Exploration of the needs of carers
from hospital based-mental health services in Indonesia

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ABSTRACT

THE UNIVERSITY OF MANCHESTER

ABSTRACT OF THESIS submitted by Herni Susanti for the degree of Doctor of Philosophy and entitled:

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One of the major issues of mental health provision in Indonesia is related to services for carers of people with serious mental illnesses. Very basic and limited services have been offered to the carers. Understanding the needs of Indonesian carers is of key importance before developing appropriate interventions for them.

The aim of this study was to explore the needs of carers from mental health hospital services in Indonesia from the perspectives of carers, service users and professionals. It consisted of three separate, but interrelated studies: (1) a review of international literature about carer needs from mental health services and Indonesian policies relating to carers contribution in the services, (2) focus groups with carers and service users, and (3) individual interviews with professionals.

In the first stage, 40 studies eliciting the needs of carers from mental health services were reviewed systematically. The results could not provide adequate information of carer needs which were suitable to an Indonesian context. Therefore, reviewing additional literature of 15 policy documents relating to the contribution of carers in mental health services in Indonesia was conducted. The policy review showed that the need of involving carers in the services was acknowledged, but there has not been clear and strong political endorsement ensuring the carers to receive adequate supports based on their own needs and for their own wellbeing.

In the second stage, focus groups with carers and service users were undertaken to explore the needs of Indonesian carers and how mental health hospital services could help to meet those needs. In total, 9 focus groups were conducted, seven with carers (n=33) and two with service users (n=13). All carer and service user participants were recruited from two government mental health hospitals in the capital city of Indonesia. The data were analysed by using framework analysis (Ritchie and Spencer 1994), and resulted in four themes: experiences in caregiving, carer needs from mental health hospital services, current support for carers, and recommendations for service improvement.

In the third stage, individual qualitative interviews with health professionals were conducted to explore their views of what Indonesian carers need from the mental hospital services, the extent to which the current services have met the needs, and ideas for service improvements. The interviews involved 24 practitioners from a wide range of health professions, recruited from the hospitals where the earlier focus groups were completed. Framework data analysis (Ritchie and Spencer 1994) was adopted and produced five major themes: Professional views of why services should involve carers, professional views of what carers need for ill relatives, professional views of what carers need for own wellbeing, focus of current contact, and perspectives of support provision.

The synthesis of the findings sourced from the focus groups and interviews was completed by adopting a thematic approach (Harden and Thomas 2008). This resulted in overall identifications of the needs of carers for own wellbeing as well as for ill persons, current support provision the carers and recommendations for service improvement within an Indonesian context. The synthesis could also identify similarities and differences between the groups of carer, service user and professional participants in viewing the needs of carers. The findings were valuable resources to aid in the design of a need-based and culturally sensitive intervention for carers in the country.
DECLARATION

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other institute of learning.

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DEDICATION

To my parents,
You are my inspiration
About working hard…
About the meaning of knowledge…
As you often quote from the Qur’an:

Allah will raise those who have believed among you and those who were given knowledge, by degrees. And Allah is acquainted with what you do (Al-Quran, Al-Mujadilah verses 6)

I love you Mom, Dad....
BACKGROUND OF THE AUTHOR

The author is a practicing nurse and educator in mental health nursing. She obtained a Bachelor degree in Nursing from the Faculty of Nursing, Universitas Indonesia in 1998. She also obtained a Master degree in Nursing from the Curtin University of Technology, Australia in 2005.

After completing her first degree, the author started working as an educator of mental health nursing in the Faculty of Nursing, University of Indonesia. The author had some experiences of conducting research in the university, and was involved in mental health nursing field until gaining admission into the University of Manchester to undertake the PhD degree.
CHAPTER ONE

INTRODUCTION

1.1. Introduction

This chapter offers an introduction into the purpose, background and structure of the study that formed an integral part of the PhD. The initial part of the chapter outlines the aim and objectives of the study. The following part describes the study background, which includes an account of the needs of carers in Indonesia, and current mental health services in the country.

1.2. Aim and objectives of the study

The aim of the study is to explore the views of carers, service users and professionals regarding the needs of carers of people with serious mental illnesses from hospital-based services in Indonesia.

The objectives:

1) To review and synthesise international literature about carer needs.
2) To review and synthesise Indonesian policy in supporting carers of people with mental illnesses.
3) To explore the views of carers, service users, and professionals of what is needed by carers of people with serious mental illnesses from mental health hospitals in Indonesia.
4) To explore the extent to which the existing services meet the carers’ needs from the views of the research participants.
5) To explore the views of potential services for meeting the carers’ needs.
1.3. **Background**

Carers have been defined as people who deliver unpaid care to a family member or a friend who need support due to limitations of age, physical or learning disability or illness (Carers UK 2014). Carers of people with serious mental illnesses have a pivotal role in supporting their loved ones (Askey et al. 2009). A serious mental illness refers to a long-term mental disorder including schizophrenia, schizoaffective disorders, bipolar disorders, or major depressive disorder (Levine and Ligenza 2002, Steadman et al. 2009). Since the policy of deinstitutionalisation occurring simultaneously throughout the Western civilization five decades ago, mental health services have largely been assisted by the contribution of carers (van de Bovenkamp and Trappenburg 2010). Services traditionally administered from formal institutions were transferred into the community. The central aim of deinstitutionalisation was treating people with mental illnesses more therapeutically and reducing governmental economic burdens resulting from hospital-based treatments (Bachrach 1983), though a significant proportion of this burden was transferred to families.

1.3.1. **The impact of caregiving on carers**

In conjunction with the advent of deinstitutionalization, about 25%–50% of persons with mental illnesses in western countries, especially those with schizophrenia, stay with their family (Chan 2011). In the UK, it is estimated that up to 1.5 million people are caring for a relative with a mental health problem (Carers UK 2014). These carers often face additional expenses associated with caregiving, like extra care services alongside higher living costs and transport costs. Almost 30% carers, including those who care for mentally ill persons, experienced a drop of £20,000 or more a year in their household income as a result of caring (Carers UK, 2014).

There is a substantial body of international literature examining other impacts on carers, although some studies report positive aspects of caring for a relative with a mental illness such as providing pleasure to the person, maximising the potential of the person, experiencing enhanced relationship and sharing mutual love and support (Nolan et al. 1996, Lundh 1999, Rose et al. 2006). However, carers have the potential to experience significant distress associated with their caregiving roles (Kuipers 2010).
Sources of tension include dealing with symptoms of mental disorder particularly negative symptoms such as a lack of motivation, emotional numbness and social isolation (Provencer and Mueser 1997, Barrowclough et al. 2003). Other sources of carer burden are their experiences in handling crises that may involve the police and coping with diagnosis uncertainty in the first episode (Glendy and Mackenzie 1998, van de Bovenkamp and Trappenburg 2010).

Carers of people with serious mental illnesses need help to cope with the above burden and related personal stress. When professional support is provided to carers, it is often delivered through family intervention (Lobban et al. 2013). The original rationale for the family intervention was based on evidence in the US and the UK in that, as a result of deinstitutionalisation policy in the countries, people with schizophrenia living with families that displayed high levels of expressed emotion (EE) tended to have higher relapse rates than those living in low EE families (Bebbington & Kuipers, 1994, Falloon 2003). Here, EE was designated to the emotional ambience within a family (Leff & Vaughn, 1985). Using the instrument of Camberwell Family Interview, a family was rated as high EE if they reached a cut-off score on scales of criticism, hostility, emotional over-involvement, or a combination of the three (Leff & Vaughn, 1985). If the cut-off was not reached, the family was rated as low EE. Finally, the above discovery in the US and UK in the 1970s prompted the development of EE-based family interventions that were aimed to reduce the level of stress within the family environment and relapse in service users (Pharoah et al. 2010).

After this period a variety of EE-based family interventions for carers of people with mental health problems, described as family intervention and family work in the literature, were developed and tested empirically (Barrowclough 2003). A review of 53 Randomised Controlled Trials (RCTs) confirmed the efficacy of interventions for families in reducing frequency of relapses, encouraging compliance with medication and improving social functioning among the service users. However, these family interventions have a number of limitations. First, carer outcomes in the trial studies have been largely neglected. Less than 10% of studies have demonstrated positive decreases in caregiver burden and/or improvement of carer coping (Pharoah et al. 2010). Although a recent review of four RCTs suggests that brief family intervention might increase the understanding of carers about mental illness, the small
number of studies and the small sample size (n=105) decreases the power of the report (Okpokoro et al. 2014).

Also, there is difficulty in extrapolating the above findings to Asian countries due to the different cultural background from the Western countries where these studies originated (Chakrabarti et al. 2011). For example, the concept of family interventions derived from Western ideology (rooted in the notion of EE as described earlier) may not be appropriate amongst Asian families. Studies in parts of Indonesia and Malaysia showed that the families had a high level of over-involvement towards the mentally ill member (Azhar and Varma 1996, Kurihara et al. 2000). It was suggested that the findings were influenced by the countries culture which put involvement as the norm, being derived from a strong family bond. Communal value from families in the Asian countries was stronger than the individual value as opposed to many western countries (Kurihara et al. 2000). While the findings of the studies (Azra and Varma 1996, Kurihara et al. 2000) cannot be generalised because of limited sample sizes, cultural adjustment of the interventions needs to be concerned with the application in other contexts (Bughra and McKenzie 2003).

Other issues are related to the implementation of the structured family interventions for carers in developing countries because they are time consuming, costly and usually require highly trained personnel (Chakrabarti et al. 2011); although to some extent these attributes are also pertinent in more developed countries such as the UK (Ince 2014, Okpokoro 2014). In a review of 22 studies investigating the implementation of family intervention based on the guidance of the National Institute for Health and Carer Excellence (NICE 2009), it was found that the average implementation rates for 53% and this varied across services in the UK. The most frequent barriers reported in the studies were a lack of professionals who were capable of delivering the family intervention, and limited funding for training and staff recruitment (Ince 2014). It is argued that such barriers might continue, given the most up-to-date NICE guidance (NICE 2014) demands the professionals to have a high level of competence for conducting at least ten planned sessions over three months or a year. However, despite the high levels of competence, professionals may find that it is difficult to implement the skills they have acquired due to time and caseload pressures (Ince 2014). The reported barriers are systemic wide difficulties which are found at all levels of mental health services in the UK (Ince 2014); and these might be more apparent
in less developed countries like Indonesia where issues of limited human resources, scarce qualified mental health services, and difficult access to the services are dominant (Shinfuku 1998, Irmansyah 2010).

1.3.2. Mental health services in Indonesia

The Republic of Indonesia is a country in the Southeast of Asia with a total population of 237,641,236 people (Statistics Indonesia 2010) (Figure 1). It is estimated that 0.46% of the population experience a serious mental illness (Basic Health Survey 2007). From 33 provinces in the country, Jakarta as the capital province is facing a serious problem of managing mental illness, as the prevalence of severely mentally ill people in the city i.e. 2.03% is higher than the national rate. It can be assumed that currently there are over one million people living with a serious mental illness in Indonesia, and 221,000 of them are living in Jakarta.

![Figure 1. Indonesia map](http://www.seasite.niu.edu) retrieved in September 2015.

People with a serious mental illness in Indonesia are mostly treated in mental hospitals, especially when they are acutely unwell (Directorate of Mental Health Service 2005b). This service follows a referral to
a general hospital or a Public Health Center (known as Puskesmas, a governmental primary health care centre in the sub-district level). Following hospital-based treatment, service users are discharged back to the families. It is important to note that families in Indonesia play an important role in making decisions about the treatment for their mentally ill relatives (Minas and Diatri 2008). For example, it is not uncommon that families determine whether the relatives should receive treatment from traditional/spiritual healers or mental health professionals.

Despite the rising rate of mental health problems in Indonesia, mental health service provision is generally poor (Directorate of Mental Health Service 2011d). This is due to a number of reasons that include a limited budget for the services and insufficient information and education about mental health amongst lay people that has an impact on stigma and discrimination. Other challenges have been identified including insufficient mental health professionals and medication, lack of carer and community empowerment, and limitations in rehabilitation programs/interventions in the community (Directorate of Mental Health Service 2011d).

The complexity of the mental health system in Indonesia is highly influenced by difficulties in accessing mental health services (Directorate of Mental Health Service 2011d). As an archipelago country comprising of 17,000 islands, Indonesia has problems in distributing mental health services to remote areas. Even in areas of a high population density, the access problems are obvious due to very limited services. For example, there are only 48 mental hospitals with a capacity of 7,700 beds, while the World Health Organisation recommends 80,000 beds for over 1 million of mentally ill people (Directorate of Mental Health Service 2011d).

1.3.3. Services for carers of people with mental health problems in Indonesia

One of the major issues of mental health provision in Indonesia is related to the needs of carers of people with serious mental illnesses (Directorate of Mental Health Service 2011d). This is the focus of this PhD. Although ad hoc services for carers are available, they remain in their infancy. It is unclear what services and information are available for carers at a national level either from hospitals, governmental policy or non-governmental agencies (Non-Governmental Organizations/NGOs).
importantly there is a paucity of research related to services for Indonesian carers. With regard to the services, professionals in mental health hospitals have offered information to individual or groups of carers related to mental illness through periodical programs, but there is no consistency of the nature or content of such information or indeed information about whether carers find such information helpful. There is no literature to suggest that emotional and practical support are routinely provided to carers. A small minority of psycho-education programmes are provided by a few nurses who are undertaking higher studies but no widespread or consistent evaluation programme has been completed.

1.3.4. The needs of carers in Indonesia

Identifying the needs of carers from services is important because it can be used as a basis to develop an intervention for carers that may maximise their potential success (Mairs and Bradshaw 2005). This is essential to avoid repeating limitations such as failure to involve carers from the established interventions for carers. The existing services commonly have been designed and delivered without involving carers. Hence, they are provided by professionals on the basis of pragmatic reasons e.g. reducing relapse became the main goal of these early interventions (Pharoah 2010).

It is important to note that the vast majority of studies about carer needs have been conducted in countries where mental health services are well established (Cleary et al. 2005, Drapalski et al. 2008, Wilkinson and McAndrew 2008, Askey et al. 2009, van de Bovenkamp and Trappenburg 2010). These studies revealed that the carers required information about the mental health condition, sufficient time with health professionals to discuss their concerns and that they want to be more involved in their relatives care and treatment.

This emphasises the difficulties in translating such finding into settings where health service provision is much less developed as in Indonesia. Understanding the needs of Indonesian carers is of key importance before devising appropriate interventions for them. In the UK, the Medical Research Council (MRC) (2008) emphasises that any development of intervention in the health and social care is to be based on scientific identification from the perspectives of stakeholders (i.e. those involved in the development or delivery)
As described previously, very basic and limited services in Indonesia have been offered to carers. It is therefore important to identify what is available, what carers require from mental health services and from this, if necessary, develop culturally adaptable interventions for carers.

1.3.5. The study in relation to the MRC framework

The MRC framework (2008) is designed to provide a structure to develop and evaluate an intervention which is iterative, flexible for different social and geographical contexts and contains sufficient guidance to develop the intervention (Craig et al. 2008). It consists of four phases namely development, feasibility/piloting, evaluation and implementation (see the following Figure 2 below). According to the MRC, the development of optimal interventions should be systematic and informed by using the best available evidence and appropriate theory. The interventions should be tested by using a careful approach such as conducting a series of pilot studies. Evaluating the interventions should be undertaken to assess the effectiveness through experimental or observational designs. Lastly, dissemination should be undertaken widely and persuasively, supported by further research to assist and monitor the implementation of the interventions (MRC 2008).
The PhD is located in the development phase of MRC (2008). The findings of the study serve as relevant evidence of what is available and what Indonesian carers require from mental health hospital services. The findings are valuable for developing a need-based and culturally adaptable support for carers in Indonesia.

1.4. Structure of the study

This PhD comprises of three separate, but, interrelated studies: (1) a review of international literature about carer needs from mental health services and Indonesian policies relating to carers contribution in the services, (2) focus groups with carers and service users, and (3) individual interviews with professionals. Figure 3 illustrates how the stages are interconnected.
1.5. Structure of the thesis

The thesis consists of seven chapters. Following the introductory chapter, a report of the reviews of literature and policy will be provided in Chapter Two. Chapter Three overviews a number of established family interventions for carers of people with serious mental illnesses. Chapter Four and Five detail the method and findings of the qualitative investigations conducted in the PhD. Chapter Six describes the synthesis of the study findings. Finally, the discussion of the findings as well as their implications for policy, research and practice is presented in the last chapter.

1.6. Summary

Exploration of what carers need from services is essential to understand how they can be helped to carry out their caregiving role. To date the majority of studies examining carer needs have been
conducted in countries where mental health services are well established (Cleary et al. 2005, Drapalski et al. 2008, Wilkinson and McAndrew 2008, Askey et al. 2009, van de Bovenkamp and Trappenburg 2010). Translating such finding into settings where services are much less developed as in Indonesia can be problematic. It is imperative therefore to explore what Indonesian carers need from mental health services from the perspectives of carers, service users, and health professionals. Understanding the needs of Indonesian carers is of key importance in devising appropriate interventions to support them in their caring role. The MRC (2008) guidance highlights how any development of intervention in health and social care settings should be based on scientific identification from the perspectives of a range of key stakeholders, including potential recipients and those who will ultimately go onto facilitate such interventions.
CHAPTER TWO
LITERATURE REVIEW

This chapter outlines the background to the study which will explore the needs of carers of people with serious mental illnesses in Indonesia. Two reviews were conducted simultaneously to provide a comprehensive contextual explanation and rationale for the study. The first part of the chapter focusses on a review of international studies eliciting the needs of the carers from mental health services. The second part is a review of the Indonesian guidance policy relating to the contribution of carers within services. Both reviews were important as there is an absence of literature relating specifically to those who care for people with mental illnesses in Indonesia. Thus, reviewing relevant literature about carers’ needs sourced from other contexts and locating guidance pertaining to the support that should be available to carers in Indonesia (that is, the policy documents), was deemed a necessary starting point for the later empirical work.
2.1. A review of literature related to carer needs from mental health services

2.1.1. Introduction

Carers play a significant role in the treatment and support of relatives living with an illness, including those who are suffering from a mental health problem. Carers do not only provide practical help and personal care but also give emotional support to mentally ill individuals (Shah 2010). It has been argued that if carers were unavailable, the cost to the social health care budget would exceed £1.24 billion a year (The Schizophrenia Commission, 2012).

It has been recognised that carers have specific needs as a result of their caring roles including maintaining their own physical and mental health as well as financial and practical assistance for supporting the caregiving duties (Goodwin and Happel 2006, Kuipers 2010, Lobban et al. 2013). For this reason, both the UK and Australian governments have gradually acknowledged that carers have a right to an assessment and appropriate support to carry out their caregiving role (the Australian Health Minister 2009, Care Act 2014). There is also a recognition that more research is required to evaluate the benefits of support provision for carers and to explore whether needs of carers are being met by health and social care services (Gasque-carter and Curlee 1999, Nordy et al. 2010).

The current study focused on exploration of carers’ needs in Indonesia. Examination of the previous studies relating to carer needs was essential because it was enabling to position the present study towards other relevant research in the same field.

2.1.2. Aim and objective

2.1.2.1. Aim of the review

The review aims to address the following question:
What does the literature suggest about the needs of carers from mental health services for their own wellbeing?

2.1.2.2. Objective of the review

The objective was to search, identify, synthesise and appraise the relevant studies about carer needs.

2.1.3. Methodology

The literature review adopted a systematic approach. Such an approach offers a more rigorous method for synthesis than the traditional review (Green 2005). Systematic reviewers undertake activities to locate and synthesise research related to a particular question comprehensively, using organised, transparent, and replicable procedures at each step in the process (Green 2005, Ryan et al. 2007).

With regard to the data synthesis, the researcher employed a thematic analysis to integrate the quantitative and qualitative evidence relating to carer needs through the identification of prominent or recurrent themes in the literature, and summarising the findings under thematic headings (Dixon-Wood et al. 2005). A detailed description of the synthesis will be presented in section 2.1.8.

2.1.4. Inclusion and exclusion criteria

One of the principles employed in this review was limiting bias sourced from the process of selecting the published research (Petticrew 2001, Aveyard 2010). This involved the use of explicit but rigorous criteria to select the articles. The criteria enabled the researcher to ensure that only papers that were relevant to the research questions were included (Green 2005). The development of the criteria was also beneficial to increase the transparency of the review so it could be replicated and updated. Specific inclusion and exclusion criteria were determined prior to the commencement of the review.
2.1.4.1. Inclusion criteria:

- Studies which examined carers' needs or expectations of mental health services.
- Studies in which the recipient of care (service users) was stated to have or to be experiencing a serious mental illness (i.e. long-term illness such as schizophrenia, schizoaffective disorders, bipolar disorders, and chronic or persistent depression) (Levine and Ligenza 2002, Steadman et al. 2009).
- Studies in which the recipients of care (service users) were adults (over 18 years of age).
- Studies which employed qualitative, quantitative or mixed methods aimed at gathering data about carers needs.
- Studies published in English and Indonesian languages
- Studies published in the last two decades, from January 1993 to December 2013. This period was chosen in order to capture all relevant work published since a number of countries introduced policy that recognised the formal caring role, for example, Australian Health Ministers (2003), Department of Health of England (2009), and the US Caregiver Library (2013).

2.1.4.2. Exclusion criteria

- Studies that recruited paid carers as the participants

2.1.5. Search strategy

A number of search terms were used including carers, mental health, and needs. Synonyms were identified such as need OR expectation; carers OR caregivers OR family. Truncation was also employed to detect a wide range of term endings such as need* to locate need and needs; and carer* for carer and carers. The search was conducted through the MEDLINE, PSycINFO, EMBASE, and CINAHL. In summary, the search was performed using the following as key words.
(Carer* OR caregiver* OR family* OR family member OR relative* OR offspring OR kin OR close friend)

AND

(Mental health OR mental health service OR mental health hospital OR mental hospital OR psychiatric hospital OR mental health institution OR psychiatric ward OR support service)

AND

(Need* OR aspiration OR hope OR perspective OR view OR perception OR need assessment OR carer assessment OR healthcare need OR healthcare need assessment)

2.1.6. Data management

The search was conducted in April 2012 and updated in December 2015. A total of 8150 publications were identified from the search and a title search excluded 7644 papers. Abstracts of the 506 remaining papers were then retrieved. A further inspection of the abstracts excluded 381 papers. Full texts of the remaining 125 articles eliminated a further 80 studies. The 45 remaining papers were discussed with the researcher’s supervisory team. In total 40 published papers were included in this review and were subsequently assessed for quality. A summary of the process as well as the reasons for exclusion are detailed in Figure 4.
Figure 4. Process and outcome of the literature searching

Excluded paper from the review studies about carer needs

<table>
<thead>
<tr>
<th>Reasons for exclusion</th>
<th>Number of studies Excluded</th>
<th>Number of studies retained (from 125 studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involving older service users</td>
<td>2</td>
<td>123</td>
</tr>
<tr>
<td>Involving children service users</td>
<td>7</td>
<td>116</td>
</tr>
<tr>
<td>Not using carer participants</td>
<td>3</td>
<td>113</td>
</tr>
<tr>
<td>Using non-mental illness cases</td>
<td>5</td>
<td>108</td>
</tr>
<tr>
<td>Not yielding carers needs</td>
<td>65</td>
<td>43</td>
</tr>
<tr>
<td>Report paper</td>
<td>3</td>
<td>40</td>
</tr>
<tr>
<td>Total excluded</td>
<td>80</td>
<td>Total: retained</td>
</tr>
</tbody>
</table>

Paper identified (n= 8150)
Excluded at title review (n=7644)
Abstract reviewed (n=506)
Full text reviewed (n=125)
Studies about carer needs from mental health services reviewed (n=45)
Studies about carer needs from mental health services included (n=40)
2.1.7. Data extraction

Detailed information was extracted on the characteristics of participants, study settings, recruitment approaches and data analysis methods. A table was developed to assist the process of the data extraction (illustrated in Table 1 below this passage). The extraction procedure also involved summarising all data in the included studies which were relevant to the review question (i.e. major findings relating to what carers need from services), and assembled them onto a matrix as illustrated in the next Table 2 on page 38. The procedure continued to identify whether the research yielded data of carer needs for their own wellbeing. This identification is important, as the existing mental health services often disregard the carers’ own interests and involved carers only on behalf of their relatives’ wellbeing (Kuipers 2010). Discussions with the supervisory team were conducted throughout the data extraction process until a consensus regarding the information retrieved was confirmed. The summaries resulted from this extraction were helpful for synthesising the reviewed studies as described after this sub-section.
Table 1. Summary of the reviewed studies about carer needs from mental health services

