrity Team by either writing to 'The Research Governance and Integrity Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester M13 9PL', by emailing: Research.Complaints@manchester.ac.uk, or by telephoning 0161 275 7583 or 275 8093.
Under One Roof; Intergenerational Care For People With Dementia In Singapore-Chinese Families - A Case Study Design

CONSENT FORM

If you are happy to participate, please complete and sign the consent form below

<table>
<thead>
<tr>
<th>Please tick the boxes on the right to indicate that you have read and understood the statements.</th>
<th>Tick (✓) the boxes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I confirm that I have read the attached information sheet on the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.</td>
<td></td>
</tr>
<tr>
<td>2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason.</td>
<td></td>
</tr>
<tr>
<td>3. I understand that the interviews will be audio-recorded.</td>
<td></td>
</tr>
<tr>
<td>4. I understand that digital photographs may be taken if I am agreeable.</td>
<td></td>
</tr>
<tr>
<td>5. I agree to the use of anonymous quotes.</td>
<td></td>
</tr>
<tr>
<td>6. I agree to the Alzheimer’s Disease Association being informed of my participation in the study.</td>
<td></td>
</tr>
<tr>
<td>7. I agree that any data collected may be published and used for research purposes.</td>
<td></td>
</tr>
</tbody>
</table>

I agree to take part in the above study.

<table>
<thead>
<tr>
<th>Name of participant</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name of person taking consent</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

Participant’s Contact Information

Phone number:
E-mail address:
Address:
个案研究设计——同一屋檐下，在新加坡华人家庭中痴呆症患者的隔代护理

同意书

如果您愿意参与，请填写及签署以下的同意书

<table>
<thead>
<tr>
<th>请在右边的方框内打勾，以表明您已经阅读并理解所陈述的语句。</th>
<th>在方框内打勾 (√)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 我确认我已经阅读所附上关于以上研究的信息表，并有机会考虑此信息，所提出问题也获得满意的答复。</td>
<td></td>
</tr>
<tr>
<td>2. 我知道我参与此研究是自愿的，我也可以随时退出，而无须说明理由。</td>
<td></td>
</tr>
<tr>
<td>3. 我知道在面谈时，会进行录音。</td>
<td></td>
</tr>
<tr>
<td>4. 我同意采用匿名的方式引述。</td>
<td></td>
</tr>
<tr>
<td>5. 我同意告知Alzheimer’s Disease Association关于我参与了这项研究。</td>
<td></td>
</tr>
<tr>
<td>6. 我同意所收集到的任何数据可以为了研究的目的而进行公布及使用。</td>
<td></td>
</tr>
</tbody>
</table>

我同意参与以上的研究。

<table>
<thead>
<tr>
<th>参与者姓名</th>
<th>日期</th>
<th>签名</th>
</tr>
</thead>
<tbody>
<tr>
<td>接收同意者的姓名</td>
<td>日期</td>
<td>签名</td>
</tr>
</tbody>
</table>

参与者的联络资料

电话：
电邮地址：
地址：

School of Nursing,
Midwifery and Social Work,
University of Manchester,
University Place,
Oxford Road, Manchester, M13 9PL, United Kingdom.

APPENDIX 18
Under One Roof; Intergenerational Care For People With Dementia In Singapore-Chinese Families - A Case Study Design