<table>
<thead>
<tr>
<th>No</th>
<th>Authors</th>
<th>Country of Origin</th>
<th>Number of carer participants and relationship with service user</th>
<th>Setting</th>
<th>Recruitment of carer Participants</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Glendy and Mackenzie (1998)</td>
<td>China</td>
<td>8 carers (3 parents, 3 spouses, 2 siblings)</td>
<td>All aspects of mental health services</td>
<td>Not stated</td>
<td>Content analysis</td>
</tr>
<tr>
<td>2</td>
<td>Johnson (2000)</td>
<td>USA</td>
<td>180 carers (70% parents 13% siblings, 6% spouses, 8% adult children)</td>
<td>All aspects of mental health services</td>
<td>Contacts with potential participants already involved in a project for carers</td>
<td>Not stated</td>
</tr>
<tr>
<td>3</td>
<td>Smith et al. (2001)</td>
<td>USA</td>
<td>45 carers (23 spouses, 16 adult children)</td>
<td>Mental health hospital services</td>
<td>Not stated</td>
<td>Not stated</td>
</tr>
<tr>
<td>4</td>
<td>Domboos (2002)</td>
<td>USA</td>
<td>76 carers (no information of the relationship with service user)</td>
<td>A wide range of mental health services</td>
<td>Postal invitation from researcher and gatekeepers (managers of support groups of carers)</td>
<td>Content analysis</td>
</tr>
<tr>
<td>5</td>
<td>Bowes and Wilkinson (2003)</td>
<td>UK</td>
<td>4 carers (no description of their relationships with service user)</td>
<td>Community mental health services</td>
<td>Used gatekeepers (professionals and leaders of community groups of carers)</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>6</td>
<td>Bollini et al. (2004)</td>
<td>Italy</td>
<td>13 carers (no description for their relationships with service user)</td>
<td>Community mental health services</td>
<td>Used gatekeepers (psychiatrists of the service users)</td>
<td>Not stated</td>
</tr>
<tr>
<td>7</td>
<td>Rose et al. (2004)</td>
<td>USA</td>
<td>31 carers (14 parents, 5 siblings, 4 children, 6 spouses, 2 others)</td>
<td>A wide range services</td>
<td>Used gatekeepers (professionals, leaders of community groups for carers and church services)</td>
<td>Content analysis in combination with thematic analysis</td>
</tr>
<tr>
<td>8</td>
<td>Lakeman (2008)</td>
<td>Australia</td>
<td>86 carers (parents 59%, spouse 17%, siblings 9%, adult children 5%, and grandparent 1%, others 8%)</td>
<td>All aspects of mental health services</td>
<td>Dissemination of the study in carer meetings, postal and phone invitations</td>
<td>Content analysis</td>
</tr>
<tr>
<td>9</td>
<td>Askey et al. (2009)</td>
<td>UK</td>
<td>22 Carers (No description for their relationships with service user)</td>
<td>All aspects of mental health services</td>
<td>Dissemination of the study in the local mental health services and carer support groups</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>10</td>
<td>Lyons et al. (2009)</td>
<td>UK</td>
<td>57 carers of people with mental illnesses (No description for their relationships with service user)</td>
<td>Mental health crisis services</td>
<td>Postal invitation</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>11</td>
<td>Mavundla et al. (2009)</td>
<td>South Africa</td>
<td>8 carers (5 mothers, one sister, one father, one wife).</td>
<td>Community mental health services</td>
<td>Contacts with potential participants in outpatients</td>
<td>Unspecified qualitative analysis</td>
</tr>
<tr>
<td>12</td>
<td>McAuliffe et al. (2009)</td>
<td>Australia</td>
<td>31 carers (25 parents, 3 partners, 3 siblings)</td>
<td>All aspects of mental health services</td>
<td>Poster display, and used gatekeepers (staff of mental health services and carer support groups)</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>No</td>
<td>Authors</td>
<td>Country of origin</td>
<td>Number of carer participants and relationship with service user</td>
<td>Setting</td>
<td>Recruitment of carer Participants</td>
<td>Data analysis</td>
</tr>
<tr>
<td>----</td>
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</tr>
<tr>
<td>13</td>
<td>van der Voort et al.</td>
<td>Netherlands</td>
<td>15 carers (all spouses)</td>
<td>Community mental health services</td>
<td>Pamphlet display and contacts with potential participants in organisation of carers</td>
<td>Coding techniques by Strauss and Corbin</td>
</tr>
<tr>
<td>14</td>
<td>Nordby et al.</td>
<td>Norway</td>
<td>18 carers (15 parents, 3 siblings)</td>
<td>Mental health hospitals services</td>
<td>Used gatekeepers (hospital staff) to contact service users to obtain consent from their carers</td>
<td>Content analysis</td>
</tr>
<tr>
<td>15</td>
<td>Thomas et al.</td>
<td>UK</td>
<td>7 carers (No description for their relationships with service user)</td>
<td>7 Community health services and 1 prison</td>
<td>Used gatekeepers (staff of mental health services and organisations of carers)</td>
<td>Not stated</td>
</tr>
<tr>
<td>16</td>
<td>Van de Bovenkamp and Trappenburg (2010)</td>
<td>Netherlands</td>
<td>18 carers (No description for their relationships with service user)</td>
<td>All aspects of mental health services</td>
<td>Contacts with potential participants involved in organisations of carers</td>
<td>Content analysis</td>
</tr>
<tr>
<td>17</td>
<td>Copeland and Helleman</td>
<td>USA</td>
<td>8 mother carers of adult children with mental illnesses</td>
<td>A wide range of mental health services</td>
<td>Dissemination of the study in community groups of carers, and used gatekeepers (nurses and social workers) for recruiting potential participants in the hospitals</td>
<td>Coding techniques by Strauss and Corbin</td>
</tr>
<tr>
<td>18</td>
<td>Jonsson et al.</td>
<td>Sweden</td>
<td>17 carers (7 mothers, 3 fathers, 1 child)</td>
<td>Mental health hospitals</td>
<td>Postal invitation, followed with phone contacts for further explanation</td>
<td>Content analysis</td>
</tr>
<tr>
<td>19</td>
<td>Weimand et al.</td>
<td>Norway</td>
<td>216 carers (156 parents, 18 partners, 27 siblings, 10 adult children, 5 others)</td>
<td>All aspects of mental health services</td>
<td>Postal invitation</td>
<td>Content analysis</td>
</tr>
<tr>
<td>20</td>
<td>Hacketal et al.</td>
<td>USA</td>
<td>7 carers (No description for their relationships with service user)</td>
<td>A community mental health centre</td>
<td>Not stated</td>
<td>Content analysis</td>
</tr>
<tr>
<td>21</td>
<td>McHugh et al.</td>
<td>Germany</td>
<td>14 carers (all spouses)</td>
<td>Mental health hospitals</td>
<td>Not stated</td>
<td>Grounded theory analysis</td>
</tr>
<tr>
<td>No</td>
<td>Authors</td>
<td>Country of origin</td>
<td>Number of carer participants and relationship with service user</td>
<td>Setting</td>
<td>Recruitment of carer participants</td>
<td>Data analysis</td>
</tr>
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<td>-----------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td>22</td>
<td>McNeil (2013)</td>
<td>Canada</td>
<td>4 carers (No description for their relationships with service user)</td>
<td>A mental health hospital</td>
<td>Not stated</td>
<td>Line by line coding, arranged into themes</td>
</tr>
<tr>
<td>23</td>
<td>Mizuno et al. (2013)</td>
<td>Japan</td>
<td>11 female carers (8 parents, 3 siblings)</td>
<td>Community mental health services</td>
<td>Dissemination of the study in support groups of carers</td>
<td>Content analysis</td>
</tr>
<tr>
<td>24</td>
<td>White et al. (2013)</td>
<td>USA</td>
<td>17 carers (all parents)</td>
<td>Assertive community treatment service (ACT)</td>
<td>Used gatekeepers (team leaders of ACT teams)</td>
<td>Content analysis</td>
</tr>
<tr>
<td>25</td>
<td>Wood et al. (2013)</td>
<td>UK</td>
<td>9 carers (No description for their relationships with service user)</td>
<td>Mental health hospitals</td>
<td>Used gatekeepers (staff of services/organisations for carers)</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>26</td>
<td>Ascher-Svanum et al (1997)</td>
<td>USA</td>
<td>197 carers, (40% mother=80, 15% sister=30, 15% father=30, 9% brother=20)</td>
<td>A wide range mental health services</td>
<td>Postal invitation</td>
<td>118 item survey questionnaire, the name of questionnaire was not specified</td>
</tr>
<tr>
<td>27</td>
<td>Gasque-Carter and Curlee (1999)</td>
<td>USA</td>
<td>80 carers (28 parents, 26 siblings, 9 daughters/sons, 3 spouses, 5 kins and 9 others)</td>
<td>A mental hospital services</td>
<td>Not stated</td>
<td>Cross sectional questionnaire using 52 items and 2 open ended questions (developed by the researchers), questioned via telephone</td>
</tr>
<tr>
<td>No</td>
<td>Authors</td>
<td>Country of Origin</td>
<td>Number of carer participants and relationship with service user</td>
<td>Setting</td>
<td>Recruitment of carer participants</td>
<td>Data analysis</td>
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<td>---------------</td>
</tr>
<tr>
<td>28</td>
<td>Chien and Norman (2003)</td>
<td>China</td>
<td>240 carers (no description their relationships with the service user)</td>
<td>All aspects in mental health services</td>
<td>Phone and face-to-face invitation</td>
<td>Cross sectional questionnaire using 45 items of Chinese Modified Educational Needs Questionnaire (CENQ)</td>
</tr>
<tr>
<td>29</td>
<td>Sung et al. (2004)</td>
<td>Taiwan</td>
<td>100 carers (39% parents, 36% spouses)</td>
<td>All aspects in mental health services</td>
<td>Used gatekeepers (nurses and physicians)</td>
<td>Cross sectional questionnaire using 45 items of Educational Needs Questionnaire (ENQ)</td>
</tr>
<tr>
<td>30</td>
<td>Cleary et al. (2005)</td>
<td>Australia</td>
<td>50 carers (50% parents, 32% spouses, 16% girlfriend/boyfriend/others)</td>
<td>All aspects of mental health services</td>
<td>Carers were recruited based on consent from the service users</td>
<td>Face-to-face interview using 3 open ended questions</td>
</tr>
<tr>
<td>31</td>
<td>Gregory et al. (2006)</td>
<td>UK</td>
<td>36 carers (22 parents, 2 partners, 2 siblings, 2 friends)</td>
<td>Assertive community Services</td>
<td>Hospital professionals distributed questionnaires as a part of an assessment program for carers</td>
<td>A standardized Carer assessment by Gloucestershire Partnership NHS Trust (2003)</td>
</tr>
<tr>
<td>32</td>
<td>Tung and Beck (2007)</td>
<td>Taiwan</td>
<td>75 carers (42 parents, 13 spouses 7 children, and 13 others)</td>
<td>Mental hospitals</td>
<td>Initiated with phone contacts, then face-to-face contacts for further information of the study</td>
<td>Cross sectional questionnaire of the Degree of Congruence between Attributes of Home Care Services Desired and Received Questionnaire (DCAHCSDRQ) to assess 19 attributes of carers unmet needs from services</td>
</tr>
<tr>
<td>33</td>
<td>Drapalski et al. (2008)</td>
<td>USA</td>
<td>308 carers (234 parents, 28 siblings, 9 adult daughters/sons, 18 spouses, 10 others)</td>
<td>All aspects of mental health services in the community</td>
<td>Postal information to service users to obtain consent for carers’ participation</td>
<td>Cross sectional questionnaire using 16 items of FANS (Family Assessment of Needs for Services), via mails</td>
</tr>
<tr>
<td>No</td>
<td>Authors</td>
<td>Country of origin</td>
<td>Number of carer participants and relationship with service user</td>
<td>Setting</td>
<td>Recruitment of carer participants</td>
<td>Data analysis</td>
</tr>
<tr>
<td>----</td>
<td>---------</td>
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<td>-------------------------------------------------------------</td>
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</tr>
<tr>
<td>34</td>
<td>Friedrich et al. (2008)</td>
<td>USA</td>
<td>746 carers (all siblings)</td>
<td>All aspects in mental health services</td>
<td>Postal invitation, advertisement in newsletter, and used gatekeepers (leaders of carer support groups)</td>
<td>Cross sectional questionnaire using 19 items of Friedrich-Lively Instrument to Assess the Impact of Schizophrenia on Siblings (FLIIS) to rate the importance carer needs and mental health services</td>
</tr>
<tr>
<td>35</td>
<td>McPherson et al. (2008)</td>
<td>UK</td>
<td>32 carers (no description their relationships with the service user)</td>
<td>Assertive Outreach team services</td>
<td>Not stated</td>
<td>Cross-sectional questionnaire using 22 items of CANSAS (Schedule Camberwell Assessment of Need Short Appraisal Schedule)</td>
</tr>
<tr>
<td>36</td>
<td>Absalom-Hornby et al. (2011)</td>
<td>UK</td>
<td>18 carers (12 parents, 5 siblings, 1 other)</td>
<td>Forensic mental health services</td>
<td>Postal invitation</td>
<td>Cross sectional interview using 48 items of FQ (Family Questionnaire) and 14 items RCNS (Relatives Cardinals Needs Schedule), questioned via telephone</td>
</tr>
<tr>
<td>37</td>
<td>Lasalvia et al. (2012)</td>
<td>Italy</td>
<td>120 carers (no description their relationships with the service user)</td>
<td>Community mental health services</td>
<td>Contacted service users to obtain permission for their carers</td>
<td>Cross sectional questionnaire using 22 items of the Italian version of Camberwell assessment of Need</td>
</tr>
<tr>
<td>38</td>
<td>Winefield, and Harvey (1994)</td>
<td>Australia</td>
<td>121 carers (68.6% parents, 17.4 % siblings, 7.4% spouses, 4.1% adult child</td>
<td>All aspects of mental health services</td>
<td>Face-to-face contacts with service users to obtain consent for carers' participation</td>
<td>Structured interviews</td>
</tr>
<tr>
<td>39</td>
<td>Jubb and Shanley (2002)</td>
<td>Australia</td>
<td>14 carers (no description of their relationships with the service user)</td>
<td>A mental hospital</td>
<td>Postal invitation</td>
<td>Cross sectional questionnaire of Needs Assessment of Caregivers/Families questionnaire from Salford Mental Health Project 1985, delivered via mails</td>
</tr>
<tr>
<td>40</td>
<td>Lloyd and Carson (2005)</td>
<td>UK</td>
<td>40 carers who attended 3 support groups</td>
<td>Community mental health services</td>
<td>Postal invitation to complete survey questionnaires and direct contacts with carers in support group meetings</td>
<td>Questionnaire and discussion meetings</td>
</tr>
</tbody>
</table>
Table 2. Data extraction of the included studies about what carers need from mental health services

<table>
<thead>
<tr>
<th>No</th>
<th>Authors</th>
<th>Summary of findings: Carers expressed needs</th>
<th>Focus on carers own needs (on behalf of carers’ wellbeing)</th>
</tr>
</thead>
</table>
| 1  | Glendy and Mackenzie (1998)| 1. Informational support from professionals (service user illness, medication, services available, management of illness)  
  2. Emotional support (talking to friends/other relatives to release tension and gain support in handling service user)  
  3. Professional support (support from social workers, nurses, doctors to give informational and emotional support) | Yes  
  Appeared in the needs of emotional support and professional support |
| 2  | Johnson (2000)             | 1. Carer involvement be regarded as a part of team in the professionals’ care provision to service users  
  2. Information | No |
| 3  | Smith et al. (2001)        | 1. Financial assistance (for daily living costs)  
  2. Legal assistance (to receive guardianship or attorney support for the service user)  
  3. Medical assistance (adequate information about the illness from the physicians, adequate physical health of service user, adequate wellbeing of themselves)  
  4. Housing assistance (house modifications, information about nursing home placement)  
  5. Emotional support/assistance (support from other family members/friends, keep involved in support group)  
  6. Spirituality (more support from religious community) | Yes  
  Appeared in the need of support and education for carers themselves |
| 4  | Domboos (2002)             | 1. 89% of carers wished for a program development for service user i.e. continuum of care that was comprehensive, multifaceted and assisted them in functioning at maximal level of wellness  
  2. 82% of carers desired support and education for carers i.e. supportive network from peers and professionals  
  3. 47% of carers needed social system change involving health care system society (collaborative effort between professionals and carers in fighting for parity in insurance coverage and allocation of additional tax for mental health services and research, effort to erase stigma and alienation related to mental illness, and mental health care to be more responsive and functional) | Yes  
  Appeared in the need support and education for carers themselves |
| 5  | Bowes and Wilkinson (2003) | 1. Support from someone who can come to the carers for company or for a break from the caring task  
  2. Receiving services at home instead of residential care | Yes  
  Appeared in the need of to break from caring role |
| 6  | Bollini et al. (2004)      | 1. Information about the disease and treatment with anti-depressant  
  2. Psychological help or self-help group  
  3. Domiciliary assistance  
  4. Decreasing stigma associated with mental illness in the society | Yes  
  Appeared in the need of psychological help |
<table>
<thead>
<tr>
<th>No</th>
<th>Authors</th>
<th>Summary of findings: Carers expressed needs</th>
<th>Focus on carers own needs (on behalf of carers' wellbeing )</th>
</tr>
</thead>
</table>
| 7  | Rose et al. (2004)           | 1. Professionals to be more caring to carers  
2. Professional support during crisis (e.g. calling the police, bringing the service user to hospital and dealing with verbal and physical abuses from the service user)  
3. Education about mental illness to the community  
4. Equal treatment/no discrimination in using services | No                                                        |
| 8  | Lakeman (2008)               | Improvement of family involvement in the following areas:  
1. Information sharing  
2. Professionals' access to family  
3. Family functioning through the provision of family therapy  
4. Family’s access to treatment  
5. Mental health services in general | Yes  
Appeared in the needs of improving family functioning and communication |
| 9  | Askey et al. (2009)          | 1. Improved care for service user (standardized inpatient services, well preparation for discharge, and early intervention in the course of illness)  
2. Carer Involvement (being included in the care process, professionals able to take carers seriously, considered as a part of the multidisciplinary team, and being respected by professionals)  
3. Emotional and practical support from professionals (professionals able to listen to carers' needs, be supportive, help carers to deal with the sense of loss and offer them reassurance, provide practical help early in the course of illness, yet do not contact carers only during crisis)  
4. Information, education and training (carers need information about psychosis and treatment available in the initial stage of the illness and throughout the time they contact with services, early warning signs, how to prevent relapse, and how to deal with difficult behaviours of service user. Carers also need sufficient information but not overwhelming in the initial phase of the illness, and non-conflicting/non confusing information from the multidisciplinary team) | Yes  
Appeared in the needs of emotional support; information, education and training to deal with difficult behaviours |
| 10 | Lyons et al. (2009)          | 1. Access to services (information about available services, being listened or taken seriously when carers access services, and able to immediately access them during a crisis)  
2. Suggested services (extra support at home, time outside home, extra support outside home, talking therapies for service user, telephone support, and respite of carers) | No                                                        |
| 11 | Mavundla et al. (2009)       | 1. Shelters for ill relatives  
2. Supervision of service user that ensures their medication is taken correctly | No                                                        |
<table>
<thead>
<tr>
<th>No</th>
<th>Authors</th>
<th>Summary of findings: Carers expressed needs</th>
<th>Focus on carers own needs (on behalf of carers' wellbeing )</th>
</tr>
</thead>
</table>
| 12 | McAuliffe et al. (2009)  | 1. Information about basic mental health services  
2. To be listened  
3. To be included  
4. To be treated as a source of knowledge  
5. Clarity about confidentiality and privacy  
6. Involvement/connecting with other carers through psycho-education  
7. Education program for public, general practitioners and children (as this is related to stigmatisation)  
8. Community-based mental health support groups as a bridge between the family and the outside world  
9. Greater access respite care for the service user  
10. On-going research                                                                 | Yes  
Appeared in the needs of emotional support and interventions (i.e. psycho-education, community based support groups and the need of respite care) |
| 13 | van der Voort et al. (2009) | 1. Professionals become someone to listen to  
2. Information about disorder  
3. Professional help with appraisal of carers’ situation  
4. Networking among carers and other stakeholders  
5. Support for relaxing, work, education or maintaining contact with others.                                                                 | Yes  
Appeared in all of the professional support |
| 14 | Thomas et al. (2010)     | 1. A change in culture in terms of carer involvement in treatment, utilisation of partnership approach, recognition of carers’ expertise and knowledge, and taking the carers’ views more seriously  
2. Carer involvement in policy and planning (being listened to, meetings designed to truly involve carers)                                                                 | Yes  
Appeared in the need of recognition of expertise and knowledge and involvement in policy and planning (i.e. being listened) |
| 15 | Nordby et al. (2010)     | 1. Professionals able to ‘encounter’ emphatic and listening attitudes to carers  
2. Support and counselling related to carers' concerns following the service user discharge from hospital  
3. Sharing information (to be involved from the beginning of treatment, need accurate information related to service user’ illness and the information be given gradually and individually)  
4. To be acknowledged as experts                                                                 | Yes  
Appeared in the needs of counselling and emotional support |
<table>
<thead>
<tr>
<th>No</th>
<th>Authors</th>
<th>Summary of findings: Carers expressed needs</th>
<th>Focus on carers own needs (on behalf of carers’ wellbeing)</th>
</tr>
</thead>
</table>
| 16 | Van de Bovenkamp and Trappenburg (2010) | 1. Information (sufficient information about service user’ mental health status, the diagnosis, the professional care received, and the expected role of carers; professionals able to deliver information as a routine practice but not dependent upon individual practitioners)  
2. Consultation (adequate consultation regarding the decision to discharge service user, being the advocate of service user when they are incapable of representing their own interest)  
3. Strategies of information provision (be listened without working hard to be heard, professionals able to talk to carers alone without service user around, flexibility related to privacy and autonomy of service user)  
4. Support for carers themselves to cope with their carer role (sufficient support without difficult and time consuming procedures e.g. be acknowledged and understood, intervention for carers e.g. psycho-education, intervention from psychologists) | Yes  
Appeared in the needs of emotional support and intervention (i.e. psycho-education program and intervention from psychologist) |
| 17 | Copeland and Helleman (2011) | (Desires for the ill child)  
1. Child’s illness to be stabilised so he/she could experience improvement in day-to-day functioning, increased ability to maintain independence, improvement in overall health, achieve happiness, and ability to make friends/mates  
2. Child could accept and/or want the treatment that was available to him/her  
3. Child to be more independent as it can benefit him/her as well as the carer (Desires for the carers themselves)  
4. A break from caregiving, respite from the caregiving responsibilities, assistance, affirmation, and validation from the mental health community for their sacrifices and caregiving effort  
5. More opportunities to participate in mental health treatment decisions | Yes  
Appeared in the desires for the carers themselves |
| 18 | Jonsson et al. (2011) | 1. Constant support for service user  
2. Meeting with other carers  
3. Support and understanding from other colleagues, friend, relatives and public health services | Yes  
Appeared in the need of gathering among carers and receiving support from other colleagues and relatives. |
<table>
<thead>
<tr>
<th>No</th>
<th>Authors</th>
<th>Summary of findings: Carers expressed needs</th>
<th>Focus on carers own needs (on behalf of carers' wellbeing)</th>
</tr>
</thead>
</table>
| 19 | Weimand et al. (2011) | 1. Cooperation with professionals (Need for the sake of themselves)  
2. Learn how to understand and navigate the mental health care system  
3. Professional support to deal with own emotions derived from their ill relatives such as loneliness, hopelessness, grief, uncertainty, fear, guilt, shame, bad conscience and worry  
4. Professional support to deal with own emotions related to mental health services such as frustration, anger, bitterness and exhaustion  
5. Family groups (consisting of peers and mental health personnel) as they are considered as supportive arenas for questioning about how to deal with complex emotional issues | Yes  
Appeared in the needs for the sake of carers |
| 20 | Hacketal et al. (2012) | 1. Family ties or emotional-practical support from other family members in caring for service user  
2. Informational support for the community related general knowledge of mental illness and access to professional help  
3. Welcoming and comfortable atmosphere within the service | Yes  
Appeared in the needs of support from other family members |
| 21 | McHugh et al. (2012) | 1. Educational support (access to information about illness, access to local services and information of how to deal with the carers' life change)  
2. Informal support (informal networks for practical help e.g. shopping, offload feelings and concerns, contact with other carers for mentoring and reassurance e.g. sharing experience among carers to learn from the experience of other, to receive encouragement and boost motivation) | Yes  
Appeared in the need of educational and informal support (i.e. information about how to deal with change of life) and informal support (i.e. mentoring and reassurance and offload feelings) |
| 22 | McNeil (2013) | 1. Collaboration (more involvement in the care of service user, to be heard, to be informed)  
2. Information (mental health service in general, diagnosis, prognosis, treatment of service user)  
Support (able to find and access support from mental health service in the community easily) | Yes  
Appeared in the need of support |
| 23 | Mizuno et al. (2013) | 1. Psychiatrists to be clear about the illness  
2. More opportunities and places consultation with professionals (professionals come to home)  
3. Opportunities to gather among carers casually for sharing caring experiences | Yes  
Appeared in the need of gathering among carers |
| 24 | White et al. (2013) | 1. Parent needs (Family therapy, financial/resources, better communication with ill children, emotional and social support (e.g. custodial assistance)  
2. Focused services on ill children (communication/bonding, family therapy, resources for the children, transportation to visit the children, support for custody issues, social skills, activities to do with the children, and other parenting needs such as schoolwork, housing, and financial) | Yes  
Appeared in the need of support e.g. emotional and social support |
| 25 | Wood et al. (2013) | 1. Easy access to mental health hospital (e.g. free movement across the interface inside and outside the hospital)  
2. An inclusive environment (involvement in designing hospital setting, fostered by good relationships between professionals and carers)  
3. Good links to the community and spaces within the hospital that partly substitute for social and faith-based venues in their home communities. | No |
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>26</td>
<td>Ascher-Svanum et al (1997)</td>
<td>(Educational need for psycho-education were identified-each number is detailed by rank): 1. Format (phone consultation with professionals, professionally led support group, family support group that excludes mental health professional) 2. Content (future course of the illness, medication benefits and side effect, how to manage crisis situations with patients, how to deal with service user substance use) 3. Leaders (psychiatrist, psychologist, social workers, well known celebrity, recreational therapy) 4. Duration (one-two hours, a half day Saturday workshop, once weekly, all day workshop on weekday) 5. Location (community health centre, psychiatric hospital, hotel conference room, school, library; time (afternoon and evening, night and morning) 6. Cost (free, $5, $15,$10); travel time (15, 30 minutes; 2 hours, 1.5 hours, 1 hour)</td>
<td>Yes  Appeared in the format of education: family support group</td>
</tr>
<tr>
<td>No</td>
<td>Authors</td>
<td>Summary of findings: Carers expressed needs</td>
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</table>
| 29 | Sung et al. (2004)              | Pre-discharge informational needs were identified, including (by rank):ogue less effectively  
1. Ways of managing stress more effectively  
2. Coping with depression and suicidal thoughts  
3. Managing burnout  
4. What the illness is like for the person  
5. Psychiatric medication | Yes  
Appeared in the needs of information related to the ways of managing stress more effectively and managing burnout were in the 1st and 3rd position. |
| 30 | Cleary et al. (2005)            | Needs of information were identified, including:  
1. Benefits of medication  
2. Medication  
3. What to do if unwell  
4. Community resources  
5. Medication side-effects  
6. Illness or problems experienced | No |
| 31 | Gregory et al. (2006)           | Carers and service user had different priorities regarding the information they wanted  
1. Information was too often not provided to carers  
2. Someone to talk to,  
3. Help with cleaning/ironing  
4. Finances,  
5. Breaking from caring role and respite care  
6. Accommodation for service user | Yes  
Appeared in the need someone to talk to, help with cleaning/iron, finances, break, and respite care |
| 32 | Tung and Beck (2007)            | 19 unmet carer needs (by rank)  
1. Get speedy services  
2. Contact by telephone  
3. Reduce burden  
4. Maintain service user health  
5. Spiritual support  
6. Continuity of services,  
7. Inexpensive charge  
8. Insurance coverage  
9. Clear explanation  
10. Teach skills  
11. Accurate judges  
12. Frequent visit  
13. Thoroughness  
14. Familiar with knowledge  
15. Familiar with technologies  
16. Concerns for questions.  
17. Respect of care  
18. Consideration  
19. Accept suggestion | Yes  
Appeared in the questions related to spiritual support and decrease burden |
<table>
<thead>
<tr>
<th>No</th>
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<th>Focus on carers own needs (on behalf of carers’ wellbeing)</th>
</tr>
</thead>
<tbody>
<tr>
<td>33</td>
<td>Drapalski et al. (2008)</td>
<td>1. Family information and support needs identified. (Substantial number of unmet needs of information including topic presented, service user’ progress, ACT, future planning and advocating services for service user) 2. Preferred modes and methods for receiving information were identified (given in person, as needed basis, in a mental hospital/clinic or in their own home)</td>
<td>NO</td>
</tr>
<tr>
<td>34</td>
<td>Friedrich et al. (2008)</td>
<td>1. 11 carer needs (by rank): Services for service user, open communication in family, emotional support from loved ones, information about service user illness, relationships and activities outside the family, coping skills for service user illness, working through the reaction of the illness, involvement in treatment, stress management, counselling for self, genetic counselling 2. 9 mental health services needed (by rank) information, direct services for carers and support</td>
<td>Yes  Appeared in the questions related to carer need of open communication in family, emotional support from loved ones, relationships and activities outside the family, working through the reaction of the illness, stress management, counselling for self, genetic counselling –and in the questions related to mental health services (direct services for carers and support)</td>
</tr>
<tr>
<td>No</td>
<td>Authors</td>
<td>Summary of findings: Carers expressed needs</td>
<td>Focus on carers own needs (on behalf of carers’ wellbeing)</td>
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</tbody>
</table>
| 36 | Absalom-Hornby et al. (2011) | Five areas of carers needs according to the RCNS were identified:  
1. Support, information and liaison  
2. Coping with symptoms  
3. Relationships  
4. Caregiver hardship  
5. Caregiver negative emotions  
100% carer participants need support and information about mental illness and 66% of the participants perceived that carers’ negative emotions should be addressed | Yes  
Appeared in the needs to address caregiver negative emotions and caregiver hardships |
| 37 | Lasalvia et al. (2012)        | 1. The needs that most frequently reported were daytime activities (59.5%), functioning e.g. looking after the home (57.7%) and health e.g. dealing with psychological distress (56%)  | Yes  
Appeared in the needs of health |
| 38 | Winefield, and Harvey (1994)  | 1. Carers involvement in the treatment  
2. Practical help for carers  
3. Professional help  
4. Improvements to services  | Yes  
Appeared in the needs of practical and professional help |
| 39 | Jubb and Shanley E (2002)     | 1. The needs of information and health education were identified (57% carers viewed information was inadequate, 43% carers noted that advice was impractical and information was too incomplete, 75% carers stated that no information about side effect of medication, and 50% carers viewed that the provision of emotional support was neglected)  
2. Satisfaction with services (29% carers dissatisfied with services provided)  | Yes  
Appeared in the needs of emotional support |
| 40 | Lloyd and Carson (2005)       | 1. Understanding mental illness (e.g. jargon used by professionals, what happened to service user during hospitalisation, and what to do/ not to do during emergency)  
2. The law and your right (carers did not understand the law and when it should be used, thus making it difficult to make a decision during a crisis)  
3. Helping yourself (carers need help from stress related illness).  | Yes  
Appeared in the need of support from stress-related illness |
2.1.8. Synthesis

As indicated earlier, the review adopted a thematic analysis approach to synthesise the data from included studies (Dixon-Wood et al. 2005). The synthesis involved two stages based upon the principles outlined by Thomas & Hardin (2008), which offer a relatively clear and replicable process to address questions related to the participants' perspectives.