PARENT / GUARDIAN CONSENT FORM

<table>
<thead>
<tr>
<th>Please tick the boxes on the right to indicate that you have read and understood the information.</th>
<th>Tick (✓) the boxes.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Purpose of the research:</strong> To understand the care for people with dementia at home by intergenerational Singapore-Chinese families.</td>
<td></td>
</tr>
<tr>
<td><strong>2. Procedure to be followed:</strong> I will be asking your child about his or her caregiving experiences. The conversation will be audio recorded. The audio recording is for the sole purpose of examining the care for a relative with dementia by members of the intergenerational family. Your child will be asked to share digital photographs which are related to his / her everyday experiences and interactions if permissible. He / she will be given the freedom to select and photograph items in the home environment which are deemed as important to him/ her. I may also be taking digital photographs of items or the environment in and outside your house if permissible.</td>
<td></td>
</tr>
<tr>
<td><strong>3. Discomforts / risks:</strong> There are no foreseeable discomforts or dangers to either you or your child in this study.</td>
<td></td>
</tr>
<tr>
<td><strong>4. Incentives / benefits for participation:</strong> There are no direct benefits to your child except that he or she will have the opportunity to share experiences on caring for a relative with dementia.</td>
<td></td>
</tr>
<tr>
<td><strong>5. Time duration of participation:</strong> Participation in the study will not exceed 1½ hour per interview. It is estimated that at least 3 interviews will be needed.</td>
<td></td>
</tr>
<tr>
<td><strong>6. Confidentiality:</strong> All records are kept confidential and will be available only to myself and my research supervisors. If the results of this study are published, the data will not reveal your child’s identity.</td>
<td></td>
</tr>
<tr>
<td><strong>7. Termination of participation:</strong> If at any point during the study you or your child wishes to terminate the session, you are free to do so.</td>
<td></td>
</tr>
</tbody>
</table>
This research has been reviewed and approved by the University of Manchester’s Ethics Committee. If at any time before, during or after the research, your child experiences emotional distress that is a result of his / her participation, or if you have any questions about the study or its outcomes, please feel free to contact:

Koo May Yeok
Tel: 6550-1467 (Office), 96245574 (Mobile)
E-mail address: WAN_Koo_May_Yeok@nyp.edu.sg

Please return this form by _____________________________.

If you do not sign or return this form, I will understand that you do not wish to allow your child to participate.

<table>
<thead>
<tr>
<th>Name of child:</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of parent / guardian giving consent:</td>
<td>Date</td>
<td>Signature</td>
</tr>
</tbody>
</table>
个案研究设计——同一屋檐下，在新加坡华人家庭中痴呆症患者的隔代护理

家长/监护人同意书

<table>
<thead>
<tr>
<th>请在右边的方框内打勾，以表明您已经阅读并理解此信息。</th>
<th>在方框内打勾（✓）</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. <strong>研究的目的</strong>：为了了解隔代新加坡华人家庭中对痴呆症患者的家居照顾。</td>
<td></td>
</tr>
</tbody>
</table>
| 9. **须遵循的程序**：我将会向您的孩子询问关于他或她的看护经验。这段交谈将会录音，录音的唯一目的是为了调查跨代家庭的成员对患有痴呆症亲人所提供的照顾。

如果您允许的话，您的孩子将会被要求分享和他/她日常经历及交流相关的数码照片。他/她能自由地选择及拍摄家居环境中任何他/她认为是重要的东西。如果您允许的话，我也可能会拍摄您屋里及屋外的东西或环境的数码照片。 |

| 10. **不适/风险**：这项研究对您或您的孩子没有可预见的不适或危险。 |
| 11. **参与的奖励/利益**：您的孩子除了会有机会分享他/她照顾患有痴呆症亲人的经历外，不会得到任何直接的利益。 |
| 12. **参与的时长**：每次参与此研究的面谈将不会超过一个半小时，预计需要进行最少三次面谈。 |
| 13. **保密性**：所有的纪录都会保密，只有我本人及我的研究导师能够获得。如果本研究的结果被公布，数据将不会披露您孩子的身份。 |
| 14. **终止参与**：如果您或您的孩子在研究进行中的任何阶段想要终止会谈，您都可以这么做。 |

School of Nursing, Midwifery and Social Work, University of Manchester, University Place, Oxford Road, Manchester, M13 9PL, United Kingdom.
这项研究已经由曼彻斯特大学伦理委员会进行审核及批准。如果在研究进行之前、之中或之后的任何时间，您的孩子因为他/她的参与而造成情绪上的困扰，或是如果您有任何关于研究或其结果的问题，请随时联系：

Koo May Yeok
电话：6550-1467（办公室），96245574（手机）
电邮地址：WAN_Koo_May_Yeok@nyp.edu.sg

请在______________________________之前把这份表格交回。

如果您没有签署或交回这份表格，我的理解是，您不愿意让您的孩子参与。

<table>
<thead>
<tr>
<th>孩子的姓名：</th>
<th>日期</th>
<th>签名</th>
</tr>
</thead>
</table>

| 给予同意的父母 / 监护人姓名： | 日期 | 签名 |
APPENDIX 21

Under One Roof; Intergenerational Care For People With Dementia In Singapore-Chinese Families - A Case Study Design

ASSENT CONSENT FORM

• Thank you for your time to meet with me. My name is Koo May Yeok and I would like to talk to you about your experiences in caring for a relative with dementia.