The first stage was the development of descriptive themes where free line-by-line coding was applied to the findings of the included studies. The coding was undertaken onto the extraction sheets (see the previous Table 2), to identify recurring themes surrounding what carers needs and expectations from mental health services. This procedure resulted in a number of categories of carer needs.

The second phase was developing analytical themes where the previous descriptive themes were drawn to provide a new interpretation which went beyond the original studies. It involved collapsing some themes into another existing theme. The results of the first and second stages of the synthesis will be presented in section 2.1.9.2 on page 49.

2.1.9. Results

2.1.9.1. Characteristics of the reviewed studies

Of the 40 included papers, the majority were based in Western countries i.e. 11 in the US, nine in the UK, five in Australia, two in Netherlands, two in Norway, two in Italy, one in Canada, one in Germany, and one in Sweden. Only six articles were based in non-western countries; two from China, two from Taiwan, one from Japan, and one from South Africa.

Of these studies, 25 had samples of carers only, and 15 of them used mixed samples including carers and service users (n=7); carers, service users, and professionals (n=7); and carers and professionals (n=1). The total sample size of carer participants of all studies was 3099. Samples of the carer participants varied
from four carers in two studies (Wood et al. 2003 and Wilkinson and McAndrew 2005) and 746 carers in
the Friedrich et al. (2008).

2.1.9.1.1. Methodological design

25 of the 40 studies were qualitative, 12 were quantitative and three were mixed studies. Out of the 25
qualitative investigations, 16 did not report the specific methodology adopted. The remaining studies
employed various methodologies including grounded theory (n=3), content analysis (n=2), ethnography
(n=2), case studies (n=2), and social interactionist (n=1). In terms of the methods of collecting the qualitative
data, 15 used individual interviews, nine adopted focus groups, and one study examined written qualitative
data from carer participants.

Of the 12 quantitative studies, all were questionnaire surveys. In relation to the questionnaire used, the
majority of the 12 surveys used established recognised questionnaires, including:

- The Educational Needs Questionnaire (ENQ)
- The Camberwell Assessment of Need Short Appraisal Schedule (CANSAS)
- The Family Assessment of Needs for Services (FANS)
- The Relatives Cardinals Needs Schedule (RCNS), Needs Assessment of Caregivers/Families questionnaire from Salford Mental Health Project 1985,
- The Friedrich-Lively Instrument to Assess the Impact of Schizophrenia on Siblings (FLIISS),
- The Degree of Congruence between Attributes of Home Care Services Desired and Received Questionnaire (DCAHCSDRQ),
Some modified/self-developed questionnaires were also used:

- Chinese Modified Educational Needs Questionnaire (CENQ)
- Italian version of Camberwell Assessment of Need (ICAN),

All of the three mixed studies also employed surveys for their quantitative investigations. For example, studies by Jubb and Shanley (2002) and Lloyd and Carson (2005) posted written open-ended questions in a questionnaire to obtain data for their mixed methods.

2.1.9.1.2. Characteristics of participants

The relationships of carer participants to members of the family with a serious mental health problem were identified in 25 studies. The majority of the carer participants were siblings (n=1061), followed by parents (n=1051) spouses/partners (n=171), adult children (n=79) and others (n=47). Six studies used specific participants to investigate the needs of specific group of carers, such as female carers, siblings, spouses or parents.

2.1.9.2. Results of synthesis

The first stage of the synthesis (i.e. the development of descriptive themes), resulted in some categories of carer needs including informational, emotional, practical and professional support. The need for information was dominant and found in 32 of the 40 studies. This need focused around carers needing knowledge about mental health problems (e.g. signs, symptoms and treatments), the progress of their relative with mental health problems, and the mental health services available. In addition, carers in three studies (Ascher–Svanum et al. 1997, Drapalski et al. 2008, and Askey et al. 2009) suggested that information should be individualised and tailored to the specific circumstances of each family and offered at an appropriate pace, particularly in the early stages of the mental health problem. Twenty-one studies revealed data outlining needs of emotional and practical supports. Six studies uncovered the need for
professional support and emphasised that carers wanted to be respected, listened to and for health workers to demonstrate empathy. Finally, the need for carer involvement emerged in nine of the 40 studies, specified as the desire of carers to be treated as part of team care, consulted regarding decisions made for service users and acknowledged as experts.

The similarities and differences between the categories were then identified and grouped into a hierarchical structure. Seven major themes including the sub-themes were revealed to describe what was needed by carers from services as depicted in Table 3.
Table 3. Themes from the descriptive stage of synthesising the reviewed studies

<table>
<thead>
<tr>
<th>No</th>
<th>Main themes</th>
<th>Sub themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Information</td>
<td>• Method of information giving</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Content of the needed information</td>
</tr>
<tr>
<td>2</td>
<td>Emotional support</td>
<td>• Emotional support for other family members and friends</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Consultation with or therapy from professionals to express concerns</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Be involved in support groups</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Spiritual support</td>
</tr>
<tr>
<td>3</td>
<td>Adequate wellbeing of service users</td>
<td>• Mental, physical and social wellbeing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Improving services for service users</td>
</tr>
<tr>
<td>4</td>
<td>Supportive attitudes of professionals</td>
<td>• Be respectful to carers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Listen to carers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Have empathy towards carers</td>
</tr>
<tr>
<td>5</td>
<td>Carer involvement</td>
<td>• Carers as part of team-care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Carers be consulted regarding decision for service users</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Be acknowledged as experts</td>
</tr>
<tr>
<td>6</td>
<td>Adequate wellbeing of carers</td>
<td>• Emotional, physical and social wellbeing</td>
</tr>
<tr>
<td>7</td>
<td>Practical help in performing caring role</td>
<td>• Respite care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Practical help for daily life</td>
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<td></td>
<td></td>
<td>• Practical help during crisis</td>
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<tr>
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<td></td>
<td>• Easy access to services</td>
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<td></td>
<td></td>
<td>• Housing assistance</td>
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<tr>
<td></td>
<td></td>
<td>• Financial assistance</td>
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<td></td>
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<td>• Legal Assistance</td>
</tr>
</tbody>
</table>

Other similarities and differences were also identified with regard to the needs of carers across some cultures, described as western – represented by carers living in the North of America, Europe and Australia, and non-western -- represented by carers living in Asia and Africa (see the detail on the previous page 47). Several needs including the needs of information, emotional support, supportive attitudes of professionals, and practical support were voiced in the studies which were based in both western and non-western cultures. Nonetheless, while the needs of adequate wellbeing for carers and involving them in the services were expressed profoundly in the USA, Canada, and Europe; these needs did not emerge from the investigations with Asians and Africans.
The second stage of the synthesis (i.e. the development of analytical themes) involved advanced interpretation of the original studies. It included collapsing some themes into another existing theme as presented in the previous Table 3. To illustrate, the need of information and emotional support were grouped under another theme namely the need of adequate wellbeing of carers - at the end this theme was labelled as the need of holistic wellbeing of carers. In addition, this phase involved a re-examination of the data to ensure that the themes were represented. For example, the data related to improvement of services were re-examined and grouped together with the data of the need of practical support under a new theme: the need of holistic wellbeing of service users. The result of this stage was identification of four major needs of carers: (1) holistic wellbeing of service users, (2) holistic wellbeing of carers, (3) supportive attitudes of professionals and (4) carer involvement.

A further analysis resulted in a notion in that the needs (1) and (2) which were consecutively closely associated with the wellbeing of service users and carers, and needs (3) and (4) which have indirect connections to the wellbeing of carers or service users, as shown in Figure 5.

**Figure 5. Four needs of carers resulted from the synthesis of the reviewed studies**

1. Holistic wellbeing of service users
   - Services improvement
   - Practical help for caring role

2. Holistic wellbeing of carers
   - The need of information
   - The need of emotional support

3. Supportive attitudes of professionals
   - Respectful to carers
   - Listening to carers
   - Empathy

4. Carer involvement
   - Carers as a member of team care
   - Carers be acknowledged as experts
Finally, the current synthesis could describe the relationship between the emerging themes. A deeper analysis of the data related to the needs of supportive attitudes of professionals (3) and carer involvement (4) suggested that these were voiced because the carers wanted the best services to be given to their ill relatives. Likewise, many carers reported that they required information because they wanted to be more knowledgeable and skilled in caring for service users. Therefore, it can be assumed that the whole 4 carer needs uncovered in this review were actually dedicated to their ill relatives, as illustrated in Figure 6.

![Figure 6. Relationships between the themes resulted from the synthesis of the reviewed studies](image)

2.1.10. Appraisals of the studies

One of the essential stages in a literature review is critical appraisal. It is a process of careful and systematic examination of the reviewed studies in order to judge their trustworthiness, value and relevance in a particular context (Green 2005, Mhaskar et al. 2009). The appraisal of all qualitative studies in the current
review used a specific tool namely the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al. 2007). It is worth noting that the COREQ was developed to improve the quality of reporting qualitative studies, but it was deemed to be suitable to inform critical appraisal for the qualitative inquiries which mainly employed interview and focus groups as their data collection methods (Tong et al. 2007). Moreover, the tool also posed specificity regarding the appraisal questions therefore it could minimise wide interpretation for the reviewers as well as the readers. In addition, the researcher assessed the quality of survey studies on the basis of an article by Bennett et al. (2011) that reported an analysis of published guidance for survey research. The mixed studies were also assessed using the survey tool because the findings were mostly described quantitatively in nature.

2.1.10.1. Appraisal of the qualitative studies

Table 4 on the following page 55 details the score of appraisal for each qualitative study on 18 items covering three main aspects: research team and reflexivity, study design, and data analysis and reporting. None of the studies met the quality in every item, thus their quality scores were lower than 18, ranged from 5 to 14. Of the 25 reviewed studies, three were high, 14 were moderate and eight were low in their quality.

The appraisal relating to sampling covered three components; sampling methods, sample size and data saturation. Firstly, the majority of studies adopted a purposive sampling strategy. Theoretical sampling was employed in three studies (van der Voort et al. 2009, Copeland and Helleman 2011, and McHugh et al. 2012); allowing the researchers to use the emerging data during the processes of data collection and analysis so as to examine and elaborate the theories developed. Theoretical sampling is commonly used in grounded theory research in which the goal is to develop theories that are connected to, grounded in or emergent from real life events and circumstance (Marshall 1996, Higginbottom 2004, Corbin and Strauss 2008)
Table 4. Quality of the reviewed qualitative studies

<table>
<thead>
<tr>
<th>NO</th>
<th>STUDIES REVIEWED</th>
<th>RESEARCH TEAM AND REFLEXIVITY</th>
<th>STUDY DESIGN</th>
<th>DATA ANALYSIS AND REPORTING</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Glendy and Mackenzie (1998)</td>
<td>X</td>
<td>X X X X</td>
<td>X X X</td>
<td>X 10</td>
</tr>
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<td>2</td>
<td>Johnson (2000)</td>
<td></td>
<td>X X</td>
<td>X</td>
<td>X 5</td>
</tr>
<tr>
<td>3</td>
<td>Smith et al. (2001)</td>
<td>X X</td>
<td>X X X</td>
<td>X X X</td>
<td>X 9</td>
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<tr>
<td>4</td>
<td>Domboos (2002)</td>
<td>X X</td>
<td>X</td>
<td>X X X X</td>
<td>X 8</td>
</tr>
<tr>
<td>5</td>
<td>Bowes and Wilkinson (2003)</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X 5</td>
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<tr>
<td>6</td>
<td>Bollini et al. (2004)</td>
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<td>X</td>
<td>X X X X</td>
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<td>7</td>
<td>Rose et al. (2004)</td>
<td>X</td>
<td>X X</td>
<td>X X X</td>
<td>X 8</td>
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<td>8</td>
<td>Lakeman (2008)</td>
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<td>X</td>
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<td>9</td>
<td>Askey et al. (2009)</td>
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<td>X X X X X</td>
<td>X 6</td>
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<td>10</td>
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<td>X X X X X</td>
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<td>X X X X X</td>
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<tr>
<td>12</td>
<td>Van der Voort et al. (2009)</td>
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<td>X 15</td>
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<td>13</td>
<td>McAuliffe et al. (2010)</td>
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<td>X X X X X X X X X</td>
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<td>X 12</td>
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<td>NO</td>
<td>STUDIES REVIEWED</td>
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<td>STUDY DESIGN</td>
<td>DATA ANALYSIS AND REPORTING</td>
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<td>fication of bias or influence of re-</td>
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<td>searcher on research</td>
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<td>Training of the interviewer or facili-</td>
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<td>tator</td>
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<td>Sufficient</td>
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<td>contact with participant</td>
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<td>Familiarity</td>
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<td>with setting</td>
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<td>Sampling method</td>
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<td>Details of sample</td>
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<td>Inclusion and exclusion criteria</td>
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<td>Method of approach-</td>
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<td>ing participants</td>
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<td>Audio and visual recording</td>
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<td>Setting and location</td>
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<td>Data saturation</td>
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<td>Use of a topic guide, tools, questions</td>
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<td>Field note</td>
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<td>Duration of interview or focus group</td>
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<td>Participant validation</td>
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<td>Study limitation</td>
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<td>In-depth description of analysis</td>
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<td>Adequate data presented</td>
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<td>Nordby et al.</td>
<td></td>
<td>X</td>
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<td></td>
<td>(2010)</td>
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<td>15</td>
<td>Thomas et al.</td>
<td></td>
<td>X</td>
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<td>(2010)</td>
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<td>16</td>
<td>Van de Bovenkamp</td>
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<td>and Trappenburg</td>
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<td></td>
<td>(2010)</td>
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<td>17</td>
<td>Copeland and Hel-</td>
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<td>leman (2011)</td>
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<td>Jonsson et al.</td>
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<td>X</td>
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<td></td>
<td>(2011)</td>
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<td>19</td>
<td>Weimand et al.</td>
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<td>X</td>
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<td></td>
<td>(2011)</td>
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<td>20</td>
<td>Hacketal et al.</td>
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<td>X</td>
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<td></td>
<td>(2012)</td>
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<td>21</td>
<td>McHugh et al.</td>
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<td>X</td>
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<td></td>
<td>(2012)</td>
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<td>22</td>
<td>Mizuno et al.</td>
<td></td>
<td>X</td>
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<td></td>
<td>(2013)</td>
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<td>23</td>
<td>McNeil (2013)</td>
<td></td>
<td>X</td>
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<td>24</td>
<td>White et al.</td>
<td></td>
<td>X</td>
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<tr>
<td></td>
<td>(2013)</td>
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<td>25</td>
<td>Wood et al.</td>
<td></td>
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<td></td>
<td>(2013)</td>
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</table>
Secondly, the researcher examined the qualitative studies with regard to the sample size. The majority of the studies (i.e. 15 of the 25 studies) seemed to describe the sample size quantitatively. In this sense, the researchers acknowledged that one of the weaknesses of their studies was using a limited number of participants, thus compromising the transferability of the findings to other contexts. Nevertheless, it is argued that the aim of qualitative research is neither to count opinions nor people. Qualitative research aims to explore a range of perspectives about an issue; therefore approaches to sampling can be pragmatic and flexible (Gaskell 2000, O’Reilly and Parker 2012). Qualitative researchers believe that an adequate sample size is achieved when the research questions have been answered sufficiently (Marshall, 1996).

Thirdly, only five of the studies identified that theoretical saturation had been achieved (Domboos 2002, van der Voort et al. 2009, Nordby 2010, and Jonsson et al. 2011, Mizuno et al. 2103). The saturation occurs when the researcher has continued sampling and analysing data until no new data emerge and all concepts in the theory are developed thoroughly (Morse 2007). Information about the achievement of data saturation on a research paper is crucial, even though a small sample size is very common in qualitative studies. Detail about data saturation can inform the reader that the collected data has been adequate to answer the research question therefore any further data collection is not needed (Tong 2007, Trotter 2012).

With regard to the data collection, four studies did not show how the questions were derived for interviewing the participants (Johnson 2000, Bowes and Wilkinson 2003, McNeil 2013, and Wood et al. 2013). Likewise, most focus group studies did not present the questions used (Askey et al. 2009, Lyons et al. 2009, Nordy et al. 2010, Thomas 2010, Hacketal et al. 2012, and Wood et al. 2013). Questions presented in qualitative papers can facilitate the readers to examine whether or not the researchers have encouraged open conversations with the participants (Tong 2007).

In relation to the data analysis, most of the studies failed to describe the process of analysis adequately – particularly in relation as to how the data were coded. Only six studies provided clear descriptions by presenting a coding-tree i.e. a hierarchical arrangement of codes and sub-codes (van der Voort et al. 2009, Nordby et al. 2010, Weimand et al. 2011) or described the analysis stages in details (Rose et al.
2004, Mavundla et al. 2009, and Jonsson et al. (2011). According to Ryan et al. (2007) and Tong (2007), a clear description of how the themes are generated from the raw data is crucial because it may influence the credibility of qualitative research.

In addition, not all papers presented adequate quotations which might endanger the credibility of the studies (Tong et al. 2007). Eight of the 25 studies failed to identify which quotation belonged to which participant, even though the information is important to make judgements on how extent the researchers have over-used the words from particular articulate people (Corden and Sainsbury 2006). Furthermore, two studies (Johnson 2000 and White et al. 2013) failed to provide any participant quotes at all. A rich description of the phenomenon under investigation is essential because it can help the researchers to convey the actual situations that have been investigated and the context that surrounded them, and link between raw data and the emerging themes (Shenton 2003).

2.1.10.2. Appraisal of the quantitative survey and mixed studies

The quality of the survey and mixed studies in this review was relatively poor, as shown in Table 5, no study had the highest quality score of 6, and only 7 of the 15 included studies achieved a score of four or over.
Table 5. Quality of the quantitative survey and mixed studies

<table>
<thead>
<tr>
<th>NO</th>
<th>STUDIES REVIEWED</th>
<th>ASPECTS OF APPRAISAL (6 ITEMS)</th>
<th>Potential bias from researchers or respondents</th>
<th>Validity and reliability of questioner</th>
<th>Sample representatatives</th>
<th>Data analysis method</th>
<th>Response rate</th>
<th>Strengths and weaknesses of the study</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Ascher-Svanum et al (1997)</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>2</td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td>Gasque-Carter and Curlee (1999)</td>
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<td>0</td>
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<tr>
<td>3</td>
<td>Chien and Norman (2003)</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>5</td>
<td></td>
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<tr>
<td>4</td>
<td>Sung et al. (2004)</td>
<td></td>
<td>X</td>
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<td>X</td>
<td>2</td>
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<tr>
<td>5</td>
<td>Cleary et al. (2005)</td>
<td></td>
<td>X</td>
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<td>X</td>
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<td>6</td>
<td>Gregory et al. (2006)</td>
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<td>7</td>
<td>Tung and Beck (2007)</td>
<td></td>
<td>X</td>
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<td>X</td>
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<td>8</td>
<td>Drapalski et al. (2008)</td>
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<td>9</td>
<td>Friedrich et al. (2008)</td>
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<td>McPherson et al. (2008)</td>
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<td>11</td>
<td>Absalom-Hornby et al. (2011)</td>
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<tr>
<td>12</td>
<td>Lasalvia et al. (2012)</td>
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<td>13</td>
<td>Winefield, H.R. and Harvey E.J. (1994)</td>
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<td>X</td>
<td>6</td>
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<td>14</td>
<td>Jubb and Shanley E (2002)</td>
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<td>15</td>
<td>Lloyd and Carson (2005)</td>
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</table>

The surveys employed were administered in different ways including postal self-completion questionnaires, face-to-face and telephone interviews. However, only six of the 15 studies acknowledged that the chosen mode of survey had potential bias, sourced from both the researchers and respondents (Winefield and Harvey 1994, Chien and Norman 2003, Cleary et al. 2005, Lloyd and Carson 2005, Tung and Beck 2007, and Lasalvia et al. 2012). To illustrate, response bias was only
acknowledged by Lloyd and Carson (2005) as people who experienced literacy problems were less likely to respond to their postal questionnaires. Likewise, only face-to-face interviews by Cleary et al. (2005) introduced social desirability bias where the respondents might respond to questions in a manner that would be viewed favourably by the interviewer (Specter 2004, Nederhof 2006).

Only five studies used a valid and reliable questionnaire (Winefield and Harvey 1994, Chien and Norman 2003, Sung et al. 2004, Tung and Beck 2007, Lasalvia et al. 2012); while those are important for ensuring the information gathered was accurate based on a consistent tool of data collection (Fink 2013). Hence, it is unknown whether or not the majority of the included studies used questionnaires which measured what they sought to measure about carer needs from mental health services.

Only five surveys described the representativeness of the samples (i.e. the degree to which samples were selected from a group of respondents that closely paralleled the population as a whole) (Winefield and Harvey 1994, Ascher-Svanum et al. 1997, Cleary et al. 2004, Drapalski et al. 2008, McPherson et al. 2008). Nevertheless none of the five investigations provided a sample size calculation which is essential in survey research because inappropriate, inadequate, or excessive sample sizes can influence the quality and accuracy of the investigation (Bartlett et al. 2001). While representativeness of a survey is not always influenced by sample-size, displaying the result of sample-size calculation is still helpful for estimating whether the study has reflected the determined population (Aldridge and Levine 2001, Kadam and Bhalerao 2010).

The response rates of the included studies ranged from 33% to 90.4%. However, six studies failed to report response rates (Gasque-Carter and Curlee 1999, Jubb and Shanley 2002, Sung et al. 2004, Absalom-Hornby and Tarrier 2011, Gregory et al. 2012, and Lasalvia et al. 2012). Response rates are generally considered to be the most important indicator of survey quality (Aldridge and Levine 2001, Fincham 2008). Low response indicates that the study poses potential non-response bias or fewer cases which latterly may reduce the precision of estimates. Finally, the majority of the studies identified the strengths and weaknesses in the discussion section except Ascher-Svanum et al. (1997), Gasque-Carter and Curlee (1999), and Sung et al. (2004). Overall the weaknesses were related to limited sample size associated with problems for generalizability (Jubb and Shanley 2002, Cleary et al. 2005, Lloyd and

2.1.11 Discussion

The 40 studies reviewed suggest that carers have a range of needs. The findings from qualitative studies were meaningful for their rich and thick descriptions of the needs which augmented the data from the survey studies. However, a number of considerations should be taken into account before adopting the information in other contexts. First, none of the reviewed studies was based on Indonesia as the specific context of the PhD. The reviewed studies were mostly carried out in western countries which were culturally different from Indonesia, such as the UK, the US, Australia, and the Netherlands. Investigations of carer needs in Asian countries were mostly conducted with surveys which had limitations in terms of their small sample size and response bias sourced from the respondents. Moreover, Asian carers were only represented by Chinese cultural background. There was only one Asian-based qualitative study included in this review (Mizuno 2013), yet it explored the experience of homogenous carers belonged to community family associations in Japan. As stated earlier, there was a significant gap between the needs of carers from western and non-western countries, especially relating to the views about carer involvement and carers’ wellbeing (see page 51). In addition, the reviewed studies were mostly conducted in circumstances where the value of carers has been legally recognised, followed by substantial development of services for those with mental health problems. Consequently, the reported carer needs might be different if the explorations were conducted in Indonesia where services for the carers are less well developed.

Secondly, the needs of carers revealed from this review were mainly related to the service users’ needs i.e. to improve/maintain the service users’ health status. This does not mean the carers own needs were not revealed. Throughout the procedures of data extraction and synthesis, the researcher was eventually able to identify the carers’ needs for their own wellbeing. This identification was quite toiling...
because the reviewed studies failed to offer straightforward information about the carers own need. The fact relatively contradicts the existing perspective in that both carers and service users have very different needs (McFayden and Farrington 1997, Kuiper et al 2010).

In relation to the data collection method, the studies employed varied approaches to elicit information about carer needs. These included surveys, in-depth individual interviews and focus groups. In the surveys, asking the carers to respond to questionnaires might have numerous benefits including minimising costs, saving time and involving large samples (Aldridge and Levine 2001). Nevertheless, even with the assistance of reliable and valid questionnaires such as the Relatives’ Version of the Cardinal Needs Schedule (RCNS) (Absalom-Hornby et al. 2011), the adoption of the instrument must be treated with caution when used in countries where English is not the first language. The main issues of the current tools for investigating carer needs are surrounding the language translation and limited dimension of the needs covered (Wancata et al. 2006). Moreover, as affirmed by some researchers, the survey method has several flaws that can also be issues in qualitative works such as potential bias from the respondents and the researcher/interviewers; inability to capture extensive, complex and sensitive information; and the issue of social desirability (Winefield and Harvey 1994, Chien and Norman 2003, Tung and Beck 2007, Drapalski et al. 2008, Absalom-Hornby 2011, Lasalvia et al. 2012).

Alternatively, most investigators in the reviewed studies favoured qualitative methods, in particular in-depth individual interviews and focus groups. As expected, the one-to-one dialogues as well as focus groups were able to gather information about the needs that was rich, deep and extensive. Such methods allow carers to express their needs in detail, sourced from their own experience in caring for the ill family members (Smith et al. 2001). In addition to the focus groups, some investigators affirmed that the method was excellent for encouraging the carer participants to reflect on stories of others when expressing their needs based on their contacts with services and experiences in caregiving (McAuliffe et al. 2009, Nordby et al. 2010). The focus groups could also promote a safe environment for the carer as well as service user participants to discuss a topic that in other circumstances might be sensitive because of stigma, marginalisation or lack of opportunities (McAuliffe et al. 2009).
2.1.12. Limitations

This review has provided a broad overview of what is needed by carers from mental health services. The description given is comprehensive, sourced from qualitative and quantitative investigations undertaken in a large scope of regions of the world. However, the review has several limitations. First, publication bias might have been introduced because the findings only relied on data reported in academic journals, but did not cover unpublished literature such as conference proceedings, theses and dissertations, and other grey literature. Also the review excluded non-English and non-Indonesian publications and studies published before 1990, which might have raised the possibility of missing relevant studies.

2.1.13. Summary

A synthesis of what carers need from mental health services from the extant literature has been presented. Due to limitations of the reviewed studies, the adoption of the evidence in other contexts (which are culturally different) can be problematic. Likewise, as the studies were mainly conducted in places where the caring role has been formally supported; the findings might be dissimilar if the needs of carers were explored in areas where services for them are underdeveloped. The focus of this PhD is Indonesia, a country where research about carers and support for them are very limited. Clearly, the review was unable to give ample information about carer needs which were suitable to the focus of the study. Therefore reviewing additional relevant literature relating to carers in the country was deemed as important. In this sense, the researcher examined a number of policy documents relating to carers in mental health areas as presented in the next section of this chapter.
2.2. The policy review relating to supporting carers of people with mental health problems in Indonesia

This section presents a synthesis of Indonesian guidance relating to services for supporting carers of people with mental health problems. Given the limited literature about current services for the carers in Indonesia, the policy directives served as relevant literature surrounding the political efforts to support carers, especially with respect to meeting their needs from services. The results of the review will be used in planning the investigation by including issues surrounding legal endorsement of caring roles as one of key considerations.

2.2.1. Introduction

Government policies and legislation can influence the mental health of the population, including carers of people with serious mental illnesses (World Health Organisation/WHO 2005). The functions of such healthcare policies are to describe the values, objectives and strategies of the government to improve the health of the population. They also specify the standards to be applied across all services, and linking them with other organisations that have a common vision, objectives and purpose.

Recently mental health policy in Indonesia has been focused on the human rights of people with mental illnesses (Irmansyah et al. 2010). In 2012 when this review was initially conducted, the protection of human rights of people with mental illnesses had not yet been based on mental health legislation but was embedded in other general health policies (WHO 2011). Such inadequate policy support has been an influential factor of potential human rights violations amongst individuals with mental illnesses and issues of protection of the surrounding people. As a result, discussions about mental health issues in the country are dominated by attempts to protect individuals with mental health problems from discrimination and stigma of the illness (Irmansyah et al. 2010). This may explain why there has been little emphasis on supporting carers in Indonesia.

The researcher attempted to fill this gap by identifying the extent to which Indonesian government policies acknowledged the needs of carers of people with serious mental illnesses. Furthermore, issues
of the accessibility of any relevant documentation should also be identified. This is useful to understand the extent to which they can be accessed by relevant stakeholders (e.g. carers, service users, and health professionals). All information gathered from these accounts is needed before undertaking a study exploring the needs of carers in Indonesia. The information will be useful to attain a deeper understanding surrounding the Indonesian carer needs, especially factors that could influence the emergence as well as meeting the needs.

2.2.2. Aims of the policy review

The aims were:

- To identify Indonesian government guidance related to directives for mental health services to support carers of people with serious mental illnesses
- To examine and synthesise such guidance
- To assess the accessibility of the guidance to relevant stakeholders e.g. mental health professionals, carers, and service users.

2.2.3. Methodology

A systematic search was undertaken for all relevant documents related to policies, standards, and guidelines of mental health services for carers of people with serious mental illnesses in Indonesia.

2.2.4. Inclusion and exclusion criteria

2.2.4.1. Inclusion criteria:

- Related to the existing policies/standards/guidelines directing professionals in providing services for people with mental health problems.
- Designed for mental health professionals including specific disciplines such as nursing, medicine, psychology, and social workers.
2.2.4.2. Exclusion criteria:

- Not intended for mental health services and/or mental health professionals
- Focused only on mental health services for adolescents, those who misuse substances and people with psychosocial problems such as stress and domestic violence
- Dedicated for specific mental health workers except nurses
- Published as project reports for specific provinces.

2.2.5. Search strategy

A number of search strategies were employed for obtaining policy documents including searched websites for information relating to carers in Indonesia, visited national and local libraries (e.g. the Indonesian Ministry of Health Library, the Indonesian National Library and some university libraries), and communicated with the staff in the Ministry of Health who are responsible for the documents distribution. These strategies of searching were undertaken from October 2011 to June 2012, yet updating the policies from website was maintained during the PhD completion.

2.2.6. Data extraction

Relevant data were extracted to assess whether (1) carers involvement in the services and support for them have been acknowledged and (2) the guidance could be accessed by relevant stakeholders (i.e. service users, carers and professionals). These procedures allowed the researcher to synthesise the policies’ accessibility and contents whether the carers’ involvement in the services was facilitated. A summary of the data extraction is illustrated in the next Table 6 on page 68.
2.2.7. Results

The initial search found 67 documents. The documents were mainly produced by the national government (sources included documents from books, reports, presentation materials and supported by communications via emails with relevant parties). The documents were dated from 1992 to 2011 (1992 was the period when the National Health Law was issued as the foundation of mental health workers in Indonesian health care services).

The researcher excluded 52 documents which failed to meet the inclusion criteria, thus a total of 15 documents were retained for examination consisting of nine guidance papers, four papers of standards, one policy paper and one booklet. In general, they contained information regarding service provision for people with mental illnesses.
Table 6. Summary of policy directives relating to mental health services in Indonesia

<table>
<thead>
<tr>
<th>No</th>
<th>Title</th>
<th>Date</th>
<th>Written/Published by</th>
<th>Target audience</th>
<th>Focus</th>
<th>Reference to carers involvement in Services</th>
<th>Reference to needs of carers</th>
<th>In public domain Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Guidance of Comprehensive Implementation Mental Health Services and Substance Misuse in Public Health Centre in Jakarta</td>
<td>1996</td>
<td>Development Centre of Mental Health – Health Office of Jakarta in cooperation with Jakarta Mental Hospital</td>
<td>Health professionals (mainly GPs) working in front-line settings (Public Health Centres or General Hospitals)</td>
<td>Education of how to provide medical and non-medical intervention for individuals with mental health problems</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>2</td>
<td>Basic and Complex Nursing Interventions</td>
<td>2003</td>
<td>Directorate of Nursing Service - Directorate General of Medical Services - The Health Ministry of Indonesia</td>
<td>Leader of Health services, Nurse managers, Nurse practitioners, Nurse educators</td>
<td>Education related to nursing interventions can be delivered by nurses from different fields</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>3</td>
<td>Common Mental Health Problems in Society</td>
<td>2005</td>
<td>Directorate of Mental Health Service - Directorate General of Medical Services - The Health Ministry of Indonesia.</td>
<td>General public</td>
<td>Education of how to provide appropriate helps for people with a wide range of mental health problems</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>Title</td>
<td>Date</td>
<td>Written/Published by</td>
<td>Target audience</td>
<td>Focus</td>
<td>Reference to carers involvement in services</td>
<td>Reference to needs of carers</td>
<td>In Public Domain Yes/No</td>
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<tr>
<td>4</td>
<td>General Guidance of Community Empowerment in Mental Health</td>
<td>2005</td>
<td>Directorate of Mental Health Service - Directorate General of Medical Services - The Health Ministry of Indonesia</td>
<td>Policy makers and stakeholders that execute community and families empowerment (teachers, religious leaders, NGOs, etc.)</td>
<td>Education of how conducting community and family empowerment to overcome mental health problems in the society; Management of services related to strategies, referral systems, and programme development</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>5</td>
<td>Guidance of Professional Career Development in Nursing</td>
<td>2006</td>
<td>Directorate of Nursing Service - Directorate General of Medical Services - The Health Ministry of Indonesia</td>
<td>Governments (national and local), Leaders of Health of Offices, Leaders of Health Services, Nursing Education institutions, Nursing Profession Organisations, and nurses</td>
<td>Management of career development for nurses including psychiatric/mental health nurses based on its specific competencies</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>6</td>
<td>Standard of Psychiatric Nursing Practice</td>
<td>2006</td>
<td>Nursing Service - Directorate General of Medical Services - The Health Ministry of Indonesia</td>
<td>Leader of Health services, Nurse managers, Nurse practitioners, Nurse educators</td>
<td>Education related to nursing interventions should be delivered by psychiatric nurses</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>No</td>
<td>Title</td>
<td>Date</td>
<td>Written/Published by</td>
<td>Target Audience</td>
<td>Focus</td>
<td>Reference to carers involvement in services</td>
<td>Reference to needs of carers</td>
<td>In public domain</td>
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<tr>
<td>7</td>
<td>General Guidance for the Founders, the Steers, and the Practitioners of Community Mental Health Service</td>
<td>2007 (3rd Ed)</td>
<td>Directorate of Mental Health Service- Directorate General of Medical Services- The Health Ministry of Indonesia (Based on Decision of Minister of Health of Indonesia No 220/Ministry of Health/SK/III/2002)</td>
<td>The founders (national level), the steers (provincial Level), and the practitioners (district/city level) of community mental health service; incl. policymakers, community and religious leaders from national, provincial, and local levels)</td>
<td>Management of how to work collaboratively and systematically to enhance people’s mental health through community-based activities (policies, strategies, organizations, and programmes)</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>8</td>
<td>Guidance of the Implementation of Mental Health Service in Rehabilitation Facilities</td>
<td>2009</td>
<td>Directorate of Mental Health Service- Directorate General of Medical Services- The Health Ministry of Indonesia</td>
<td>Professionals and owners of mental health rehabilitation facilities; relevant governmental institutions; &amp; communities</td>
<td>Management of services in mental health rehabilitation including targets, programmes, systems of implementation and referral</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>9</td>
<td>Minimum of Standard of Services in Mental Hospital</td>
<td>2009</td>
<td>Directorate of Mental Health Service- Directorate General of Medical Services- The Health Ministry of Indonesia</td>
<td>Policymakers and Implementer of Mental Hospital Services</td>
<td>Management of services in every setting of a mental hospital involving minimum standards and indicators of human resources, services availability, time of services, and users’ satisfaction.</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>Title</td>
<td>Date</td>
<td>Written/Published by</td>
<td>Target audience</td>
<td>Focus</td>
<td>Reference to carers involvement in services</td>
<td></td>
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<tr>
<td>10</td>
<td>Standard of Mental Hospital Services</td>
<td>2009</td>
<td>Directorate of Mental Health Service- Directorate General of Medical Services- The Health Ministry of Indonesia</td>
<td>Policymakers and Implementer of Mental Hospital Services</td>
<td>Management of services in every setting of a mental hospital involving standards of administration, managerial and staff, facilities and equipment, policies and procedures, education and staff development</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Guidance of Community Mental Health Service</td>
<td>2010</td>
<td>Directorate of Mental Health Service- Directorate General of Medical Services- The Health Ministry of Indonesia (Based on Decision of Minister of Health of Indonesia No 406/Ministry of Health/SK/VI/2009)</td>
<td>Mental health workers, non-mental health workers working in community-based services, cadres including other community members who concern with mental health issues</td>
<td>Management of mental health services in community (principles, scope, mechanisms and examples of practices)</td>
<td>No</td>
<td></td>
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</tr>
<tr>
<td>12</td>
<td>Policies of Mental Health</td>
<td>2010</td>
<td>Directorate of Mental Health Service- Directorate General of Medical Services- The Health Ministry of Indonesia</td>
<td>Mental Health Professionals</td>
<td>Strategic Planning of National Mental Health Programmes</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Guidance of Mental Health Services in Primary Health Services Facilities</td>
<td>2011</td>
<td>Directorate of Mental Health Service- Directorate General of Medical Services- The Health Ministry of Indonesia</td>
<td>Health professionals working in primary health services</td>
<td>Education of how to provide medical and psychological interventions for individuals with mental illnesses in primary health services</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Guidance of Mental Health</td>
<td>2011</td>
<td>Directorate of Mental Health Service- Directorate General of Medical Services- The Health Ministry of Indonesia</td>
<td>Health cadres</td>
<td>Education of how to recognise mental health problems and to help people with varying mental health problems</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Guidance of Empowering Families of Patients with Mental Illnesses</td>
<td>2011</td>
<td>Directorate of Mental Health Service- Directorate General of Medical Services- The Health Ministry of Indonesia</td>
<td>Health professionals, policymakers in cross-sectors &amp; cross programmes health services, private/non-government institutions, health cadres, and carers.</td>
<td>Management of services to empower families of people with mental illnesses so they are capable of helping the ill member effectively</td>
<td>Yes</td>
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</tr>
</tbody>
</table>
The subject matter was varied but included guidance for:

- The general implementation of mental health services (no 1 and 14)
- Community and family empowerment (no. 4 and 15)
- Implementation of mental health services in specific facilities/settings i.e. community, rehabilitation and primary healthcare facilities (no. 7, 8, 11 and 13)
- Nurse practitioners (no. 5).

The reviewed standards regulated basic and complex nursing interventions e.g. helping service users for feeding and elimination (basic) and delivering group activities for service users (complex). This was shown in document no. 2. Other standards were about psychiatric nursing practice to service users, containing directives of assessment, planning, implementation and evaluation of services to service users as well as involvement of carers in helping the professional care (no. 6); and the minimum services expected in mental hospitals (no. 9 and 10).

The document no. 12 described policies of mental health in Indonesia in which strategic planning for the national programmes was explicated e.g. policies and planning for partnerships amongst stakeholders, primary mental health services, community-based mental health services, systems of mental health workforce and finance. Lastly, the document no. 3 was a booklet to inform the general public of how to help people with mental illnesses.

The majority of the examined documents were published by the Directorate of Mental Health Service-Directorate General of Medical Services the Health Ministry of Indonesia (12 documents). This is a specific division of the Health Ministry that regulates mental health delivery nationally and covers all mental health professionals. There were two documents from the Directorate of Nursing Service -Directorate General of Medical Services- the Health Ministry of Indonesia. The directorate focuses on directing any health service (including mental health) delivered by nurse practitioners. One document was published by Development Centre of Mental Health–Health Office of Jakarta in cooperation with Jakarta Mental Hospital. This is a local organisation based in Jakarta, the capital city of Indonesia. In relation to accessibility, the majority of the directives could be retrieved via the internet, but the other 5 documents were simply located in the library of Ministry of Health (no. 1, 2, 6, 12 and 15) that are commonly accessed by health professionals but not by carers.
These documents were intended for various audiences, though they were mostly dedicated to health professionals (no.1-2, 5-13 and 15). Documents no. 5-10 and 15 could be used by policymakers including those who were at local, provincial and national levels of government. Managers of mental health services were the target audience of documents no. 2, 5, 7 and 8 to guide the services provision. Documents no. 2, 5, 6, and 8 were dedicated to stakeholders in the community such as cadres, teachers, religious leaders and Non-Government Organisations. The contribution of health educators in mental health services was guided in documents no. 2, 5 and 6. How the general public can assist mentally ill people was informed in the document no. 3. However, only the document no. 15 was explicitly intended for carers of people with mental illnesses in the country.

2.2.7.1. Reference to the need to involve carers

In terms of acknowledgment to carers of people with mental illnesses, 10 directives contained reference to the need to involve carers in helping their ill relatives with regard to medication and activities of daily living. However, such positive trends did not occur of providing support to the carers' own wellbeing, with the exception of three documents (no. 3, 4 and 15), which provided information of how to care for mentally ill relatives, offered counselling services for carers as well as peer support meetings.

2.2.8. Discussion

The results demonstrate that the policy documents have attempted to acknowledge the need of involving carers in mental health services. This suggests that the Indonesian government does not underestimate the contribution carers can make in helping people with mental illnesses. In developing countries with scarce mental health resources like Indonesia, the involvement of family members is financially important for the service development (Shinfuku 1998), even though this may be not cost effective if the families contribute to the increased rates of relapses. Minas and Diatri (2008) emphasise that families in Indonesia play an important role in making decisions about the treatment for their mentally ill relatives. Communal value in the country is stronger than individual value (Kulihara et al. 2000).
Unfortunately such positive recognition has not been followed by strong political endorsement ensuring that carers receive adequate support based on their own needs and for their own wellbeing. As shown from the policy review, there were only three documents (no. 4, 5 and 15) as reference for services to support carers by providing information of how they can help their mentally ill relatives, providing counselling by professionals and involving them in support groups/networking. However, these documents were mainly designed on behalf of relatives with a mental health problem so the carers can be effective helpers for the person. There was no specific guidance dedicated to carers supporting their own needs and for the sake of their wellbeing. The lack of attention to the carers’ interests/wellbeing is not only happening in Indonesia, but also in other countries that have strong policies to support the carers (van der Voort 2009, Kuipers 2010). For instance, Kuipers (2010) criticises the mental health system in the UK for not prioritising efforts to address the needs of carers of mentally ill people and to enhance their mental state. The existing services for carers in the country are often offered only in relation to the service users’ interest, even though there have been two national Acts of Parliament as the basis to support carer’s i.e. The Carers (Recognition and services) Act in 1995 and the Carers and Disabled Children Act in 2000 (Carers UK, 2014). The newest Care Act 2014 is promising because it sets out carers’ legal rights in the same way as those they care for in terms of assessment and support provision (Department of Health 2015), though the funding for the implementation has been a main concern (Community Care 2015).

The most pragmatic explanation to the Indonesia context (i.e. no policy addressing the carers’ needs and wellbeing) is that currently the priority of the mental health leaders is to introduce the Mental Health Act (Directorate of Mental Health Service, 2011d). Instead of providing considerable attention on carers, issues surrounding legal aspects in mental health areas are being more focused i.e. impacts of the unavailability of the act such as violation of human rights against mentally ill people (Irmandyah et al. 2010).

2.2.9. Accessibility of the guidance

How people can access these policy documents is still unknown. Although the researcher was able to identify how the documents were retrieved (the process was completed on a personal basis). The documents could (mainly) be accessed via Indonesian Ministry of Health websites. It is unknown whether such easy access is applicable for mental health professionals, carers and service users across the country. It is possible that every mental health service is equipped with computer-based facilities, but the quantity
and quality may be inadequate. Similarly, it is possible that the carers and service users access the websites to seek guidance which is relevant to their task as caregivers; however they may find difficulties in obtaining straightforward and simple information formats, as there is no specific guidance designed for carers and service users. The printed documents can also be inaccessible. The researcher found that the documents for this policy review were mainly stored in the library of Ministry of Health which is located in the centre of business areas. There is no adequate fact showing that these documents were available in every mental health facilities i.e. Mental Hospitals and Public Health Centres in the country.

2.2.10. Summary

The findings of this policy review suggest that there are significant challenges ahead for mental health services in Indonesia to support the carers on behalf of their needs and wellbeing. The crux of the matter is to involve the carers in services, yet (still) clear and strong policies to support them are unavailable. There have even been policies that should be useful to professionals, carers and service users; problems to access these documents may exist. Information from this policy review has enhanced the researcher’s understanding about current mental health services in Indonesia. It is a valuable source for the researcher to direct an investigation about what Indonesian carers want from the services (study two and three of the PhD). Finally, it is also meaningful to have recommendations, so as to respond to the needs which are practical and realistic in adjusting to the country’s own limitations in terms of policy support and information access.
CHAPTER THREE
AN OVERVIEW OF INTERVENTIONS
FOR CARERS OF PEOPLE WITH SERIOUS MENTAL ILLNESSES

This chapter presents an overview of existing interventions to meet the needs of carers of people with serious mental illnesses. As stated in the previous chapter, some of the needs (e.g. information and emotional support) are similar across different cultural contexts and this raises the possibility that the tested interventions for carers might be relevant or have the potential to be adapted in Indonesia. The chapter examines the existing interventions for carers (so-called as family interventions) which consider the content and delivery of the interventions as well as their effectiveness in a wide range of carer population.

3.1. Family intervention

In this chapter, family intervention refers to other terms in the literature including family work, psycho-education, family education, family consultations or family therapy (McFarlane 2002, Withnell and Murphy 2012). Nonetheless, some authors (Kuipers et al. 2002) avoid using ‘family therapy’ because it implies that family, as clients, are blamed for the service users’ mental illness and need treatment from professionals.

3.2. Definition of family intervention

Family intervention is defined as any strategy or programme designed to educate carers, enhance their capacity in problem solving, and prepare appropriate skills which will help them to deal with difficulties resulting from having a family member with serious mental illnesses (Fadden 1998, Kuipers et al. 2002). Family interventions are not only delivered to reduce the service users’ relapse and to improve their compliance with medication (Pharoah et al. 2010); but also to reduce carers’ distress and to improve their wellbeing state (Kuipers et al. 2010)
3.3. Models of family intervention

Family interventions have been developed as a response of the shift from viewing family as the cause of mental health problems, to a source of support that facilitates psychiatric rehabilitation and enhances recovery (Kuipers et al. 2002, McFarlane et al. 2003, Withnell and Murphy 2012).

A variety of models of family interventions exist as a treatment plan for people with serious mental illness, including behavioural family management, family psycho-education, psycho-educational multi family groups, relatives groups, family consultation and therapeutic short term family educations (McFarlane et al. 2003). These models are mainly focused on family resiliency and strength but differ in terms of the format (multi-family groups, single family, relatives or combined), structure (service user inclusion or exclusion), setting (hospital, out-patient clinic or home), method (didactic skills acquisition, cognitive behavioural strategies, rehabilitative and/or systematic techniques), duration (brief or prolonged), and how it is led (professional or family led) (Barbato and D’Avanzo 2000, McFarlane 2002, Pharoah et al. 2010, Withnell and Murphy 2012, Lobban et al. 2013,).

The following differences are also documented such as what constitutes each family intervention model and the underpinning theoretical approaches (Dixon and Lehman, 1995; Fadden 1998). Critiques arise because it is difficult to identify the carers’ outcomes in any particular model over the other and the key components of the intervention (Kuipers et al. 2010, Pharoah et al. 2010, Lobban et al. 2013).

Nevertheless, a major consensus about critical components of family interventions emerged in regard to the goals and principles of working with carers of individuals with serious mental illnesses (Kuipers et al. 2002, McFarlane et al. 2003). For example, all family works programmes aim to accomplish the best possible outcome of the ill people through collaboration among the service users, carers and mental health professionals. Every family intervention is also intended to reduce high EE by reducing levels of criticism, hostility and over-involvement.

Other common elements of family intervention models are also reported, including their delivery which are offered in conjunction with routine drug treatment, duration which are delivered between 3 and 12 months within a minimum of 10 planned sessions, the educational components which consist of information about
the nature of mental illness, and the skills acquired such as problem solving, crisis intervention, coping skills, relapse prevention, and effective communication (McFarlane 2002, Pharoah et al. 2010, Lobban et al. 2013).

Table 7 shows a summary of some common elements in family intervention models.

Table 7. Common components in family interventions

<table>
<thead>
<tr>
<th>No</th>
<th>Common components</th>
<th>Description</th>
</tr>
</thead>
</table>
| 1  | Aims                        | • To achieve the best possible outcome of service users through collaboration of carers, the users and professionals  
                                   • To reduce high EE (criticism and over involvement) by maximising non-distressful environment in the family. |
| 2  | Key principles              | • Carers as equal partners in treatment plan and delivery  
                                   • Assess carers’ expectations of the treatment and their strengths and limitations to support service users prior to family intervention delivery  
                                   • Establish and maintain supportive relationships with carers (i.e. showing empathy, non-judgemental, and non-blaming approaches)  
                                   • Offer social support, provide relevant information, and address the impact of caregiving |
| 3  | Duration                    | Last for at least 9 months                                                  |
| 4  | Educational components      | • Information about the nature of mental illness  
                                   • Information of how to access to mental health services |
| 5  | Skills taught               | • Problem solving  
                                   • Crisis intervention  
                                   • Relapse prevention  
                                   • Coping management  
                                   • Effective communication |
3.4. Effectiveness of family intervention

3.4.1. Effects on service users and carers

There is adequate evidence to support the effectiveness of family interventions in relation to the service users’ outcomes, including reducing the risk of relapse and enhancing their mental state, social and work functioning. In addition, family interventions are effective for increasing the carers’ wellbeing and other family-related variables such as ability to cope and EE within the family (Barbato and D’Avanzo 2000, Giron et al. 2009, Pharoah et al. 2010).

A number of systematic reviews and meta-analyses have shown the efficacy of family interventions in reducing relapse rates (Barbato and D’Avanzo 2000, Pitschel-Waltz et al. 2004, Pfammatter 2006, Pharoah et al. 2010). The evidence in the Cochrane systematic review suggests that family interventions have reduced the frequency of relapse significantly by over one year (Pharoah et.al 2010). However, the rate of relapse rate as an outcome indicator can be problematic because clinical criteria for definition of relapse are often vague, inconsistent and poorly standardised across studies (Barbato and D’Avanzo 2000, Falloon 2003).

The effects of family interventions on service users’ mental state have been measured by using Brief Psychiatric Rating scale (BPRS) for any psychosis and Positive and Negative Symptom Score for schizophrenia (PANSS) (Barbato and D’Avanzo 2000, Falloon 2003, Pharoah 2010). Although some studies indicated equivocal findings, generally BPRS and PANSS data favoured family intervention at least at one year post treatment (Barrowclough et al. 2001, Dai et al. 2007)

There is an impression that family interventions can improve service users’ social functioning. The results of some early RCTs (Xiang 1994, Doanne et al. 1985) suggested that family interventions could reduce general social impairment significantly, even though the data were heterogeneous. Some reviews showed that service users’ ability to live independently increased following one year treatment, but the sample size was small (n=164, 3 RCTs) and the results were not statistically significant (Pharoah 2010). With regard to the effect of family interventions on service users’ work functioning, the majority of the studies in the Cochrane review yielded equivocal results (Pharoah 2010).
A positive effect of family interventions on any variable related to the service users’ relatives has been found in some trials. For example, some families given the intervention in an early study reported a statistically significant decrease in levels of over involvement and criticism (n=63) (Tarrier et al. 1988). Likewise data from Chien (2004) suggest a significant reduction in the family burden according to the Family Burden Interview Schedule (n=108). It is important to note, however, these family outcomes are weakened by the small number of participants included in the study samples.

3.4.2. Effectiveness between different technical models

The majority of family works examining the impact of psycho-educational or behavioural approaches showed positive results, especially in reducing relapse rates (Dyck 2000, Pitschel-Waltz et al. 2004, Pfammatter 2006.). Nevertheless, psycho-educational or behavioural interventions alone have not been considered as the most effective strategy in working with carers of people with mental illness (Barbato and D’Avanzo 2000) The effective family treatment should consist of a clear set of psycho-educational and behavioural techniques following a structured skill building format (Barbato and D’Avanzo 2000, Pitschel-Waltz et al. 2004 ).

3.4.3. Effectiveness between single and multi-family groups

There is evidence to confirm that multi-family interventions could reduce hospital admissions, even though this benefit is demonstrated following a long-term maintenance (Dyck et al. 2000). Here, multi-family interventions refer to a psycho-educational approach, consists of a group of six to eight carers including the service users and directed by two clinicians, designed to improve the carers’ coping and illness management skills (Dyck et al. 2000). While multi-family may be more cost-effective than single family treatment, it is important to consider all cost needed but not only the time spent itself. Moreover, no significant economic data has been reported to support the cost effectiveness of multi-family interventions (Pharoah 2010).
3.4.4. Effectiveness between with and without the participation of service users

A number of early studies with groups of carers without service user inclusion (Posner et al. 1992, Vaughan et al. 1992, Buchkremer et al. 1995) shows negative results in regard to relapse rate, suggesting that the effect is influenced by the service user’ participation. Further, Dyck et al. (2000) suggest that reduction of negative symptoms in their study is directly related to the level of participation of service users in the group-based family interventions, presumably through their direct exposure to social interactions and practice at social engagement.

3.4.5. Effectiveness between home and hospital settings

There is no strong evidence that conducting family interventions in service users’ home has brought greater effects than in hospital settings (Pharoah et al. 2010). However, it is worth to note that the usefulness of family interventions during in-patient care depends on the continuation after discharge.

3.4.6. Effectiveness with respect to duration

Some family interventions that were provided on short-term basis (i.e. no more than 10 sessions over less than 6 months) failed to show convincing and long-lasting results (Barbato and D’Avanzo 2000, Falloon 2003, Pharoah 2010). As a result, the Schizophrenia Patient Outcome Research Teams/PORT (Lehman and Steinwachs 1998), and the National Institute for Health and Care Excellence (NICE 2014) recommend family interventions should be offered to carers of people with serious mental illnesses-especially those with schizophrenia-that include at least 10 planned sessions between 3 -12 months. .