• The interview should take 1½ hour or less. I will be audio taping the session because I don’t want to miss any of your comments. Although I will be taking some notes during the session, I can’t possibly write fast enough to get it all down. Because we’re on tape, please be sure to speak up so that I don’t miss your comments.

• All responses will be kept confidential. This means that your interview responses will only be shared with my research supervisors. I will ensure that any information I include in my report does not identify you as the respondent.

• Remember, you don’t have to talk about anything you don’t want to and you may end the interview at any time.

• You will be asked to share digital photographs which are related to your everyday experiences and interactions if permissible. You are free to select and photograph items in the home environment which are deemed as important to you. I may also be taking digital photographs of items or the environment in and outside your house if permissible.

• Are there any questions about what I have just explained?

• Are you willing to participate in this interview?

Participant’s name and signature ____________________________ Date ________________

Name and signature of parent or legal guardian (if participant is under 21 years old) ____________________________
Participant’s Contact Information:

Phone number:

E-mail address:

Address:
APPENDIX 22

Under One Roof; Intergenerational Care For People With Dementia In Singapore-Chinese Families - A Case Study Design

PARTICIPANT REPLY FORM

Please complete if you are happy for the research investigator to contact you.

Name of Researcher: Koo May Yeok

1. I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without detriment to myself or my family member with dementia.

3. I understand that the above researcher from the University of Manchester who is working on the project will have access to my personal details.

4. I understand that any data or information used in any publications which arise from this study will be anonymous.

5. I understand that all data will be stored securely and is covered by the data protection act.

6. I agree that the researcher can contact me via the telephone number below to arrange an interview at a time and location to suit me.

<table>
<thead>
<tr>
<th>Name of participant</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

Participant’s Contact Information
Phone number:
E-mail address:
Address:
CASE STUDY PROTOCOL TEMPLATE

1. Background
   • Identify previous research on the topic
   • Define the main research question being addressed by this study
   • Identify any additional research questions that will be addressed

2. Design
   • Identify the multiple-case design which will be used, and show the logical links between this and the research questions
   • Describe the objective of the study
   • Identify any propositions or sub-questions derived from each research question and the measures to be used to investigate the propositions

3. Case Selection
   • Criteria for case selection

4. Case Study Procedures and Roles
   • Procedures governing field procedures
   • Roles of case study researcher (the author)

5. Data Collection
   • Identify the data to be collected
   • Define a data collection plan
   • Define how the data will be stored

6. Analysis
   • Identify the criteria for interpreting case study findings
   • Identify which data elements are used to address which research question/sub question/proposition and how the data elements will be combined to answer the question
   • Consider the range of possible outcomes and identify alternative explanations of the outcomes, and identify any information that is needed to distinguish between these
   • The analysis should take place as the case study task progresses

7. Plan Validity
   • Construct validity - show that the correct operational measures are planned for the concepts being studied. Tactics for ensuring this include using multiple sources of
evidence, establishing chains of evidence, expert reviews of draft protocols and reports

- External validity – identify the domain to which study finding can be generalized. Tactics include using multiple-case studies to investigate different contexts.

8. Study Limitations
- Specify residual validity issues including potential conflicts of interest (i.e. that are inherent in the problem, rather than arising from the plan).

9. Reporting
- Identify target audience, relationship to larger studies

10. Schedule
- Provide Gantt chart - Give time estimates for all of the major steps: Planning, Data Collection, Data Analysis, Reporting. Data Collection and Data Analysis are not expected to be sequential stages.

11. Appendices
- Cover letter
- Interview guide
- 23-item questionnaire
- Participant Information Sheet
- Consent form