3.4.7. Effectiveness with respect to carers’ characteristics

There is limited evidence that a long term multi-family group format can be properly offered to parent carers (Falloon 2003); yet it is unclear whether the same format is effective for other carers who are spouses, partners, siblings, children and close friends. Likewise, there is no adequate evidence to show the efficacy of family interventions when they are delivered to male or female carers. Many studies that investigated
family works showed gender bias in the sample selection (Barbato and D’Avanzo 2000). Perhaps the most notable characteristics from the existing trials are the socio-demographic and cultural aspects of the carer participants. The majority studies in some main systematic reviews were carried out in the western such as the UK, the USA, Australia, and some European countries (Falloon 2003, Pitschel-Waltz et al. 2004, Pharoah 2010, Lobban et al. 2013). Non-western countries were only represented by studies conducted in China.

The effectiveness of some existing family interventions have been presented. Although the tested interventions posed limitations, it is clear that they have been effective for many outcomes of service users and carers. Unfortunately, only few services have incorporated the carer-based approach into the routine practice (Haddock et al. 2014). Issues surrounding providing well training for professionals in order to deliver structured and long term interventions are prevailing (i.e. limited budget, lack of human resources and attrition issues). These issues seem to be universal but they are more obvious in settings where mental health services are inadequate as Indonesia. In adapting family intervention models designed for the first world countries, considerations need to be given to aspects such as language, educational level, and accessibilities to facilities (Asmal et al. 2011). It is also crucial when implementing the existing family programmes to consider cultural factors that may influence the expression and experiences of caring for people with serious mental illnesses.

3.5. Conclusion

This chapter has presented an overview of some existing family interventions. Their effectiveness to the service users’ and carers’ outcomes have also been examined. It is evident that the interventions have been effective for reducing service users’ relapse, enhancing their mental health state and social functioning as well as increasing carers’ ability to cope with caregiving problems. However, adapting the existing interventions in Indonesia may be problematic unless issues such as insufficient mental health professionals, very limited budget for mental health, difficult access to facilities, and cultural gaps can be well addressed.
CHAPTER FOUR

METHODS

4.1. Introduction

This chapter details the methods used in the second and third studies of the PhD. The second study was focus groups with carers and service users to explore the needs of Indonesian carers from mental health hospital services, followed by individual interviews with professionals to examine their views about the carer needs and how these could be met by the services. This chapter also includes the aims and objectives of the studies, a description of the chosen methodology and the ethical considerations as well as rationales of selecting framework approach for the data analysis. Lastly, it outlines approaches employed to enhance the methodological rigour of both inquiries.

4.2. Aims

The aims of the focus groups and the interviews were:

- To explore the views of carers, service users, and professionals about hospital-based mental health services in Indonesia.
- To explore the views of the research participants about carer needs.
- To explore the experience of caring for individuals with serious mental illnesses, especially from the perspective of carer participants.

4.3. Objectives

The specific objectives of the two studies with the carer, service user and professional participants were:

- To explore the views of what carers need from hospital-based mental health services in Indonesia.
- To investigate current service provisions for meeting the needs of carers of people with serious mental illnesses.
To explore the extent to which the existing services have met the carers’ needs from the views of the research participants.

To explore the views of potential services for meeting the carers’ needs.

4.4. Methodology

The aim of qualitative research is to elicit rich findings as it is founded on a commitment to viewing events, actions, norms, and values from the perspective of the people under study (Morse and Field 1995, Murphy et al. 1998, Ormston et al. 2014). Lincoln and Guba (1985) emphasise that qualitative research is appropriate for studies exploring one topic in an in-depth which is sourced from different perspectives. The methodology allows the researcher to attain open-ended and subjective data from the relevant participants. This is in contrast to quantitative research where such subjective views are excluded intentionally to guarantee its objectivity. Quantitative researchers gather data in numerical form that requires statistical analysis to explain the phenomena under investigation (Morse and Field 1995, Brown and Lloyd 2001, Corbin and Strauss 2008).

Flick (2009) specifically underlines that exploration related to mental illness can produce ‘rich’ data if conducted qualitatively because this area of research is complex. Mental health issues are commonly multifactorial in their aetiology and the consequences they have on the individual, families, and society (Flick 2009, Peters 2010, Harper and Thompson 2012). Hence, meaningful investigations in the mental health field can be achieved through the application of qualitative research which requires subjective responses stemming from the perspectives of relevant people. To illustrate this, a thick description of mental illness stigma can be obtained through comparison of qualitative data from various participants (i.e. service users, carers, and health professionals) explaining that the stigma is multi-dimensional and different interventions may be required to target these different dimensions (Schulze and Angermeyer 2003, Whitley and Crawford 2005).

Qualitative research is suitable for investigating mental health topics which may be highly sensitive or private (Peters 2010). Scepticism of mental health services can also result in reluctant research participants. For the reasons, qualitative inquiries offer an effective way of allowing the participants to voice their opinions,
criticisms and expectations related to mental health services under an accommodating circumstance of interviews or group discussions.

Finally, qualitative investigation is useful to examine issues in mental health policies as the researcher can explore information related to the source of the problem exhaustively (Davidson et al. 2008, Peters 2010). The research can provide insights as to where difficulties may occur when implementing a particular policy. For example, throughout in-depth interviews researchers can explore how stakeholders value a psychosocial or medical intervention and what barriers exist to its uptake when the service is implemented into a routine practice. In this respect, important inputs for the mental health policy development can be sourced from the views and experiences of the service users (Brown and Lloyd, 2001))

The following presents a discussion of data collection implemented in the focus group and interview studies. It includes two main accounts surrounding the methods of sampling and collecting the data.

4.5. Data collection

4.5.1. Sampling

Sampling is defined as a process of deliberately selecting the most appropriate participants to be included in a study (Morse 2004). Sampling is an important phase in any research project because investigating the whole population is usually impractical, inefficient or unethical (Marshall 1996, Ritchie et al. 2003).

4.5.1.1. Sampling methods in qualitative research

Using the terminologies of quantitative research, qualitative investigators generally employ non-random or non-probability sampling in which the process provides unequal chance of selection to all participants in the population (Marshall 1996, Teddlie and Yu 2007, Abrams 2010).

There are three major approaches of non-probability sampling employed in qualitative investigations: convenience, purposive and theoretical sampling (Marshall 1996, Koerber and McMichael 2008). Theoretical sampling is a component of grounded theory, one of qualitative methodologies to generate or
discover a theory grounded in the data (Creswell 2006). The sampling method enables the researcher to explore new or emerging categories of data during the process of data collection and analysis (Marshall 1996, Higginbottom, 2004, Corbin and Strauss 2008). Purposive or purposeful sampling is a technique where the researcher uses his/her judgement to select participants who will provide the richest data about the phenomenon on the basis of specific characteristics or features (Coyne 1997, Higginbottom 2004, Ritchie et al. 2014). Lastly, convenience sampling is used by relying on participants who are readily available and accessible to the researcher (Marshall 1996, Koerber and McMichael 2008, Ritchie et al. 2014).

Of the three methods, purposive sampling is the most frequently used because it allows the researcher’s judgement to drive the sample selection and to obtain the most productive participants (Coyne 1996, Marshall 1996, Ezzy 2002, Tong 2007). However, applying purposive sampling in the focus groups and interviews was not possible due to pragmatic problems with recruiting, such as complex bureaucracy for accessing participants in the governmental hospitals and restrictions of time and budget for collecting the data on the research sites. Alternatively, convenience sampling was adopted.

Convenience sampling is an approach which employs an open period of recruitment and maintains it until a number of participants who are willing to join the study are enrolled (Luborsky and Rubinstein 1995, Abrams 2010). While the method may have limitations of producing biased findings and yielding perspectives which are lacking of understanding of the breadth and depth of a studied experience (Phua 2004, Polkinghorne 2005, Abrams 2010); this technique is valuable to provide rich data in a qualitative research project (Morse 2004, Koerber and McMichael 2008). With regard to the current studies, the method was valuable for discovering rich data surrounding the needs of carers from mental health services in Indonesia in a quick and inexpensive way, sourced from those who were more readily accessible to the researcher. Furthermore, the adoption of convenience sampling was based on an assumption that recruiting carers and service users in the focus groups was challenging due to the stigma associated with mental illness and some unpleasant experiences in hospital settings which might result in a reluctance to taking part in a study (Woodall et al. 2010). Unlike purposive sampling which relies on the researchers’ judgement in selecting the sample, convenience sampling was used because the researcher was dependent on referrals from gatekeepers to recruit. Nevertheless, some systematic activities were involved by referring to the ethics approvals in reaching and recruiting the convenient sample such as identified potential
participants based on the established criteria and provided them information about the research adequately (Koerber and McMichael 2008).

4.5.2. Inclusion criteria

Establishing inclusion criteria is essential for identifying candidates who are likely to provide significant accounts of the perspective under investigation (Polkinghorne 2005, Eide 2008). These involve criteria such as age group, diagnosis, geographic location; and occasions when the participant candidates are recruited (e.g. experiencing a specific stage of illness).

4.5.2.1. The inclusion criteria for carer and service user participants:

- Adult carers aged 18 years who have a relative admitted to one of two mental health hospitals in Indonesia (i.e. Soeharto Heerdjan or Duren Sawit hospitals)
- Adult service users aged 18 years and over who were inpatients registered at the two government hospitals for a serious mental illness (i.e. medically documented as suffering from schizophrenia, schizoaffective disorders, bipolar disorders, or chronic depression).

The focus groups required information from those who have spent significant periods of time for caring for a seriously mentally ill person. The information gathered in qualitative inquiry should be sourced from people who have adequate experience in the field of investigation (Polkinghorne 2005)

4.5.2.2. The inclusion criteria for professional participants:

- Professionals including mental health nurses, psychiatrists, psychologists, social workers and general practitioners who were working in inpatient settings in government mental health hospitals.

The professional interviews required data relating to the current support for meeting Indonesian carers’ needs including how the practitioners have helped the carers and the obstacles met. Hence, data from professionals who were working in the hospitals and had contact with carers, even minimal, would be valuable in describing the fulfilment of the needs. In addition, the involvement of multidisciplinary
practitioners was expected to provide a wide range of perspectives of what was needed by the carers from mental hospital-based services.

4.5.3. Ethical considerations

Both focus group and interview studies required approval from two ethical committees: the University of Manchester and the Indonesian Nursing Ethics Committee. The approval from the University was relayed to the Indonesian Nursing Ethics Committee so that approval to conduct research in the country could be issued. This was followed by obtaining approval from two mental health hospitals where the studies were conducted. With regard to the focus groups, having support of two ethical approvals from the University and the Indonesian Nursing Ethics Committee in July 2012, formal permissions were obtained in August 2012 for conducting the study in the two hospitals (a total of 4 approvals were required). Likewise, two ethical approvals for the interview study were completed in July 2013, then data collection commenced in the two hospitals in the following month.

One of the ethical issues that could have potentially arisen was related to distressing or uncomfortable feelings of participants when discussing experiences in both the focus groups and service users (Lewis 2003). In the current focus groups, the group moderator was mindful of the potential distress during the course of the data collection to carers and service users. At the beginning of the discussions, these participants were informed that they could withdraw from the focus group if any level of distress was experienced or for any other reason. In addition, a protocol for managing distressed participants had been established and approved by the ethics committee of the university (see Appendix 1 for details). Also, interviewing health professionals’ experiences in involving carers in their services might be upsetting for some participants. Similar explanations therefore were given regarding the participants’ freedom to terminate the interview at any point.

In addition, confidentiality potentially became one of the major ethical issues arising from the studies. In the carer and service focus groups, the issue was associated with protecting the confidentiality of all group members (Kitzinger and Barbour 1999, Robinson 1999, Finch et al. 2014). A concern was addressed by the researcher of this study by confirming that information from one participant would be
shared with other members as well as the supervisors and co-moderator. This information was verbally stated prior to a discussion and written on the Participant Information Sheet as shown in Appendix 2 and 3. All participants, however, were requested to keep what they heard during the meeting confidential. The participants were also informed that quotes might be used in the presentation of the study report and in any publications but these would be kept anonymous (Powell and Single 1996, Robinson 1999).

In the individual interviews, a confidentiality issue was related to information about the professionals’ practice with carers which could be deemed to be sensitive data and might elicit evidence of bad practice (i.e. a fault or negligence by health professionals resulting in serious injury, physical or mental disability, or death of service users and carers). Therefore, the professional participants were informed that when an interview elicited bad practice, disclosure would be made to relevant authorities in the hospital (Orb et al. 2001, Lewis 2003). This information was also written on the Participant information Sheet (PIS) for professional participants as presented in Appendix 4.

Another ethical consideration was ensuring that principles of fairness and autonomy were applied to participants with mental illnesses who are generally identified as vulnerable groups (Orb et al. 2001). Fair research procedures were applied to the carers and the service users by providing clear information about the focus groups and enough time to determine whether to participate or not, and in protecting their confidentiality by concealing their identity to health professionals as much as possible. Equal measures were also maintained by the group moderator when guiding both service user and carer participants so that they had enough time and opportunities to talk freely during the discussion. The service user participants’ autonomy was established by informing them that with or without their participation they would receive the same treatment or care from the hospital.

Finally, both studies considered the health and safety aspects of the researcher, since it required travelling to reach the participants. For this reason, the researcher conveyed consistent information about the progress of the research to the university (through her main and second supervisor) and the local research ethics board (Broom 2006).
4.5.4. Sample size

Sample sizes in qualitative studies is not determined to indicate the representativeness of the population; rather, it is determined by how adequately, the number of participants can answer the objective of the research (Luborsky and Rubinstein 1995, Trotter 2012). Sampling in qualitative research usually continues until data saturation i.e. when patterns of the gathered information are recurring or no new data emerges (Fossey et al. 2002, Trotter 2012). A target of 38-48 carers and service users (i.e. for 6 focus groups) was expected to elicit sufficient data for data saturation to occur (Krueger and Casey 2009). Similarly, around 20 mental health professionals were anticipated to participate in the individual interviews. The sample size of the two studies was within a broad range of sample sizes in qualitative research that is between 12-60 participants, with 30 people on average (Adler and Adler 2012).

4.5.5. Recruitment

Recruitment refers to the process of identifying and inviting participants to take part in the study (Eide 2008). It is an essential phase in any research, as the recruited participants should meet the study criteria and represent the richest data which is relevant to the phenomena under study (Arcury and Quandt 1999, Eide 2008).

All group participants were recruited from two government-operated mental health hospitals in Jakarta, Indonesia. Firstly, Soeharto Heerdjan Hospital that provides inpatient and outpatient services. Mostly it is occupied by people living in the region of the hospital (i.e. west of Jakarta and its surrounding area). As one of the largest and oldest psychiatric hospitals in the country, it has 300 beds and is divided into 11 wards (6 for males, 3 for females and the others are dedicated to people with mental-physical problems and substance misuse). There are 469 staff working in this hospital, including mental health professionals and administration personnel. Secondly, Duren Sawit Hospital is one of the hospitals managed by the provisional government of Jakarta. It was established in 2002 at the east of the province to support mental health services provided by the first hospital (i.e. Suharto Heerdjan hospital). It provides inpatient services with 148 beds which are spread into 10 wards. It also consists of 15 outpatient services which include psychiatric and substance misuse at the forefront of services.
4.5.5.1. Recruitment of service users and carers

The researcher approached a number of personnel (e.g. senior and ward managers) in the hospitals and discussed the potential for recruitment service user and carer participants. In order to recruit service users, the researcher talked to a number of managers of inpatient wards to generate a list of potential service users. The potential service users were then invited to a meeting to discuss the study as detailed on the Participation Information Sheet (PIS) (Appendix 2).

Carers were recruited in a series of stages because access to them could only be initiated after the service user consented their caregiver for participation. Having had invited the potential service users, they were asked, if they had a relative, to consent for their relative to be approached to take part as a carer participant. The consented relatives were then contacted to receive an information sheet about the carer part of the study (Appendix 3).

After all, both potential service user and carer participants were given 48 hours to decide whether to participate or not. Those who agreed to participate were asked to sign a consent form and invited to focus group discussions which were held separately for both samples.

4.5.5.2. Recruitment of professional participants

The researcher approached the hospital managers regarding possible wards/clinics to access prospective professional participants. A presentation was delivered to the potential participants to describe the research and how they can take part in the investigation. They were given a couple of hours to decide whether or not they could be contacted after the presentation. Those who gave their contact consent were called or met, so the researcher could explain the research in more detail (see Appendix 5 for the contact consent form). Next, these professionals were given 24 hours to decide whether they wished to participate or otherwise. In the end, the professionals who agreed to participate were asked to sign a consent form and invited to take part in an interview.
4.5.6. Method of data collection

Two techniques of data collection will be discussed (i.e. focus groups and individual interviews).

4.5.6.1. Method of data collection in qualitative research

The techniques that are most commonly used for collecting data in qualitative research are focus groups and individual interviews (Gill et al. 2008, Ayres 2007, Coenen et al. 2012). These methods encourage the participants to think about and disclose their experiences, understanding, points of views and expectations related to the issue under investigation.

4.5.6.1.1. Focus groups

Focus groups are a method for gathering information by involving a group of participants, usually consisting of 5-8 people, selected by the researcher, to discuss and comment on specific issues related to the subject of the research (Powell and Single 1996, Robinson 1999, Krueger and Casey 2015). The aim of focus groups is to obtain adequate data about attitudes, opinions and behaviours of participants regarding a research subject through the interactions of the group (Kitzinger and Barbour 1999, Bauer and Gaskell 2002, Krueger and Casey 2015). While the dynamic nature of focus groups can encourage people taking part in research to speak, organising the group gatherings can be challenging especially to unite participants with specific characteristics such as busy professionals or physically disabled people with mobility restrictions (Gibbs 1997, Bauer and Gaskell 2002).

The adoption of focus group methods in mental health research is advantageous for a number of reasons. The group interaction usually stimulates the participants to reflect on the stories of others, especially when discussing opinions about mental health services. McAuliffe et al. (2009) emphasise that focus groups with carers are a suitable strategy, so that they can discuss a topic more openly on the basis of common experiences associated with caring for mentally ill people. Focus groups are also deemed to be practical because they can elicit data from larger numbers of participants within a short time-frame. Nonetheless, the time saved in focus groups may then be lost due to the complicated
procedures required, such as preparing the operational meetings and analysing the complex data (Gibbs 1997, Kidd and Parshall 2000, Krueger and Casey 2015).

4.5.6.1.2. Individual interviews

The individual interview is a strategy for searching through information within an individual context to explore topics under investigation in order to seek detailed information (Fretchling and Sharp Westat 1997, Lambert and Louiselle 2008, Coenen et al. 2012). A number of authors (Fretchling and Sharp Westat 1997, Bauer and Gaskell 2002) emphasise that individual interviewing is particularly suitable for participants in certain circumstances, such as mothers with young children, high status people, and some people like mental health professionals who consider the research topic as having a highly sensitive subject matter. However, individual interviews can be time consuming as participants must be interviewed for about an hour each to attain adequate data (Morse and Field 1995, Bauer and Gaskell 2002, Yeo et al. 2014). A summary of the distinction between focus groups and individual interviews is illustrated in Table 8.
Table 8. Differences between focus groups and individual interviews

<table>
<thead>
<tr>
<th></th>
<th>Individual Interviews</th>
<th>Focus Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aims</strong></td>
<td>(1) To explore thoughts, attitudes, beliefs and knowledge of an individual in depth</td>
<td>(1) To explore interaction of participants in a group discussion; thus, their attitudes, opinions, and behaviours can be observed and analysed</td>
</tr>
<tr>
<td></td>
<td>(2) To focus on a particular participant; thus, richer detail about the life world of the individual can be elicited</td>
<td>(2) To benefit from the group dynamics, which encourage the participants to talk, to respond to each other, and to compare their experiences</td>
</tr>
<tr>
<td><strong>Characteristics of participants</strong></td>
<td>(1) Flexible for participants with specific conditions, e.g. elderly, mothers with young children, elite/high status informants, younger children, or those who consider the topic research to be a highly sensitive subject</td>
<td>Difficult to unite participants with specific characteristics, e.g. ethnic minorities, disabled people, or busy professionals</td>
</tr>
<tr>
<td></td>
<td>(2) Unsuitable for hesitant participants to speak truthfully in one-to-one circumstances</td>
<td></td>
</tr>
<tr>
<td><strong>Practical issues</strong></td>
<td>Time consuming</td>
<td>Time efficient, yet need complex preparation and data analysis</td>
</tr>
</tbody>
</table>

4.5.6.2. Focus groups and interview schedules and collection of demographics

A focus group schedule is a tool to organise the discussion topics so that the consistency of the data collection can be maintained and relevant issues can be covered systematically (Morgan 1997, Arthur and Nazroo 2003). In the current focus groups, a discussion schedule was developed from the literature review to identify common issues surrounding the needs of carers from mental health services. Subsequently, the researcher phrased a number of questions and sequenced them from general to specific questions (Krueger and Casey 2015). These procedures were undertaken in conjunction with discussions with the researcher’s supervisors for feedback and revisions. The developed discussion guide is presented in Appendix 6. Similarly, an interview schedule was developed by the researcher as her guidance for interviewing a wide range of health professionals (see Appendix 7). During its development, the researcher also received feedback from the supervisors, ensuring the questions could
encourage the professionals to express their experiences/opinions about the research topic freely (Morse and Field 1995).

Demographic data were gathered in a standardised form once participants consented to inclusion in one of the studies (Appendix 8). For the carer focus groups, the details included gender, age, and relationship to the member of the family who had a mental health problem. For the service user focus groups, the details included gender, age, and duration of using mental health hospital services. For the professional interviews, the demographics included gender, occupation and time spent in contact with carers.

4.5.6.3. Location of focus groups and interviews

Although it could be argued that the setting for focus groups should be a neutral place so that participants can speak more freely (Powell and Single 1996), it is also the case that the location can be selected based on the participants' preference (Garrison et al. 1999, Kitzinger and Barbour 1999, Finch et al. 2014). The focus group discussions were not conducted outside the hospitals which might be considered as a neutral setting of research. Instead, all discussions were held in the hospitals because the carer and service user participants deemed the venues to be more familiar to them. In addition, conducting the discussions in the hospital was also favourable in ensuring the researcher's safety. Skilled mental health personnel were available in the hospitals to manage participants who could potentially become distressed when discussing mental health services for carers. Likewise, the setting of the interviews with professionals was preferable inside of the mental health hospitals. This location was determined based on the professionals' preference on condition that the conversations were conducted in a private and quiet place (Morse and Field 1995, Finch et al. 2014).

4.5.6.4. Conducting the focus groups and interviews

For every focus group, the researcher undertook the role of moderator, a person who has an authority to direct the session and keep it flowing (Krueger and Casey 2015). The moderator is also functional to guide the discussion to achieve the research objectives (Robinson 1999). Being a focus group moderator is a challenging and demanding task (Gibbs 1997, Kitzinger and Barbour 1999, Krueger and Casey 2015). It requires good communication and interpersonal skills. With regard to the current focus
groups, the researcher benefited from her experiences as a mental health nurse in conducting several group sessions for carers and service users. She also had previous experience of being a co-moderator with Indonesians, thus allowing her to observe some discussions facilitated by a skilled moderator.

In the interviews, the researcher was the sole person interviewing the mental health professionals. The researcher used her current knowledge of interviewing, obtained in the course of qualitative research module in the first year of the PhD. Moreover, the researcher had previous experiences interviewing a number of nurses exploring their lived experiences as foreign workers.

All conversations in both studies were digitally recorded. The focus groups used video equipment, while the interviews with professional used digital recording. In comparison to the audio equipment, the video recording was not only useful for scrutinising the study as the raw data were readily available for review; but it was also advantageous for gathering non-verbal and verbal data (McLafferty 2004, Flick 2009, Finch et al. 2014). It is important, however, to be thoughtful of whether the videoing will affect the interactions such as participants may not speak more freely with the device around (Arthur et al. 2014). Also, other human factors such as unfamiliarity with the video equipment should be taken into account (Penn-Edwards 2012). For these reasons, the researcher offered the participants the choice as to whether or not they were willing to be video recorded.

With respect to the carer and service focus groups, the researcher worked with a co-moderator to take notes and check the video recording during every meeting. Two people were available to take turns in undertaking the role of co-moderator. In detail, the tasks of the co-moderator were to take notes of non-verbal communications which might not be covered by the audio-visual recording, operating video recorders, managing environmental distractions (such as controlling noises), and responding to interruptions (Garrison et al. 1999).

Having discussed the data collection methods, it is necessary to present a description of the approach in analysing the data about carer needs as follows.
4.6. Methods of data analysis in qualitative research

There are a number of methods of data analysis which are aligned with particular epistemological, philosophical or theoretical approaches in qualitative research such as those that seek to develop theory derived from data through a set of procedures and interconnected stages so-called as grounded theory (Ezzy 2002, Gale et al. 2013, Spencer et al. 2014); those that detail the way of life of particular individuals, groups or organisation so-called as ethnographic accounts (Hammersley and Atkinson 2007); and those that focus on understanding individuals’ experience and interpreting their accounts with reference to established psychological concepts so-called as interpretive phenomenological analysis (Larkin and Thompson 2012). However, some methods such as content analysis, thematic analysis, and framework analysis are flexible and can be adapted in many qualitative approaches. These analyses aim to generate themes, referring to interpretive concepts that describe the whole dataset which are usually developed by interrogating the data categories (Spencer et al. 2014, Gale et al. 2013).

The development of categories in most of the qualitative data analysis can be derived inductively (i.e. obtained gradually from the data), or can also be generated deductively (i.e. predefined categories are used through analysis as a strategy of approaching the data) (Pope et al. 2000, Gale et al. 2013). Content analysis is a deductive form of qualitative data analysis as it involves identifying predetermined categories to interpret data (Morse and Field 1995, Ezzy 2002, Hsieh and Shannon 2005). By adopting this method, the predetermined categories are used to analyse the content and contexts of the data and at the same time focus on the frequency of its occurrence. On the contrary, thematic analysis identifies themes within the data therefore the categories into the themes are not determined prior to coding (Ezzy 2002, Braun and Clarke 2006). Finally, framework analysis is a method which employs a deductive approach as the objectives of the study are determined in advance and its process of analysis starts from the pre-set aims (Ritchie and Spencer 1994, Pope et al. 2000). However, some authors (Pope et al. 2000, Gale et al. 2013) argue that, depending on the research question, the method can also be inductive as the results of the analysis can reflect the original accounts and observations of the people studied.

While the previous strategies (i.e. content, thematic and framework analyses) tend to focus on coding and categories, but do not consider participants as a personal account; narrative analysis offers a
method to recognise the extent to which the entire participants’ stories can provide insights about their experiences (Sandelowski 1991, Ezzy 2002). Further, each of these four approaches of analysis is discussed as follows.

Narrative analysis focuses on the whole person’s account, reflected in their story of how they explain what they did, or what happened (Sandelowski 1991, Ezzy 2002). The researcher using this method needs to examine the participants’ word choice, phrasing, imagery and the structure of the clauses; and then tries to search for certain themes or patterns within a data item, such as an individual interview (Riessman 2008). The advantages of employing narrative analysis in qualitative inquiry includes bringing together elements of human experience (e.g. rhythm and pacing in the conversation, times and place during the data collection, and factors of narrators/researchers) in the integrating concept of the story. As it focuses on individual experiences, narrative analysis can empower participants to allow their stories to be heard and told in their own culture (Viney and Baufield 1991; Ezzy 2002). Nevertheless, the truth of the given information is often questionable because the researcher does not attempt to identify the true interpretation of participants’ stories. The main goal of narrative analysis is to identify the cultural and social context that facilitates the everyday practice of telling stories about one self and one’s world.

Content analysis allows the researcher to use the data to confirm or negate the ideas which have been identified before undertaking the analytical process (Ezzy 2002). It begins with the identification of categories before searching for them in the data (Ezzy 2002, Hsieh and Shannon 2005). The method then involves selecting the sample to be categorised and identifying units of analysis (e.g. words or characters). Lastly content analysts count or systematically log the frequency of the categories occurring, and follow this with an interpretation of the results. It is a useful technique to test a pre-existing theory (Spencer et al. 2014). Nevertheless, strong bias can arise as the researcher may be more likely to find evidence that is supportive of a theory (Hsieh and Shannon 2005). Likewise, this method limits the researcher and others in providing new ideas or thoughts which may develop during the progression of analysis. Applying this technique may cause difficulties in developing a complete understanding of the context as well as identifying key categories (Hsieh and Shannon 2005). In addition, as counting the frequency of certain terms appear is a core aim of the analytic process, content analysis is believed to minimise the value of qualitative research which emphasises the ability of the researcher in describing
how a phenomenon varies, identifying meanings and process, and offering explanation without any presence of numbers (Spencer et al. 2014).

Thematic analysis is an approach to discover, interpret and report patterns and clusters of meaning within the data (Spencer et al. 2014). The technique requires essential skills of searching across a data set (e.g. a number of interviews or focus groups) to detect repeated patterns of meaning as referred to themes (Braun and Clarke 2006). Because it is not tied to any particular discipline or set of theoretical constructs, the analysis method has been a widely used approach in qualitative research. For example, a process of thematic coding can be used in different analytic traditions such as grounded theory or phenomenology (Spencer et al. 2014). The strength of this method is in its flexibility or openness to intuition, creativity and details derived from the researcher (Ezzy 2000, Braun and Clarke 2006). There are no certain rules in relation to the analysis process. Thus, different choices are possible to determine the themes (e.g. whether data driven or analyst driven; or whether to produce explicit or interpretative themes). However, such a benefit can be considered as a pitfall as it is difficult to decide what aspects of the gathered data to focus on (Braun and Clarke 2006).

Moreover, many researchers employing thematic analysis fail to provide clear accounts for the analytical process undertaken (Braun and Clarke 2006, Spencer et al. 2014). For example, the researchers only focus on detailing the process of data management (e.g. familiarisation and then organising a set of headings which represent participant’s views, experience and behaviours) without any explanation of how the abstraction and interpretation has been completed. Also, the thematic analysts often fail to enable themselves to move ahead to the stage of analysis, as well as revisit what is emerging and reflect on how much sense these have been representing the original material (Spencer et al. 2014). Qualitative analysis is not an exactly linear process as there is a constant need to revisit the original data to search for new clues, to check assumption or identify underlying factors, or find the more suitable definitions (Ezzy 2000).

Framework analysis is a method which facilitates and displays the key processes of qualitative analysis (i.e. data management, abstraction and interpretation), permits within and between case searches, and allows emergent ideas, concepts and patterns to remain rooted within the original data (Spencer et al. 2003, Spencer et al. 2014). Framework analysis was developed initially by specialist qualitative
researchers in the UK for applied policy research (Ritchie and Spencer 1994). The features of this method are influenced by the characteristics of policy relevant research (Ritchie and Spencer 1994, Pope et al. 2000). Applied policy research sets particular objectives because it aims to discover answers to problems in a short time. Similarly, a study using framework analysis must have specific objectives about what is being explored (Pope et al. 2000). This method of analysis should also allow other people, in addition to the analyst, to view the progress of the analysis for discussion. For the purpose of transparency, the framework method has established analytical stages that enable others to review how the final interpretation has been developed (Ritchie and Spencer 1994, Furber 2010, Ward et al. 2013, Spencer et al. 2014).

4.6.1. Transcribing and translation

Transcription is a process of representing audio or audio visual data into written form. This process allows a qualitative researcher to become familiar with the data through multiple hearings or viewings, therefore it is often considered an essential first stage in data analysis (Bailey 2008, Nikander 2008, Gale et al. 2013). In the current focus groups, all audio-visual data from the discussions with carers and service users were transcribed by the researcher alone. However, several data from interviews with professionals were transcribed by the researcher’s co-worker who had experiences in conducting qualitative research, had been trained about transcribing qualitative data in his master program, and was ethically permitted to access the data. Bailey (2008) highlights that transcribing can be undertaken by non-analysts as long as they have been prepared, ensuring the produced transcripts are based on repeated careful listening or watching.

In both the focus groups and interviews, the transcription was initially completed by producing Indonesian transcripts. Following this, the entire transcripts of the focus group and interview studies were translated into English. The researcher was the single translator for a number of reasons. Firstly, translating the whole transcript helped the researcher familiarise herself with the data (Spencer et al. 2003). Secondly, performing the role as the translator allowed the researcher to give thoughtfulness to cross-cultural meanings and interpretation. The researcher could be considered to be the most suitable person to do cross language data analysis, due to her capability of translating transcripts from the original language (Indonesian) into English (Temple and Young 2004). Nevertheless, the accuracy of
the translation was confirmed by others who were able to comprehend both languages (Smith et al. 2008). Two Indonesian speaking researchers checked four of the English transcripts against the original language to ensure accuracy in meaning was captured as best as possible.

4.6.2. Method of data analysis for the focus groups and interviews: Framework analysis

4.6.2.1. Selecting a method of analysis

Framework analysis was selected for analysing the data from both studies for a number of reasons. Firstly, this is an explicit method of analysis which provides a clear process of how data moved from focus groups or interviews to transcripts to themes (Ritchie and Spencer 1994, Spencer et al. 2003). A number of authors (Popay et al. 1998, Furber 2010, Dixon-Woods 2011, Gale et al. 2013) criticise most inductive methods of qualitative analyses due to their unsystematic processes in managing and interpreting data. Alternatively, framework analysis allows the researcher to apply the principle in that qualitative analysis can be conducted through a series of interconnected stages that guide the process systematically (Ritchie and Spencer 1994, Spencer et al. 2003, Spencer et al. 2014). Researchers who use this method can work with structured topic guides to elicit and manage data. Framework analysis also enables the researcher to explore data in depth while simultaneously maintaining an effective transparent audit trail (Ritchie and Spencer 1994, Spencer et al. 2003). The use of charting in this type of analysis is beneficial to track the decisions that have been made, ensuring the link between the original data and the findings; thus, enhancing transparency (Spencer et al. 2003, Smith and Firth 2011, Spencer el al. 2014). Ultimately, the rigour of the research process is increased and the credibility of the findings are enhanced if the study has been well conducted (Smith and Firth 2011).

4.6.2.2. Approach to analysing the data from the focus groups and interviews

There has been a debate, as to whether data from focus groups and interviews is different. Krueger and Casey (2015) underline that data from focus groups is different from other forms of qualitative data, including those from individual interviews. The likelihood of inconsistency of data from focus groups is greater because participants could persuade others so they could make statements that they later
amend or revise. In contrast, a number of authors (Mays and Pope 1995, Morgan 1996, Ritchie et al. 2003, Rabiee 2004) emphasise that processes and outputs of analysis of data from focus groups are generally similar to those from individual interviews. Every qualitative analysis is aimed to reduce the amount of data collected through a number of generic activities: categorising, tabulating or recombining the evidence so as to answer the research questions (Robson 1993, Rabiee 2004). At the very least, regardless of the method used, the findings from any qualitative research are drawn together, then similar themes are compared, discussed and examined to demonstrate how they relate to the variables within the sample population (Morgan 1996).

The data from the current focus groups and interviews were scrutinised using the same approach of framework data analysis (Ritchie and Spencer 1994, Spencer et al. 2003, Rabiee 2004). Nevertheless, the researcher considered the dynamic nature of group discussions when working with the focus group data. For example, a note of which the dynamics that occurred within a group process (e.g. interactions between members or non-verbal communication) was recorded carefully (Morgan 1996). In addition, some illustrations of the discussions between participants were included when reporting the focus groups, ensuring that the report was true to its data (Morgan 1996).

4.6.3. The framework analysis process

Five key stages of framework analysis were undertaken, following the phases by Ritchie and Spencer (1994). Each stage of the framework is described in the following section. It is worth mentioning that, in the focus group study, initially the framework was applied separately for data from carers and service users before the two data sets were synthesised. For clarity, the process of these analyses are not presented in this chapter but they are detailed in Appendix 9. Alternatively, a general description of the framework process in this section was referring to the analysis of data from professional interviews (more details of the interview analysis is presented in Appendix10)

4.6.3.1. Familiarisation

Familiarisation is the first step of framework analysis, where the analyst immerses herself in the data for an in-depth cognisance (Ritchie and Spencer 1994, Ritchie et al. 2003). This stage is frequently
accomplished through listening to recordings, reading transcripts, and studying observational notes (Ritchie and Spencer 1994). In relation to the immersion of data from the professional interviews, the researcher was already familiar with the data set because she was the only one who was responsible for interviewing the professional participants. The researcher was also responsible for completing the majority of transcriptions and translating all of the transcripts from Indonesian into English. This allowed her to listen to the recorded discussions/interviews repeatedly. Braun and Clarke (2006) argue that the familiarisation phase can be completed more quickly when the researcher has collected the data and produces the transcriptions by themselves. The reason is, when undertaking the initial stage of analysis, the researcher already has some initial thoughts and prior knowledge of the data.

In addition, reading and re-reading the transcripts allowed the researcher to familiarise herself with the data from the study (Ritchie and Spencer 1994, Ritchie et al. 2003). At the same time, the researcher made notes on the document margins, containing the researcher’s ideas or preliminary themes which emerged during the reviewing process. The themes were documented and used terminologies that were as close as possible to the language spoken by the participants (Spencer et al. 2003). Recurrent thoughts were then carefully recorded since the main aim of examining the materials was to identify repeated ideas or topics which may ultimately lead to the development of the themes (Spencer et al. 2003). Finally, this initial stage of framework produced a long list of topics or ‘inventory’ of what appear to be essential matters of interest within the data (Spencer et al. 2003, Spencer et al. 2014); and these would be applied in the following stage of data analysis i.e. devising a conceptual framework, as described below.

4.6.3.2. Constructing a conceptual framework

In this stage, the recurring topics were sorted and grouped under a number of higher and broader categories (assigned as main or key ‘themes’). The final result of this stage was a workable structure which illustrates a hierarchy of some main themes and their subthemes. A conceptual framework resulting from the professional interviews is shown in following Table 9.
### Table 9. A preliminary conceptual framework from the interviews analysis

<table>
<thead>
<tr>
<th>Key theme</th>
<th>Subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Current contact with carers</td>
<td>1.1. Duration</td>
</tr>
<tr>
<td></td>
<td>1.2. Focus of contact</td>
</tr>
<tr>
<td></td>
<td>- Administrative activities</td>
</tr>
<tr>
<td></td>
<td>- Express feeling of carers</td>
</tr>
<tr>
<td></td>
<td>- Information provision</td>
</tr>
<tr>
<td></td>
<td>- Service user medication</td>
</tr>
<tr>
<td></td>
<td>1.3. Initiated by</td>
</tr>
<tr>
<td></td>
<td>- Professionals</td>
</tr>
<tr>
<td></td>
<td>- Carers</td>
</tr>
<tr>
<td></td>
<td>1.4. Payment scheme</td>
</tr>
<tr>
<td></td>
<td>- Paid by governmental insurance</td>
</tr>
<tr>
<td></td>
<td>- Paid by carers</td>
</tr>
<tr>
<td></td>
<td>1.5. Views of current contact</td>
</tr>
<tr>
<td></td>
<td>- Efforts have been done to support carers</td>
</tr>
<tr>
<td></td>
<td>- The existing support have partly fulfilled carers needs</td>
</tr>
<tr>
<td></td>
<td>- Improvement needed for the available support for carers</td>
</tr>
<tr>
<td></td>
<td>- No significant impact for carers and service users from the given support</td>
</tr>
<tr>
<td>2. Rationale for carer involvement</td>
<td>2.1. Carers are responsible for service users’ adherence to treatment</td>
</tr>
<tr>
<td></td>
<td>2.2. Carers are the main support of service users</td>
</tr>
<tr>
<td></td>
<td>2.3. Carers as the cause of mental illness and its relapses</td>
</tr>
<tr>
<td></td>
<td>2.4. Carers continue professional care at home</td>
</tr>
<tr>
<td></td>
<td>2.5. Research project-based interaction</td>
</tr>
<tr>
<td></td>
<td>2.6. To obtain information related service users</td>
</tr>
<tr>
<td></td>
<td>2.7. The professionals are under supervision</td>
</tr>
<tr>
<td>3. What carers need from professionals</td>
<td>3.1. Information</td>
</tr>
<tr>
<td></td>
<td>- Administration for using hospital services for service users</td>
</tr>
<tr>
<td></td>
<td>- Illness progress of service users</td>
</tr>
<tr>
<td></td>
<td>- Medication and other treatment given to service users</td>
</tr>
<tr>
<td></td>
<td>- General mental health issues</td>
</tr>
<tr>
<td></td>
<td>3.2. Psychological support</td>
</tr>
<tr>
<td></td>
<td>- Catharsis</td>
</tr>
<tr>
<td></td>
<td>- Peer group support</td>
</tr>
<tr>
<td></td>
<td>3.3. Technical support to use hospital services for ill relatives</td>
</tr>
<tr>
<td>4. Potential support for carers</td>
<td>4.1. Barriers to developing services</td>
</tr>
<tr>
<td></td>
<td>- Barriers related to carers</td>
</tr>
<tr>
<td></td>
<td>- Barriers from professionals</td>
</tr>
<tr>
<td></td>
<td>- Barriers from hospital</td>
</tr>
<tr>
<td></td>
<td>4.2. Focus on service users</td>
</tr>
<tr>
<td></td>
<td>4.3. Need or no need to provide additional support</td>
</tr>
<tr>
<td></td>
<td>- Need additional support</td>
</tr>
<tr>
<td></td>
<td>- No need additional support</td>
</tr>
</tbody>
</table>
4.6.3.3. Indexing

This stage was accomplished by applying the initial conceptual framework across the entire data set (Ritchie and Spencer 1994, Ritchie et al. 2003). The researcher read each phrase, sentence and paragraph of the whole transcripts in detail; in order to identify where the emerging ‘themes’ or ‘subthemes’ as presented in the previous conceptual framework occurred. Figure 7 illustrates how the researcher indexed a phrase of one transcription from the professional interviews. It is shown that from an original phrase, a number of sentences could be assigned for some themes or subthemes as developed in the initial conceptual framework.

**Figure 7. An illustration of indexing in the framework analysis**

**Original phrase**

P1: For at least half an hour. Maximum ... It’s up to the carer (laughs)... to complete their need to talk and be heard... because consultation with doctor is only brief. Especially for doctors who are careless. Merely asking how is it? Then say this is the prescription ... the time to wait for the call is much longer that the time for consultation. But in nursing consultations, I often give a chance, ‘Come on Mom, do you want to say anything else. Do you want to vent about something?’ Moreover, there are even tears, and it usually takes more time.

**Indexed phrase**

P1: For at least half an hour. Maximum ... It’s up to the carer (laughs). To complete their need to talk and to be heard because consultation with doctors is only brief. Especially for doctors who are careless. Merely asking how is it? Then they say this is the prescription ... the time to wait for the call is much longer that the time for consultation. But in nursing consultations, I often give a chance, ‘Come on Mom, do you want to say anything else. Do you want to vent about something?’ Moreover, there are even tears, and it usually takes more time.
This phase was supported with the NVivo software which assisted the researcher in managing the indexed phrases, as well as memos that consisted of a number of arising ideas/issues. Some of the memos recorded the researcher’s ideas to refine the initial conceptual framework such as restructuring the existing themes and subthemes, and then composing additional themes and collapsing several subthemes and categories (Table 10 shows the result of these refinements). Such modifications were highly supported through discussions with the researcher’s supervisors. The developed categories were frequently refined at the beginning of indexing but then became more consistent at the end of the phase (Ritchie et al. 2003).

Table 10. A refined conceptual framework derived from the interviews analysis

<table>
<thead>
<tr>
<th>Key Themes</th>
<th>Subthemes</th>
</tr>
</thead>
</table>
| 1. Why services should involve carers | 1.1. Carers as the cause of mental illness and relapses  
1.2. Medication adherence responsibility  
1.3. Carers as main support of service users  
1.4. Carers should help professional care  
1.5. Supervisory activities |
| 2. Professional views of what carers need for ill relatives | 2.1. Aftercare service engagement  
2.2. Recovery |
| 3. Professional views of what carers need for own wellbeing | 3.1. Information  
3.2. Psychological support |
| 4. Focus of current contact | 4.1. Information provision  
4.2. Emotional support  
4.3. Data exploration related to service users |
| 5. Perspectives of support provision | 5.1. Views of current support provision  
✓ Hospital endeavours for supporting carers  
✓ Current support have partly fulfilled carers needs  
✓ Limited impact on service users’ mental health and carers’ knowledge  
✓ Improvement needed  
5.2. Views of potential support for carers  
✓ No need/need to provide additional support  
✓ Focus on service users  
✓ Barriers in developing support |
Having indexed the data set, the process of framework analysis went on to the charting stage as described below

4.6.3.4. Charting

Charting is a distinctive feature of framework analysis due to its thematic matrices which allocate data from every participant in a row and represent a separate subtheme in each column (Spencer et al. 2003, Spencer et al. 2014). The development of the chart was an essential element of the framework analysis because it allowed the researcher to produce a more manageable form of data (Ritchie and Spencer 1994, Ritchie et al. 2003). It was a process to develop a whole picture of the data by sorting and placing them with similar contents or properties collectively. During the charting process, reviewing the original data was inevitable to ensure the synthesised charts were adequately understood.

The researcher undertook two main activities to complete this stage of framework analysis: created charts by sorting the data by theme and summarised/synthesised the key points of each piece of the data to be inserted into the charts (Ritchie et al. 2003). Similar to the previous phase, the researcher was assisted by the computer program of NVivo in the course of charting.

In the data analysis of the professional interviews, the researcher initially adopted a thematic approach to devise five charts in which the headings were drawn from the key themes of the latest conceptual framework as presented in Table 10). Each chart signifies one key theme comprising of a number of columns which represent the subthemes, and 24 rows which represent each participant in the study. The second activity was summarising the key points of each piece of data (i.e. sourced from the indexed phrases) to fill out relevant cells in the charts. This was a synthesising process where the qualitative data of this study was reduced, and allowed the researcher to focus on the subject of each theme. Ritchie et al. (2003) emphasise that the summarised phrases were retained as much as possible from the participants’ language and interpretation was kept to a minimum so that there was always an opportunity to revisit the original expression in this stage of analysis.
A part of a thematic chart of the first theme is presented in Table 11 (the complete chart in Appendix 10. It is necessary to state that the key theme will be employed to illustrate the processes of framework analysis of this study in further description of this section.

Table 11. A thematic chart of a main theme:
Professionals’ views of what carers need for own wellbeing
(from the interview analysis)

<table>
<thead>
<tr>
<th>Cases/Participants</th>
<th>A : Information</th>
<th>B : Psychological Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. P4</td>
<td>Carers need some information from professionals including the condition of their ill relatives, what therapy/treatment given as well as its side effects of the service users</td>
<td>Carers come to psychologists because they want to express their feelings.</td>
</tr>
<tr>
<td>2. P8</td>
<td>Carers need to know how to care for service users at home or in acute conditions. There were carers who locked their ill relative in a room for 10 years as they did not know how to manage the effects of medication on the service user. Finally, carers also need information about health insurance.</td>
<td>Carers experience burnout because they meet their ill relative every day; therefore they need to share the burden with others.</td>
</tr>
<tr>
<td>3. P20</td>
<td>Mostly carers ask how to cope with specific behaviours of their relatives such as irritability and smoking.</td>
<td></td>
</tr>
<tr>
<td>4. P22</td>
<td>Carers need detailed verbal information of how to handle their ill relatives on a daily basis, such as strategies to give reinforcement or with respect to the service users.</td>
<td>Carers want to talk more to express their feelings to professionals.</td>
</tr>
</tbody>
</table>

The development of the charts became the final procedure of data management in framework analysis (Spencer et al. 2003). The following is a general description of the subsequent phase which focused on developing descriptive and explanatory accounts, and involved the activities of mapping and interpreting the data.
4.6.3.5. Mapping and interpretation

4.6.3.5.1. Mapping

In this stage the data were interpreted as a whole (Ritchie and Spencer 1994). The constructed charts and memos were compared and contrasted against the researcher’s perception, who searched for patterns and connections, and eventually sought the explanations within the data. The mapping was carried out through two main stages: 1) Detection of elements and dimensions of the summarised data from the thematic charts and 2) categorisation where categories were refined and the data were classified.

The mapping procedures in the professional interviews were assisted by developing a separate table to display the elements/dimensions and categories identified from a particular theme across cases. Each table consists of 3 columns: Column A was assigned for the summarised data of all cases/participants transferred from the thematic chart; Column B was assigned for elements/dimensions identified from a particular case (i.e. the phase of detection); and Column C was assigned for categories, derived from a more conceptual interpretation of the identified elements/dimension (i.e. the phase of categorisation). Table 12 on the next page displays how the mapping phases were carried out for several cases/participants under one key theme, namely professionals’ views of what carers need for their own wellbeing.

As shown in Table 12, several elements/dimensions could be detected from each participant and recorded in column B by using the terms which were close to the original data. The colouring method was employed by highlighting the identified elements/dimensions with different colours so as to trace their sources from the initial data. For example, yellow colour was used to characterise the whole synthesised elements/dimensions in Column B and their original data in Column A which was related to information about medication and treatment.

In the next phase of mapping, all elements/dimensions were fully inspected, determined for their categories and labelled into a more abstract categorisation. The decisions for the categorisation were based on the recurrence as well as their similarity (i.e. similar or linked elements/dimensions were
grouped into one category). The highlighting approach implemented in columns A and B was continued in column C to indicate which elements/dimensions were relevant to the established category as demonstrated in Table 12 next:

Table 12. A descriptive analysis of one key theme: Professional view of what carers need for own wellbeing (from the interviews analysis)

<table>
<thead>
<tr>
<th>A. Synthesised data</th>
<th>B. Elements/Dimensions detected</th>
<th>C. Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. P4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers need some information from professionals including the condition of their ill relatives, what therapy/treatment is given as well as its side effects on the service users</td>
<td>Need information about the condition of ill relatives Need information about therapy given and the side effects on ill relatives</td>
<td>Individual information about relative’s mental health and progress Information about medication and other treatments</td>
</tr>
<tr>
<td>Carers come to psychologists because they want to express their feelings</td>
<td>Want to express feelings</td>
<td>Psychological support catharsis</td>
</tr>
<tr>
<td>2. P 8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers need to know how to care for service users at home or in acute conditions. There were carers who locked their ill relatives in a room for 10 years as they did not know how to manage the effects of medication on the service user. Finally, carers also need information about health insurance.</td>
<td>Need to know how to care for service users at home Need to know how to care for ill relatives in acute conditions Did not know how to manage the effects of medication Locking up ill relatives due to having no knowledge about the effects of medication Need information about health insurance</td>
<td>Information about managing service user at home Information about medication and other treatments Information about services and access to financial support Carer emotion associated with caregiving: tiredness Psychological support: peer group support</td>
</tr>
<tr>
<td>Carers experience burnout because they meet their ill relative every day; therefore they need to share the burden with others</td>
<td>Experience burnout because they meet ill relatives every day Need to share the burden with others</td>
<td></td>
</tr>
<tr>
<td>3. P 20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly carers ask about how to cope with specific behaviours of their relatives at home such as irritability and smoking. Carers need time to talk to professionals because sometimes they are stuck and don’t know where to go</td>
<td>Asking how to cope with ill relatives’ behaviour(s) at home Need time to talk with professionals Don’t know where to go</td>
<td>Information about managing service user at home Psychological support catharsis Carer emotion associated with caregiving: confusion</td>
</tr>
<tr>
<td>4. P22</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers need detailed verbal information of how to handle their ill relatives on a daily basis, such as strategies to give reinforcement or with respect to the service users Carers want to talk more to express their feelings to professionals</td>
<td>Need verbal information Need information of how to handle ill relatives on a daily basis Need information about strategies in giving reinforcement and with respect to ill relatives Need to talk with professionals Need to express feelings to professionals</td>
<td>Method of potential information given Information about managing service user at home Psychological support catharsis</td>
</tr>
</tbody>
</table>
The procedure of categorisation was not complete until all material in column C were fully investigated and a decision was made about what categories to be used for describing each subtheme. During this process, some categories were refined. Categories which were relevant were maintained, and those which were clearly irrelevant to the conceptualisation of descriptive categories were eliminated.

Such an approach of categorisation was also employed for another subtheme under the same key theme (i.e. the need of carers for psychological support). This resulted in two categories: the needs of catharsis and peer group support. In the end, the key theme of the professionals’ views of what carers need for their wellbeing posed a number of categories under two subthemes as shown in the subsequent Table 13. A general description of the whole findings after the categorising approach was employed to all subthemes of this study is provided in Appendix 10.

Table 13. Descriptive accounts for one key theme: Professionals’ views of what carers need for own wellbeing (from the interviews analysis)

<table>
<thead>
<tr>
<th>No</th>
<th>Subthemes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Information needed by carers</td>
<td>• General information regarding mental health problems</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Managing service user at home</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Medication and other treatments</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Individualised illness progress</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Services and access to financial support</td>
</tr>
<tr>
<td>2</td>
<td>Psychological support</td>
<td>• Catharsis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Peer group support</td>
</tr>
</tbody>
</table>
Throughout the mapping stage, the researcher could establish typologies (Ritchie and Spencer 1994, Ritchie et al. 2003). This part of analysis is described as follows.

4.6.3.5.2. Typology

Typology is a specific classification system that helps to describe and explain the segmentation of the phenomena within a qualitative study (Lofland and Lofland 1995, Spencer et al. 2003). Typology has two characteristics (i.e. combining two or more different dimensions so a complex portrayal of characteristics of the phenomena can be recognised); and offering a classification in which its categories are distinct and independent of each other (Spencer et al. 2003). Spencer et al. (2014) argue that identification of typologies for group-based data, rather than individual-based data, is quite problematic because it cannot be carried out unless the groups themselves are very homogeneous in representing the predefined sectors of the population.

The current typology referred to the data from the individual interviews with professionals. It is important to note that the interviews did not only focus on the exploration of the views of needs of Indonesian carers, but also to understand the extent as to whether existing mental health hospital services have met the carer needs (see the previous page 86). Therefore, typologies in the study used two dimensions which were able to describe a link between the need of improvement and the extent of carer needs have been met through the existing support provision. The two dimensions were:

- Views whether the current support provision has fulfilled carers’ needs or not
- Views whether the current support provision needed improvement or not

Four categories were then established to illustrate the associations of both dimensions as shown in the subsequent Table 14:
To clarify, the four typologies of the professionals’ views regarding the need of improvement of the current support provision are presented as follows:

1) A view that carer needs have been met but current support provision could be enhanced.
2) A view that carers needs have been met therefore current support provision could not be enhanced.
3) A view that carers needs have not been met therefore current support provision could be enhanced.
4) A view that carers needs have not been met but current support provision could not be enhanced.

All categories were subsequently tested and applied to all cases (i.e. by inspecting each case as a whole and looking at them horizontally through the set charts, then checking each of the above four classifications that formed the typologies). It was discovered that most participants viewed the current support provision have not been adequate in fulfilling carers needs; therefore the improvement was required (typology 3).
Having established typologies, the final stage of framework analysis was completed by developing interpretation from the findings.

4.6.3.5.3. Interpretation

This phase allowed the researcher to compare themes and sub-themes and check them against transcripts, field notes and video recording to accurately confirm proper context and minimise interpretation (Ritchie et al. 2003, Smith and Firth 2011, Ward et al. 2013). The researcher also returned to the objectives of the research that had been set in the beginning (Pope et al. 2000).

The analysis was completed when the researcher was able to provide explanations of the overall findings. Explanations were sought in order to answer the research questions of this interview study (i.e. what do carers need from mental health services in Indonesia from the perspectives of professionals?), and how the current support has fulfilled these needs?

Having presented the data analysis process, a discussion surrounding the methodological rigours of both investigations is provided below.

4.7. Methodological rigour in qualitative research

All researchers including those undertaking qualitative investigations need to establish criteria to evaluate their research findings. They must be explicit about how and why they select the criteria to ensure the robustness of their inquiries (Tobin and Begley 2004). The methodological rigour in qualitative research is commonly based on its credibility, conformability, dependability, and transferability (Lincoln and Guba 1985). In the studies reported upon here, evaluation of each criterion is justified as follows:
4.7.1. Credibility

Credibility refers to whether the qualitative researcher is investigating what they intended to investigate (Lewis and Ritchie 2003). The credibility of qualitative research is often doubted because the findings of the study are considered merely as an assembly of anecdote and personal impressions thus strongly subject to personal bias (Mays and Pope 2000). However, the credibility of qualitative research could be achieved through peer debriefing to ensure the application of designs in the research (e.g. data collection and data analysis) as well as the presenting of data that is in context (Patton 1999, Morrow 2005). With regard to the focus groups and interviews, the peer debriefing was carried out by working together with supervisors who posed more neutral views of the research. The supervisors examined and provided feedback of the researcher’s transcripts, final reports, and general methodology which was focused on the application of framework analysis. The supervisors also reviewed and agreed the themes which emerged from the studies. In addition, the credibility of the studies was demonstrated by employing a research methodology which incorporated a range of different perspectives (i.e. service users, carers and health professionals). Therefore, the viewpoint of one group cannot be considered as the only truth about the topic under investigation (Mays and Pope 2000).

Nonetheless, the credibility in qualitative research cannot be simply explained as it has accurately reflected the experience being studied (Ezzy 2002). The foundation of qualitative inquiries does not restrict the researcher’s subjective interpretations, which always influence the process of understanding the phenomenon under investigation (Mays and Pope 2000). For this reason, the credibility of the qualitative studies of the PhD was also enhanced through reflexivity. This means the researcher acknowledged openly and honestly that her subjective preconceptions might have influenced the data collection (Ezzy 2002, Morrow 2005). Details of reflexivity of the studies are provided in the subsequent section of this chapter.

4.7.2. Transferability

Transferability refers to the extent to which others can generalise the findings of a qualitative study in their own context (Ezzy 2002, Morrow 2005). Many authors (Mays and Pope 1995, Sim and Snell 1996, Pope et al. 2000, Ritchie and Lewis 2003, Morrow 2005) argue that generalising is not necessarily the
primary concern in a qualitative inquiry due to the following reasons. Firstly, it is impossible to generalise a qualitative study in the conventional quantitative sense because it is usually conducted within a small sample size and an absence of statistical analysis (Pope et al. 2000, Morrow 2005). Sim and Snell (1996) emphasise that if it is essential for a study to strictly produce representative findings, an extensive survey using probability sampling should be employed instead of adopting focus groups or qualitative interviews which do not always need a large number of participants. Secondly, replicating a qualitative investigation as is required by reliability in quantitative view is also impracticable (i.e. the findings should be transferrable to other settings). The reason is that the meanings and interpretations that people give in one qualitative study constantly change in response to the changing conditions. However, the transferability of qualitative research including the current focus groups and interviews was achieved through different strategies such as providing ample descriptions regarding the research context, processes, participants, and participant-researchers relationships (Mays and Pope 2000, Morrow 2005). These accounts would assist the reader to decide whether the findings can be transferred to other populations or settings.

4.7.3. Dependability

The idea of dependability emphasises the need of the researcher to account for the ever-changing context within the research (Morrow 2005). The dependability of both studies was accomplished by undertaking an audit trail when the researcher discussed with her supervisors surrounding the progress of data collection and analysis (Tobin and Begley 2004, Morrow 2005). Regular meetings with the supervisors were helpful in revealing the researcher’s bias, assumptions, and data misinterpretation. The audit trail was also undertaken in a way of providing transparent explanation of the data analysis method in the research report. Any changes that occurred during data collection has been described in the thesis report. In addition, the application of framework analysis allowed the researcher to portray a clear account of the data analysis process to non-researchers, thus they could judge whether the interpretation of the participants’ perspectives have been supported by adequate data (Lewis and Ritchie 2003). Finally, the only one single moderator in the focus groups with carers and service users and one interviewer in the professional interviews could maintain the consistency of the data collection procedures, even though this advantage is arguable as the sole moderating/interviewing could threaten a neutral stance of the data collector (Sim and Snell 1996).
4.7.4. Conformability

Conformability addresses the neutrality of the naturalistic inquiry (Tobin and Begley 2004, Morrow 2005). This lies on the perspective that the interpretation, as far as possible, is derived from the data, representing the situation being researched rather than the beliefs, imagination or biases of the investigator. The conformability of the focus group and interviewing studies was enhanced by using comprehensive multiple sources of evidence (carers, service users and health participants), which was useful to confirm the findings (Guion et al. 2011). Employing framework analysis, as will be clearly reported in this thesis, also enables non-researchers to confirm the adequacy of the findings in relation to the process of producing a set of data (Lewis and Spencer 2003).

4.8. Reflexivity of the studies

Reflexivity in qualitative inquiry means the researcher being aware of his/her perspectives, position and presence will have some kind of effect on the process, method and outcomes of the research (Finlay 2002, Snape and Spencer 2003). It is a tool for non-researchers to examine the integrity and trustworthiness of qualitative research based on a notion that it is impossible for qualitative investigators to remain ‘outside’ of the subject matter (Anderson 2008 p 184).

With regard to the focus groups and qualitative interviews in the PhD, I was concerned that my motivations, prior experiences and knowledge about mental health services for carers would affect the studies (Finlay 2002). My compelling motives to investigate issues surrounding Indonesian carers were not only for completing the PhD, but also for revealing my dissatisfactions due to minimal attention to the carers in the country. In addition, the passion about the research developed because of its novelty, especially in terms of exploring the needs of carers’ from the views of carers, service users and health professionals in Indonesian context. However I realised that involving some groups of participants in one research project was challenging. For example, I expected difficulties from the focus groups with service users, assuming that discussing a focused topic of research with them might not be easy. Likewise, I anticipated difficulties in recruiting non-nursing professionals for the interview study as the involvement of wide-ranging health professionals in nursing research within the country was uncommon.
Such reflections during this pre-research stage (as well as in the subsequent phases of the studies) were recorded in field notes, a methodological log and diary to document experiences when I was sensitive to my own feelings regarding the research process (Cutcliffe 2003). Reflectivity, therefore, was beneficial for my catharsis (Corbin and Strauss 2008), and its analytical nature assisted in transforming the challenges above to becoming opportunities to develop my research capabilities (Finlay 2002). In this respect, reflexivity practices helped me to evaluate the research process, method and outcomes based on my reflection upon the impact of my position, perspectives and presence on the research activities.

To illustrate, I realised that the way the research was approached, analysed and evaluated was influenced by my position as a mental health professional who was conversant with the research settings (Hockey 1993). In this sense, I would consider myself as an ‘insider’ to the population of interest which had some advantages such as providing opportunities to access the complex social worlds of those involved in the research more readily, and improving the rapport between myself and the participants. Yet, I was also thoughtful of not being ‘an outsider’, which encouraged a conflicting role within the area being studied, and raised complications in being able to retain an objective outlook of the research process (Robson 1993).

Finally, as a qualitative researcher I considered myself as the primary source of data collection. Thus, I had the potential to introduce bias and subjectivity into the data collected. Reflecting on my performance in moderating the focus groups with carers and service users, I noted that sometimes I unconsciously played a counselling role and provided empathy when the participants expressed their frustrations surrounding mental health services for carers. I realised that I might have precipitated some of these interactions and encouraged the carers and service users to express negative feelings more openly. This was especially apparent when I reiterated the confidentiality of the discussions and reassured them that their participation would not have any effect on the hospital service for their ill relatives. Nevertheless, discussions with my supervisors and documenting my feelings during the data collection in field notes were helpful to maintain a more neutral stance towards the study participants (Sword 1999).
4.9. Summary

This chapter has described the method used in the focus group and interview studies. The description included a justification of using qualitative methodology as well as convenience sampling for selecting the participants. The chapter also discussed the rationale behind selecting focus groups and interviewing for collecting data and the framework analysis for analysing the data. The next chapter will present the findings of the focus group and interviewing studies.
CHAPTER FIVE
FINDINGS OF THE FOCUS GROUPS AND INTERVIEW STUDIES

This chapter details the findings of two studies exploring what carers need from hospital-based mental health services in Indonesia. The first section discusses the findings of focus groups with carers and service users. The final section focuses on the findings of interviews with professionals. The synthesis of the findings of focus groups and interviews will be presented in the following chapter.

5.1. Section one: findings from focus groups with carers and service users

5.1.1. Introduction

This section details the findings of the focus groups with carers and service users.

5.1.2. Study participants

Nine focus groups of between three to nine participants were conducted with a total of 46 participants; seven groups with carers (n=33) and two groups with service users (n=13). The focus groups were held in two government mental health hospitals in the capital city of Indonesia over a period of four months in 2012. All sessions, lasting 40-120 minutes, were video-taped and facilitated by the researcher (issues surrounding the use of video recording in the focus groups have been detailed in Chapter Three).

5.1.3. Demographic data of carer and service user participants

A summary of the demographic data of carer and service user participants is presented in Table 15 and Table 16.
Table 15. Demographic data of carer participants

<table>
<thead>
<tr>
<th>Number of participants</th>
<th>Age</th>
<th>Gender</th>
<th>Relationship with service user</th>
<th>Gender of service user</th>
<th>Duration of illness of service users (Year)</th>
<th>Diagnosis of service users</th>
</tr>
</thead>
<tbody>
<tr>
<td>1A</td>
<td>25</td>
<td>M</td>
<td>Son</td>
<td>M</td>
<td>21</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>2A</td>
<td>36</td>
<td>M</td>
<td>Brother</td>
<td>F</td>
<td>2</td>
<td>Bipolar</td>
</tr>
<tr>
<td>3A</td>
<td>34</td>
<td>F</td>
<td>Sister-in-law</td>
<td>F</td>
<td>2</td>
<td>Bipolar</td>
</tr>
<tr>
<td>4A</td>
<td>50</td>
<td>F</td>
<td>Mother</td>
<td>F</td>
<td>5</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>M</td>
<td>15</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>5A</td>
<td>56</td>
<td>F</td>
<td>Mother</td>
<td>M</td>
<td>10</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>6A</td>
<td>28</td>
<td>F</td>
<td>Sister</td>
<td>M</td>
<td>10</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>7A</td>
<td>49</td>
<td>F</td>
<td>Mother</td>
<td>M</td>
<td>3</td>
<td>Bipolar</td>
</tr>
<tr>
<td>8A</td>
<td>54</td>
<td>F</td>
<td>Mother</td>
<td>M</td>
<td>15</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>9A</td>
<td>60</td>
<td>M</td>
<td>Father</td>
<td>M</td>
<td>15</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>10A</td>
<td>48</td>
<td>F</td>
<td>Mother</td>
<td>M</td>
<td>16</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>11A</td>
<td>53</td>
<td>F</td>
<td>Mother</td>
<td>M</td>
<td>8</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>12A</td>
<td>48</td>
<td>F</td>
<td>Mother</td>
<td>M</td>
<td>7</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>13A</td>
<td>50</td>
<td>F</td>
<td>Mother</td>
<td>M</td>
<td>10</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>14A</td>
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<td>F</td>
<td>Mother</td>
<td>M</td>
<td>8</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>15A</td>
<td>48</td>
<td>F</td>
<td>Mother</td>
<td>F</td>
<td>3</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>16A</td>
<td>32</td>
<td>F</td>
<td>Daughter</td>
<td>F</td>
<td>3</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>17A</td>
<td>30</td>
<td>M</td>
<td>Brother</td>
<td>M</td>
<td>7</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>18A</td>
<td>50</td>
<td>F</td>
<td>Mother</td>
<td>M</td>
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<td>Schizophrenia</td>
</tr>
<tr>
<td>19A</td>
<td>59</td>
<td>F</td>
<td>Mother</td>
<td>M</td>
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<td>Schizophrenia</td>
</tr>
<tr>
<td>20A</td>
<td>55</td>
<td>M</td>
<td>Father</td>
<td>M</td>
<td>12</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>21A</td>
<td>68</td>
<td>M</td>
<td>Father</td>
<td>M</td>
<td>10</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>22A</td>
<td>64</td>
<td>M</td>
<td>Father</td>
<td>M</td>
<td>6</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>23A</td>
<td>62</td>
<td>F</td>
<td>Mother</td>
<td>M</td>
<td>3, 5</td>
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</tr>
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<td>Uncle</td>
<td>M</td>
<td>3</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>25A</td>
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<td>M</td>
<td>Husband</td>
<td>F</td>
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<td>Schizophrenia</td>
</tr>
<tr>
<td>26A</td>
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<td>M</td>
<td>Father</td>
<td>F</td>
<td>2</td>
<td>Bipolar</td>
</tr>
<tr>
<td>27A</td>
<td>47</td>
<td>F</td>
<td>Mother</td>
<td>F</td>
<td>2</td>
<td>Bipolar</td>
</tr>
<tr>
<td>Number of participants</td>
<td>Age</td>
<td>Gender</td>
<td>Relationship with user</td>
<td>Gender of service user</td>
<td>Duration of illness of service users (year)</td>
<td>Diagnosis of service users</td>
</tr>
<tr>
<td>------------------------</td>
<td>------</td>
<td>--------</td>
<td>------------------------</td>
<td>------------------------</td>
<td>---------------------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>28A</td>
<td>69</td>
<td>M</td>
<td>Father</td>
<td>M</td>
<td>27</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>F</td>
<td>25</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>29A</td>
<td>65</td>
<td>F</td>
<td>Mother</td>
<td>M</td>
<td>27</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>F</td>
<td>25</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>30A</td>
<td>45</td>
<td>M</td>
<td>Brother</td>
<td>M</td>
<td>1</td>
<td>Bipolar</td>
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<tr>
<td>31A</td>
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<td>F</td>
<td>Mother</td>
<td>M</td>
<td>2</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>32A</td>
<td>64</td>
<td>M</td>
<td>Father</td>
<td>M</td>
<td>4</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>33A</td>
<td>46</td>
<td>F</td>
<td>Sister</td>
<td>M</td>
<td>10</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>N=33 carers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>F=10</td>
<td>Average= 8.5 years</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>M=26</td>
<td></td>
</tr>
</tbody>
</table>

**Table 16. Demographic data of service user participants**

<table>
<thead>
<tr>
<th>ID</th>
<th>AGE</th>
<th>GENDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>1B</td>
<td>27</td>
<td>M</td>
</tr>
<tr>
<td>2B</td>
<td>41</td>
<td>M</td>
</tr>
<tr>
<td>3B</td>
<td>40</td>
<td>M</td>
</tr>
<tr>
<td>4B</td>
<td>44</td>
<td>M</td>
</tr>
<tr>
<td>5B</td>
<td>31</td>
<td>F</td>
</tr>
<tr>
<td>6B</td>
<td>60</td>
<td>F</td>
</tr>
<tr>
<td>7B*</td>
<td>36</td>
<td>F</td>
</tr>
<tr>
<td>8B</td>
<td>43</td>
<td>M</td>
</tr>
<tr>
<td>9B</td>
<td>37</td>
<td>M</td>
</tr>
<tr>
<td>10B</td>
<td>30</td>
<td>F</td>
</tr>
<tr>
<td>11B</td>
<td>50</td>
<td>F</td>
</tr>
<tr>
<td>12B*</td>
<td>28</td>
<td>F</td>
</tr>
<tr>
<td>13B</td>
<td>35</td>
<td>F</td>
</tr>
<tr>
<td>N=13 service users</td>
<td>Average= 38.6 Y0 M=6 F=7</td>
<td></td>
</tr>
</tbody>
</table>
5.1.3.1. Carer participants

The average age of carer participants was 50 years (range 25-69). Most of the carers were parents (n=23), followed by siblings (n=5), children (n=2), spouse (n=1), uncle (n=1), and sister in law (n=1). The carer participants were mostly female (20:13).

5.1.3.2. Service user participants

The average age of service user participants was 39 years (range 27-60). All service user participants were diagnosed with Schizophrenia according to their medical records. Of the 13 service users, only two who had relatives participated in the carer focus groups.

5.1.4. Themes identified

As indicated in the previous chapter, framework was employed separately on the data sourced from carers and service users, and each process of the analysis is detailed in Appendix 9. What follows is an explanation of how the themes produced from each analysis were merged and at the end resulted in four main themes.

5.1.4.1. Themes identified from carer focus groups

The application of the whole steps of framework generated four main themes as presented below:
### Table 17. Themes identified from carer focus groups

<table>
<thead>
<tr>
<th>Main themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Experiences in caregiving</strong></td>
</tr>
<tr>
<td>1.1. Emotional reactions associated with caregiving</td>
</tr>
<tr>
<td>1.2. Coping strategies in undertaking caregiving roles</td>
</tr>
<tr>
<td><strong>2. Carer needs and expectations from mental health hospital–based services</strong></td>
</tr>
<tr>
<td>2.1. Information</td>
</tr>
<tr>
<td>2.2. Emotional support</td>
</tr>
<tr>
<td>2.3. Financial support</td>
</tr>
<tr>
<td>2.4. Recovery for service users</td>
</tr>
<tr>
<td>2.5. Professionalism in contact with service users and carers</td>
</tr>
<tr>
<td><strong>3. Current support for carers</strong></td>
</tr>
<tr>
<td>3.1. Available support for carers</td>
</tr>
<tr>
<td>3.2. Positive views of current support for carers</td>
</tr>
<tr>
<td>3.3. Weaknesses of current support for carers</td>
</tr>
<tr>
<td><strong>4. Recommendations for service improvement</strong></td>
</tr>
<tr>
<td>4.1. Group-based emotional support</td>
</tr>
<tr>
<td>4.2. Improvement for information provision</td>
</tr>
</tbody>
</table>

#### 5.1.4.2. Themes identified from service user focus groups

The procedures of framework were applied in correspondence to the data from service user focus groups. It is important to note that the data produced from service users were not as rich as those from carer participants. The most plausible reason being that only two groups with service users were conducted (n=13) in comparison to seven groups with carers (n=33). In addition, the level of attention of the service users was lower, as they could not maintain their participation longer than 60 minutes, whereas the carer participants could engage in discussions for up to 120 minutes.

The results of current analysis were comparable with those sourced from carer participants, possibly because each group utilised a similar discussion guide as shown in Appendix 6. However, the discussions with service users were mainly focused on exploring what their carers need from services, whereas the discussion with carers also invited them to talk about potential services. Finally, the current
analysis produced five major themes as presented in Table 18. The fifth theme (i.e. service users’ needs and expectation) was in addition to the four themes that emerged from the data analysis in carer focus groups.

Table 18. Themes identified from service user focus groups

<table>
<thead>
<tr>
<th>Main themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. The views of service users about caring for a person with a mental illness</strong></td>
</tr>
<tr>
<td>1.1. Emotional reactions associated with caregiving</td>
</tr>
<tr>
<td>1.2. Coping strategies in undertaking caregiving roles</td>
</tr>
<tr>
<td><strong>2. Carer needs and expectations from mental health hospital –based services</strong></td>
</tr>
<tr>
<td>2.1. Information</td>
</tr>
<tr>
<td>2.2. Emotional support</td>
</tr>
<tr>
<td>2.3. Financial support</td>
</tr>
<tr>
<td>2.4. Recovery for service users</td>
</tr>
<tr>
<td>2.5. Professionalism in contact with service users and carers</td>
</tr>
<tr>
<td><strong>3. Current support for carers</strong></td>
</tr>
<tr>
<td>3.1. Positive views of current support for carers</td>
</tr>
<tr>
<td>3.2. Weaknesses of current support for carers</td>
</tr>
<tr>
<td><strong>4. Recommendations for service improvement</strong></td>
</tr>
<tr>
<td>4.1. Improvement for information provision</td>
</tr>
<tr>
<td><strong>5. Service users’ needs and expectations from carers and hospital services</strong></td>
</tr>
</tbody>
</table>

5.1.4.3. Triangulation of findings of focus groups with carers and service users

As indicated previously, the qualitative data sourced from carers and service users yielded somewhat different results. One form of triangulation, namely data triangulation (Denzin 1979 in Flick 2008), assumes that the use of different sources of information can help to confirm and improve the clarity of the research findings. However, Flick (2008) argues that triangulation of two or more sources of data can only serve to validate the research findings if the investigation employs clear different methods for data collection. Here, the triangulation will result in convergent results which facilitate comprehensiveness in grasping the issues under the study. As occurred in the current focus groups, triangulation of data from carers and service users, complement each other in order to promote the
quality of the research (Patton 1999, Flick 2008). Three steps of triangulation by Farmer et al. (2006) were employed: sorting out, assessing the level of convergence, and completing the comparison.

Firstly, the results related to the research questions from each data set were sorted and separated into two files: findings from carers and service users. Next, the content of both files were reviewed with the purpose of identifying comparable key themes and creating a unified list of themes. The list of unified themes was established by transferring the similar themes that had emerged from the discussions with two different groups of participants (i.e. the themes recorded in Table 17 and 18 on page 126 and 127) into a separate paper as presented in Table 19. The fifth theme from the service user focus groups (i.e. service users’ needs and expectations from carers and hospital services) were eliminated as it was not considered to be really relevant to the research question.

Table 19. Unified themes from focus groups with carers and service users

<table>
<thead>
<tr>
<th>Main themes</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. <strong>Experiences in caregiving</strong></td>
<td></td>
</tr>
<tr>
<td>1.1. Emotional reactions associated with caregiving</td>
<td></td>
</tr>
<tr>
<td>1.2. Coping strategies in undertaking caregiving roles</td>
<td></td>
</tr>
<tr>
<td>2. <strong>Carer needs and expectations from mental health hospital–based services</strong></td>
<td></td>
</tr>
<tr>
<td>2.1. Information</td>
<td></td>
</tr>
<tr>
<td>2.2. Emotional support</td>
<td></td>
</tr>
<tr>
<td>2.3. Financial support</td>
<td></td>
</tr>
<tr>
<td>2.4. Recovery for service users</td>
<td></td>
</tr>
<tr>
<td>2.5. Professionalism in contact with service users and carers</td>
<td></td>
</tr>
<tr>
<td>3. <strong>Current support for carers</strong></td>
<td></td>
</tr>
<tr>
<td>4. <strong>Recommendations for service improvement</strong></td>
<td></td>
</tr>
<tr>
<td>4.1. Group-based emotional support</td>
<td></td>
</tr>
<tr>
<td>4.2. Improvement for information provision</td>
<td></td>
</tr>
</tbody>
</table>

Secondly, assessing the level of convergence was conducted by comparing the two files of findings with respect to the meaning, interpretation, frequency and prominence of the unified themes (i.e. number of references/quotes mentioning each unified theme/subtheme) (Farmer et al. 2006). A matrix
was developed to assist the procedure of comparing the presence and frequency of the unified themes/subthemes as shown in Table 20.

Table 20. Comparison of presence and frequency between the data from focus groups with carers and service users

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subthemes</th>
<th>Number of references/quotes assigned for the theme/subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Service user participants in 2 FGDs (n=13)</td>
<td>Carer participants in 7 FGDs (n=33)</td>
</tr>
<tr>
<td>1. Experiences in caregiving</td>
<td>Emotional reactions associated with caregiving</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Coping strategies in undertaking caregiving roles</td>
<td>3</td>
</tr>
<tr>
<td>2. Carer needs and expectations from mental health hospital -based services</td>
<td>Information</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Emotional support</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Financial support</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Recovery for service users</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Professionalism in contact with service users and carers</td>
<td>1</td>
</tr>
<tr>
<td>3. Current support for carers</td>
<td></td>
<td>18</td>
</tr>
<tr>
<td>4. Recommendations for service improvement</td>
<td>Group-based emotional support</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Improvement for information provision</td>
<td>2</td>
</tr>
</tbody>
</table>

The assessment continued by analysing the level of convergence for each unified theme/subtheme on a basis of categorisation (Farmer et al. 2006). Table 21 shows how each theme/subtheme was examined on categorisation scheme: AG (Agreement=full agreement or minor difference), PA (Partial agreement), S (Silence=findings in one set are silent), and D (Dissonance=no agreement between the two sets of findings).
Table 21. Assessment of level of convergence between the unified themes/subthemes from focus groups with carers and servicers

<table>
<thead>
<tr>
<th>THEME</th>
<th>SUBTHEMES</th>
<th>AG</th>
<th>PA</th>
<th>S</th>
<th>D</th>
<th>DETAILS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiences in caregiving</td>
<td>Emotional reactions associated with caregiving</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>• Both data sources identified same positive and negative emotions resulted from caregiving i.e. shame, sadness, distressed, frustration, tiredness, worried, confusion, resentment, anger, gratefulness, and a sense of caring and compassion for the service users</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• A minor difference: service user groups did not yield data about the feelings of shame and gratefulness</td>
</tr>
<tr>
<td></td>
<td>Coping strategies in undertaking caregiving roles</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>• Data were mostly derived from carers</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Data surrounding coping strategies from service users only surrounded withdrawing them from social life, while data from carers were diverse</td>
</tr>
<tr>
<td>Carer needs and expectations from mental health hospital – based services</td>
<td>Information</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>• Both data sources identified what information needed by Indonesian carers’ i.e. general knowledge of mental illness, progress of illness, medication and other treatments, and hospital regulation.</td>
</tr>
<tr>
<td>THEME</td>
<td>SUBTHEMES</td>
<td>AG</td>
<td>PA</td>
<td>S</td>
<td>D</td>
<td>DETAILS</td>
</tr>
<tr>
<td>------------------------------</td>
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<td>-----------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Emotional support           |                                  |    | X  |   |   | • Data were mostly derived from carers  
  • Data from service users only surrounding the need of carers to express feelings in peer groups                                      |
| Financial support           |                                  | X  |    |   |   | • Both carer and service user groups provided adequate data about the need of financial support                                         |
| Recovery for service users  |                                  | X  |    |   |   | • Both carer and service user groups revealed data relating to expectation of recovery for ill relatives  
  • No significant differences in terms of ideas about the meaning of recovery                                                      |
| Professionalism with service users and carers |                                  | X  |    |   |   | • Both carer and user groups revealed data about the expectation of professionalism of health workers.  
  • The differences laid on the emphasis of what the health worker should do to enhance their professionalism(carers thought the professionalism should be focused on their ill relatives’ wellbeing, while users thought it should be also focused on the family-professional relationship ) |
| Current support for carers  |                                  | X  |    |   |   | • Both carer and service user groups provided data about the positive and flaws of the existing support for carers  
  .                                                                                                                                 |
| Recommendations for service improvement | Group-based emotional support |    | X  |   |   | • Data were only derived from carers  
  • Data were mostly derived from carers  
  • Data from service users were brief and narrow e.g. did not cover all areas of improvement such as the strategy, time delivery, setting, people involved and anticipated barriers |
| Improvement for information provision |                                  | X  |    |   |   |  
  • Data were mostly derived from carers  
  • Data from service users were brief and narrow e.g. did not cover all areas of improvement such as the strategy, time delivery, setting, people involved and anticipated barriers |

**TOTAL**  

- 6 of 10  
- 3 of 10  
- 1 of 10  
- 0
Lastly, the comparison was completed by reviewing the findings which were relevant to the research questions (Farmer et al. 2006). Based on the previous step (i.e. convergence assessment), it is evident that there were many theme/subtheme areas where two data sets agreed and confirmed the unified key themes. The most notable difference was that only the discussions with carer participants elicited ideas for developing a group-based emotional support for Indonesian carers. Nevertheless, the researcher decided to include the ideas for emotional support development because one of the aims of the focus groups was to explore potential services for carers in Indonesia.

In summary, the established unified themes/subthemes presented in the previous Table 18 have more similarities than differences, therefore they are utilised to describe and discuss the findings of focus groups with carers and service users exploring of the needs of carers in Indonesia.

5.1.5. Discussion of findings

5.1.5.1. Main theme 1: Experiences in caregiving

During the discussions relating to caregiving experiences, the study participants mainly spoke about their emotional reactions and coping strategies of carers in managing their caring role.

5.1.5.1.1. Emotional reactions associated with caregiving

The participants reported a wide range of emotional reactions when caring for relatives with serious mental illness including feelings of shame, stigmatised, sadness, distressed, frustration, tiredness, worried, confusion, resentment, anger, gratefulness and compassion for the service users. These reactions have also been found in previous investigations that explored caregiving experiences in mental health fields (Szmukler et al. 1996, Karp and Tanarugsachock 2000, Veltman et al. 2002, Schulze and Angermeyer 2003, Rose et al. 2006).

Clearly, most participants discussed negative emotional responses even though a few positive responses were also elicited. For example, the carer participants felt a sense of shame of having to live
with a family member with a mental illness. Furthermore, the carers reported being stigmatised by friends or the public as a direct result of mental illness being present within their respective households. Some of the stigmatised attitudes of public were exposed, including calling the service users ‘crazy’ or avoiding interaction with them. Unsurprisingly, the carers lamented that such unsupportive attitudes were not only held by public, but also other family members who could be critical to service users. The carers frequently expressed the feelings of humiliation and being stigmatised along with grief. This is evident in the case of carers who were sad when describing how their relatives were humiliated by neighbours because of suffering from a mental health problem:

32A: Our neighbours often mock my brother; therefore he does not want to go outside. One day there was a woman who suddenly shut her door house when seeing my brother. The woman taunted him ‘crazy’. At the end, he became upset then raged at home [crying]

26 A: People do not want my children [service users] to live in the neighbourhood. One day, my daughter was unstable and hit someone. Then she was dragged on the street by the people…she was bleeding badly… Bleeding on her knees [showing knee and crying]. (Focus group 5)

The participants in the groups of carers and service users concurred that distress among families of people with mental illnesses was substantial. Some parent carers maintained that the distress was primarily because their adult children were unemployed. Unemployment caused significant difficulties for the parents who assisted the service users financially, by means of contributing to their expenses for meals, groceries, clothes and transportation to visit mental health services. Some parents blamed the government for their financial issues, believing that the anguish would not be so intense if there was a grant programme for people with mental health problems and their carers. The World Health Organisation (WHO, 2008) has indicated that the small amount of budget for relatives (2.6%) assigned to mental health in middle-income countries, including Indonesia, has contributed to family burden significantly. Parallel with the carer participants, the service users in the study also realised that meeting the caregiving costs was very distressing, as reflected in the following quote:
It is hard, in terms of finance and other things related. My brother has to help me financially... So if it is said to be stressful... yes, it is very stressful for him... especially when he has to expend money for my needs... for the cost of medication and treatment and my daily life... the costs for everything... (9B, focus group 7).

The carer participants acknowledged that caring for people with mental disorders over many years could be exhausting. To illustrate, some of the carers stated that their caregiving tasks were not only physically tiring (e.g. for staying awake when their relatives were unable to sleep for days); but also psychologically draining (e.g. persistent and enduring stress resulting from caregiving roles). One carer expected her son to recover, or if it was not possible she accepted the service user to die; thus it would reduce her exhaustion in caring for a family member with mental illness as shown in the following quotation:

*I plead God in every prayer, “O... Allah, if You can heal him... please give him the healing... if he can’t be cured, just take him. I am so tired!”*  
(32A, focus group 5)

Finally, frustration was reported by the carers in regard to their relatives’ inability to control symptoms which reflected a decrease in or loss of normal functions (so-called as negative symptoms). The negative symptoms observed in family members included a lack of interest to carry out self-care and/or household activities. This finding is similar to the data from previous studies which considered negative symptoms to be more burdensome than other symptoms like hallucination and delusion (so-called as positive symptoms) (Provencher and Mueser 1997, Tucker et al. 1998, Barrowclough et al. 2003). In the current study, the level of frustration was not only verbalised but also demonstrated during the discussions with specific behaviours like the raising of voices and clenching hands. One carer was shouting when revealing the amount of time that her husband spent for caring for his ill sibling:

*She [service user] is my husband's sister. He is looking after a depressed person. She does nothing... does not want to eat... does not want to do households... I feel frustrated as my husband is only taking care of this sister. Like no one else can take care of her. Then he does not care about his own wife. His attention is dedicated only to his sister (31A, focus group 5).*

As indicated previously, some positive emotional reactions associated with caregiving were also revealed. For example, gratefulness was obvious in carer focus groups, even though it was not apparent in service user groups. Some of the carers were relieved when their relatives’ diagnosis was
established. These carers had relied on the common cultural belief in that a mental health problem was
ciaused by a supernatural power therefore they sought help from traditional healers. However, after
some months or years, the carers found that the traditional healers’ help was not really satisfying as
they still had remaining questions about the problems that their relative was experiencing. Having a
definitive diagnosis of mental disorder was comforting, as the carers no longer had to live under a cloud
of confusion of what was wrong with service users which had continued for a long period of time (Karp
and Tanarugsachock 2000). This was reflected by one of the carer participants as follows:

So now I’m very grateful because I already know [the illness], and we
can be tolerant to him. Eventually it is true that my son has a mental
disorder. Before now, there were many opinions from lefts and rights,
such as that he might be possessed and so on (5A, focus group 2)

Despite the distress and frustration elicited by carers they all expressed compassion or sympathy for
their ill relatives. In this sense, the carers understood that the life opportunities of their relatives were
reduced because of their illness. The carers also reflected how difficult it was to manage mental health
symptoms including hallucinating, self-harm and withdrawal from social activities. It seemed that the
carers’ sympathetic feelings had augmented a willingness to provide the best care for their relatives
(Karp and Tanarugsachock 2000, Veltman et al 2002), as asserted by a mother in one discussion:

I feel sympathy on her and then we are doing what we can do. We
are trying to give what she wants... What she needs… (11A, focus
group 2)

The sense of being cared for was also evident in service user groups even though it was less prevalent
than in carer groups (i.e. only expressed by four of the 13 service users). The four service users believed
that their carers had done the best by facilitating them to be treated in the inpatient care as illustrated in
the following conversation:

9B: When my emotions were very high, I could even hurt my nieces and
nephews. Therefore, I was finally brought into this hospital. I knew
my brother actually did not want to put me here. But what could he
do? I think my brother really cares about me ... he is very
sympathetic towards me ...as the youngest sister... having stress
problems like this.

10B: Yeah… my sister also sympathises with me … she loves me. She
cares about me. My brothers also care about me.

(Focus group 8)
Nevertheless, in the view of two service users, helping them to be treated in inpatients was not a mean of expressing a sense of caring. Rather, it was deemed that families were disappointed with the ill relatives’ condition (e.g. ‘being imperfect’ or ‘unable to solve problems’); therefore the carers tried to minimise contacts with the service users by means of hospitalisation.

5.1.5.1.2. Coping strategies in undertaking caregiving role

The focus groups uncovered data of how Indonesian carers coped with stressful events stemming from the relatives’ illness, including detecting early signs of the illness, managing the symptoms and maintaining a good relationship with the service users. The findings were mainly revealed in the carer focus groups. To illustrate, most of the carer participants spoke about their journey in discovering their relatives’ mental health problem. The described endeavours were not unusual in Indonesian culture which is not reliant upon the medical model for confirming the underlying nature of mental health problems, especially in the first episode of occurrence (Kurihara et al. 2001). The medical model emphasises that mental health problems have an organic or physical cause such as chemical imbalance or abnormality in a part of the brain, the problems are then labelled by a doctor on the basis of specific behaviours—so-called as symptoms—which are reported by families or observed by health professional; and eventually the treatments are designed by the professionals to deal with the health impairment (Klerman 1977, Elkins 2009). Alternatively, the carer participants had relied on the common cultural beliefs in many non-industrialised countries; emphasising that mental health problems are caused by demons, witchcrafts, or spirits; therefore they sought help from traditional healers (Kurihara et al. 2001, Mavundla 2009). Kurihara (2001) notes that the perception that mental health problems is influenced by a supernatural power has led to supportive attitudes of Indonesian carers (e.g. not blaming service users for the presence of problems and having strong willingness to help through the traditional healers). In the current study, the carers’ commitment to help service users in the early stages of mental health problems is shown in the following conversation:

27A: Yeah… I brought my son to a healer ... then I followed what the healer said. He said, “Bring him back here ... bring 1.5 million rupiahs as well. Also bring a special chicken ..."
28A: yeah the same with me...I brought him to a healer. Then he stayed in the healer's house for 2 days. But then, the healer said, “You have sold your house for treating him to many healers, haven't you?” I replied, “Yes, you’re right ”. The healer then said, “This is too late Ma'am. This is like a rusty nail. It's better to bring him to a hospital… go to psychiatrists” (focus group 5)

The above conversation clearly reflected the carers’ endeavours for supporting their ill relatives. Such support continued after they had accepted a psychiatric diagnosis – a label for a mental health problem determined by health professional (Klerman 1977). Some of the carers disclosed their efforts to assist their relatives in controlling the symptoms, especially by following the professionals’ suggestions related to caregiving.

Nevertheless, other carers in the focus groups exposed diverse responses, amplified the evidence that labelling relatives’ problem as a mental disorder could also be disadvantageous for the service users (Karp and Tanarugsachock 2000, Rose et al. 2006). Once the relatives were diagnosed with a mental health disorder which exhibited negative symptoms (e.g. deprivation of motivation for daily activities and social contacts), their carers might limit their activities and interactions with other people (Rose et al. 2006). In the current focus groups, some carers believed that people diagnosed with a mental health disorder were violent thus restricting them for social contacts was deemed necessary to anticipate their unexpected behaviours, such as throwing things or becoming aggressive towards surrounding people. For example, a mother disclosed that her adult son had been isolated by placing him in 'a special space' of the house. The isolation was ended after some health professionals visited the house then brought the service user for hospitalisation:

I prepared a special room for my [ill] son, because if he was outside the room, he would be furious… Yes, a room with a WC and a bed... My brother said, "Please, sister... don't bring your son anywhere else. Even if you sell your house for his treatment, he will not recover". Therefore, I made a special room for my son. Then he has been in the room for five years, but finally he is now here [in a mental health hospital] because a staff from the community health centre came to my house and told me to hospitalise my son (32A, focus group 5)

In the following conversation it was found that the decision of hospitalisation did not change the carer’s intention to terminate the seclusion. The carer affirmed that while the service user was being treated in the inpatient, refurbishment of the ‘special room’ was made for re-occupation. It is argued that the health professionals applied the paternalistic model in making the decision concerning the service
user’s treatment. Within this model, professionals are the main decision makers who articulate what is best for service users, and carers’ opinions related to treatment for their ill relatives are often overlooked (Llewellyn-Thomas 1995, Charles et al. 1999).

Thus far, the first theme concerning the experiences of Indonesian carers in looking after individuals with mental illnesses has been discussed. In general, the experiences revealed were consistent with the findings of other investigations, suggesting that taking care of individuals with serious mental illnesses was not just a burden but that it could also be rewarding (Karp and Tanarugsachock 2000, Veltman et al. 2002, Rose et al. 2006). In the current study some burdensome feelings like tiredness, frustration and distress which understandably emerged when caring for people with enduring illnesses were exposed together with some contrasting emotions such as gratefulness and compassion. Likewise, while some coping strategies which seemed to be disadvantageous to service users were identified (e.g. protecting them from social life); more endeavours were uncovered (e.g. detecting the illness and managing the symptoms) suggesting that the carers were relatively attentive to their ill relatives.

The focus groups, however, have discovered the main source of burden of Indonesian carers are financial. The fact is unsurprising for research conducted in developing countries like Indonesia; however it is compelling to call for a more serious attention to support carers financially. The study also has uncovered essential facts about the carers’ cultural values that have influenced their efforts in dealing with caring roles. For example, the cultural beliefs have guided the carers for seeking help from traditional healers instead of medical professionals especially in the initial phase of the relatives’ illness. At the end, this finding recommends to an application of culturally-based approaches in order to deliver effective professional support for the carers. The approach opens for negotiation, instead of imposing, between traditional beliefs and biomedical practices (Mavundla et al. 2009). The approach also regards the carers as the active rather than passive recipients of the professional support, allowing them to employ non-hazardous traditional beliefs in caring for their relatives (Peterson et al. 2009).
5.1.5.2. Main Theme 2: Carer needs from mental health hospital services

This is a central theme because the focus groups mainly aimed to explore what Indonesian carers need from the views of people who played the caring role and those who had contact with mental health hospital services.

5.1.5.2.1. Information

Both carer and service user participants identified a wide range of carer needs in relation to information. The finding is consistent with previous literature which has found that carers need general knowledge of mental disorders (e.g. causes, symptoms and how to care for people with the illnesses); as well as information relating to the service users’ mental health state, medication and other possible treatments, and hospital regulations (Glendy and Mackenzie 1998, Smith et al. 2001, Chien and Norman 2003, Bollini et al. 2004, Cleary et al 2005, Askey et al. 2009, Van de Bovenkamp and Trappenburg 2010, McHugh et al. 2012, McNeil 2013).

The need for information about medication was not discussed in service user focus groups. However, the topic was essential in the view of carer participants. This finding echoed some surveys of other carers which highlighted medication as one of the most requested pieces of information in their interactions with health professionals (Gasque-Carter and Curlee 1999, Chien and Norman 2003, Cleary et al. 2005). The current focus groups allowed the carers to detail this need of education (i.e. suggesting the professionals to explain various techniques of drug administration, medication alternatives, and procedures to utilise the free medication policy). In one discussion, it was uncovered that a lack of knowledge about how to administer medication resulted in an ethical issue regarding obtaining consent from service users:
We need to know how to give medication to the ill person... in many ways... When there was no family member around, he would discard the drugs in the trash or store them in other places. Therefore I have been looking for information on how to [give the medication]... Once I asked a doctor whether there was an alternative drug replacement with similar functions ... well it was told that there were injections which were only given by doctors, drops or tablets...but even with the tablet. I had to crush them before giving them to my father. I did that with no knowledge of how to give medication to service users (33A, focus group 8)

Further, the carer and service user participants had divergent views about what was important to be informed relating to caregiving strategies. According to the carers, it was necessary to know about strategies to build supportive communications with service users. In a different way, the service user participants emphasised that the provision of knowledge to carers should increase their enthusiasm to visit in-patient care more frequently. Clearly, the service users did not only expect education for their carers; but it should also lead to behavioural change in carrying out the caring role as illustrated in the following conversation:

8B : Family therapy in this hospital is still lacking. My family even force me to stay here for a long time. That’s why I continue living here.

HS : Do you feel like that?

8B : Yes... My family do not want to face my problems. Until now, no family member ever sees me. It’s been 2 weeks... so what is needed by every family is... information on how to care for us... how to visit their ill relative member... because my family have not come here yet.... (focus group 7)

5.1.5.2.2. Emotional support

Most of the data relating to emotional support emerged from the carer groups. The need for psychological support was acknowledged with regard to opportunities to talk with other family members, carers, friends, and health professionals. The need to talk with other carers is shown below:
33A: It is important and very necessary to [talk with other carers] ... in other words, talking in a group of carers

33A: Yes, there should be a community for families of people with mental illnesses...

5A: For example a community of family of people with schizophrenia ... so we could share our experiences (focus group 8).

Although the demand for emotional support emerged in all discussions, only two carer participants reported their interactions with professionals brought positive impacts on their emotional state. A carer even emphasised that the psychological benefit was not obtained directly from the health workers but from other carers who were considered as having similar caregiving experiences. Obviously, the carer embraced the concept of universality in mental illness; underlining that mental disorders have general impacts to the sufferers and significant others across a wide range of cultures (Patel and Winston 1994, Hall 2009). The carer expressed the benefit of meeting with other carers along these lines:

_Honestly, I want to come to the education for carers not only to learn about the material given. Sometimes I am happy to chat with similar carers ...to find a friend in the same boat! (5A, focus group 8)"

Almost all carer participants valued their involvement in the focus groups for sharing opportunities which at the end could reduce their level of stress. Being involved in gatherings like focus groups was deemed as a proper approach to give the carer participants a safe environment for sharing ideas and feelings about caregiving role (Chambers et al. 2001, McAuliffe et al. 2009, Mizuno et al. 2013). Similarly, the service user participants also anticipated the positive impression of the focus groups, thus expecting similar gatherings for their families to be held in the hospital:

_It would be a good input if a discussion like this is held in this hospital ... for our families, performed by nurses (3B, focus group 6)_

5.1.5.2.3. Financial support

The findings related to the need of financial support was prevailing throughout the whole discussions with carer and service user participants, as detailed on page 133 about the carers’ experiences and stress related to finances. Perhaps the demand was prevalent because most of the participants
recognised the very serious impact of economic problems on the burden of carers in Indonesia. The evidence has supported the fact that economic issue has been the most urgent problem of mental health care in Asian countries (Lauber and Roosler 2007, WHO 2008).

In the view of the carer participants, the financial assistance should be dedicated to supporting service users on a daily basis. This was discussed by carers who were already burdened with the cost of living of other family members. Likewise, the service user participants acknowledged that family expenses increased for supporting their needs, even during a hospitalisation period (e.g. food and phone communications with friends and relatives). The following is the expression of some carer participants related to the need for financial support:

5A: If we are asked about our needs... of course, financial needs! Honestly, ma’am... the [financial] needs that we have with family members like them are twofold compared to normal people

11A: You’re right!

5A: For funding their cigarette... Coffee... (focus group 2)

The need for financial support was also revealed in regard to long-term health insurance to individuals with serious mental illness. Reasonably, this expectation was only voiced by the carer participants in anticipation of a condition when they were no longer present to look after their ill relatives eternally. In one discussion, a mother was inspired by mental health policies of some countries (e.g. the US) that offers low-cost or free psychiatric medication for individuals with financial difficulties. Nonetheless, the carer expected more and demanded the current free medication policy in Indonesia to be applied permanently:

Especially for mental illness, there should be a letter like a valid card…you know… and it can be applied to all hospitals anywhere... the government hospitals which offer mental health services. So when we die... [stopped]...or even if he [service user] does not use the card because he does not want to, at least the government has guaranteed his medication for life… Such a guarantee… (5A focus group 2)
5.1.5.2.4. Recovery for service users

The participants in both samples concurred about what carers want in relation to service users’ wellbeing. Here, a sense of optimism regarding recovery for service users was expressed recurrently, supported by the carers’ spiritual beliefs that God always offers cure for every disease as illustrated below:

*Thank God we have a religion which explains that He will not give a disease without cure. In my situation, perhaps I have not found the suitable medicine [for my son] now...I meant, the suitable one. In the Qur’an it is clearly stated that every disease is curable… [7A, focus group 2]*

The above belief seems to support the development of a medical model which considers serious mental problems like schizophrenia are being curable and this contradicts the traditional medical models of psychosis which suggest that such a mental health problem is deteriorating (Lam et al. 2005, Andresen et al. 2011, Barber 2012). The cured condition is characterised by an absence of psychotic symptoms but no longer requires medication support (i.e. so-called as clinical recovery) (Slade et al. 2008).

Furthermore, it was evident that carers in this study referred to recovery as multifaceted, and focused on the process of healing (Ramon et al. 2007). For example, recovery was characterised as showing no relapses for a long period, having a job or social relationships with others, or involving in after-care activities. Another meaning of recovery also emerged in service user groups, emphasising individualised expectation about their own illness (Ramon et al. 2007, Slade 2009). A service user defined recovery for the self as having a stable mental health state and a willingness to work as follows:

*If the progress of service users is good, or if I am fine, or already have a passion for work… then these can make them [carers] happy ... so this is connected to my recovery (12B focus group 7)*
5.1.5.2.5. Professionalism in contact with service users and carers

From the perspective of carer participants, professionalism of health workers should be demonstrated for the intention of improving service users’ wellbeing. The carers wanted mental health professionals to establish good communication with service users by being ‘friendly’ when talking to the ill persons or providing them ample time for giving information about mental illnesses. Obviously the carers wished for the adoption of a medical model which emphasises the duty of professionals to care about their relatives and respects to the patients’ rights to grasp sufficient knowledge about diagnosis and treatment (Klerman 1977, McManus 1992, Colombo et al.2003). The carers might also understand that supportive relationships initiated by the professionals could lead to positive changes and outcomes for the service users (Gilburt et al. 2008). On the contrary, in the view of service user participants, good communication by professionals should also be offered to carers. The service users expected equal relationship (i.e. stated as ‘horizontal relationship’) to indicate egalitarianism in communication between the professionals and their families, as illustrated in the following conversation:

6B: I think, how the nurse connects to the family ... well ... a link of communication is needed here ... they [nurses] should have good communication with families. Yeah ... also between doctors and families ... so they are connected. When there is an issue it can be communicated, then everything becomes easy

4B: Right, there should be a horizontal relationship (focus group 6)

To summarise, the wide-ranging needs of carers presented in this section reflects the findings of previous studies in similar areas. There were slight differences between the carer and service user participants in describing the identified needs. Both had comparable opinions with regard to the emotional and financial support, as well as recovery from mental illness. Some discrepancies between the two samples were obvious with respect to the expectations of carer education and professionalism of health workers in contact with carers. The service user focus groups did not only uncover what was needed by those who cared for mentally ill people, but also suggested the service users’ own need, particularly the need to be cared for by families (more attentively). Finally the two groups of participants concurred that the focused discussions were valuable for the opportunities of sharing thoughts, feelings and experiences among the members.
5.1.5.3. Main theme 3: Current support for carers

One of the focus groups objectives was to explore the extent to which the existing mental health hospital-based support to meet the carer needs. The available support was mainly information provision about mental illness (e.g. cause, symptoms and strategies for caring for people with the illness). The information was delivered face-to-face to individual carers (e.g. during consultation of service users) or groups of carers (e.g. in the hospital education programme). The carer group education was offered every month at one hospital, and every six months at another hospital. Although minimally reported, written information was also offered through flyers or booklets about mental health problems. Finally, the study participants only mentioned nurses when talking about emotional support by professionals. Perhaps the participants recognised nurses as professionals who are most likely to be contacted within their non-stop working shifts (Chambers et al. 2001).

There are a small number of positive views with regard to the current information provision. For example, some carers implied that the group education has brought some benefits such as improvement of knowledge about mental illness as illustrated below:

Well, honestly, if I did not come to [the group education], I would have known nothing about the illness… (5A, focus group 8).

A number of limitations were revealed when the carers commented on the current education provision, including difficulties to access information from the mental health hospitals. Some classic causes emerged to explain why many carers could not participate in the offered education such as lack of time, distance between the hospital and the carers’ residence, and problems associated with transport costs. Moreover, it seemed that the existing education which was designed for a group of carers was not known by most of the participants. Only seven of the 33 carer participants knew about the group education, and four divulged their experience of attendance. Likewise, all service user participants had never heard about the group education. This finding is not unexpected because similar issues were also found in countries like UK and US where the mental health services including support for carers have relatively been well established (Rose et al. 2004, Askey et al., 2009, Lyons et al. 2009). The next limitation was related to the extent of information given by the health professionals. Many carer participants criticised insufficient information given by psychiatrists when accompanying service
users for consultation. Although this was reasonable due to the professionals’ workload, the provided information was considered so brief that the service users and carers failed to comprehend about mental illness clearly. This finding repeated other studies which exposed complaints of carers regarding the quality of consultation by medical professionals (Smith et al. 2001, Askey et al. 2009, Van de Bovenkamp and Trappenburg 2010). A similar criticism was also asserted by service user participants in this study as follows:

_In my opinion, the information given to my family is still lacking. At least my family should be given information about my mental health state. Even when I stayed at home after hospitalisation, my brother treated me like ...he was so rigid to me... well. He actually needed all information about me...such as my mental health state when I was hospitalised and what I could do during that time. So in my opinion the information given to our families is still lacking! (9B, focus group 7)_

Further limitation was related to the content of the given information. Some carer participants were disappointed because the group education for carers offered similar unneeded information:

_Yes... Sometimes they give the same topic, such as treatment for mental illness. We already know the topic, like we've heard about it before. It seemed that we already know. The difference was only the doctors who delivered the education (7A, focus group 2)_

The description of the current theme emphasises hospital endeavours in supporting carers, especially through education provision. No evidence to suggest that structured established family interventions have been introduced for the carers, even though psycho-education as the upmost component of the interventions was factual. Frequent disappointments emerged in all focus groups with carers and service users, obscuring the advantages of the existing education programmes. However, the presented evidence was valuable to know the extent to which carers in Indonesia could access the existing support. Also, it was useful to understand what has worked well and what has hindered the carers to access. Finally, the information can be meaningful inputs to improve the current support based on first-hand experiences of using the hospital services.
5.1.5.4. Main theme 4: Recommendations for service improvement

The suggestions presented under this theme were mainly sourced from the carer participants, and directed to address two main needs of carer (i.e. emotional supports and Information).

5.1.5.4.1. Group-based emotional support

As mentioned earlier, most carer participants experienced reduction of stress level following their involvement in the focus groups. For this reason, the carers suggested such a group meeting for the future emotional support provision.

Strategies of group-based emotional support

The carer participants suggested a group-based emotional support to be conducted in conjunction with information provision

Yeah... one day is divided into two times ... there will be time for education provision and then time for the families ... I meant time for sharing among the families (5A, focus group 8)

According to the carers, the potential group-based emotional support should provide opportunities to express feeling and should be collaborative and involve information sharing about caring strategies:

Facilitator/the researcher: What is the expected content of the future meeting among carers?

2A: It could be about the service users’ behaviour at home, his progress....

11A: Yeah ... so we can exchange information

33A: Sharing information so that we know everybody’s experience... how to care for people like them… (Focus group 8)

Although the carers thought that a peer-led meeting was appropriate, they felt that the infrastructure (i.e. organisational and venue) would be provided by the hospital in the initial stages of the group set up.
It still needs to be managed by the hospital in the beginning because if it is managed only by the families, I am afraid it would not go on... (5A, focus group 8)

Time for group-based emotion support

It was suggested that the group should converge for about an hour, once a month:

Once in a month is fine (11A, focus group 8)

3 hours is nice enough, 2 hours for education provision and 1 hour for express feeling among carers (5A, focus group 8)

Setting

Similar to the ideas for information delivery, the carer participants considered hospital as the most feasible setting for them to participate in the group-based emotional support:

2A: It won’t be possible to be held... somewhere else … if [the group-based emotional support] is implemented in other places; we have to make an appointment to meet ...so it is not possible
33A: yeah…We have to search the location (focus group 8)

People involved

It was suggested that the optimum number of carers involved in any one group was about 10 people. In addition, when carers would lead the meeting, a mental health professional could play a moderator role in the beginning of group meeting, then replace by carers when they are ready to be the group leader:

11A: Maximum 10 people
33A: If it is too many, then each person talks, it will take a very long time
5A: Yeah too long, but the time is only 1 hour (focus group 8)

They (professionals) can (lead) the group… it would be like the moderator. Later on carers could replace the moderator position. They can start by saying, “I will start...” and then other opinions will come such and such, so it would go on and on (23A, focus group 9)
Anticipated barriers

Finally, some anticipated barriers were identified including time constraints and transportation costs; which were common during the implementation of formal family psycho-education in western countries (McFarlane et al. 2003). Some of the barriers were expressed as follows:

*Depending on our time ... it's quite confusing ... better if I come but, really I cannot come too often (11A, focus group 8)*

*Once a month is enough, but the time should be made along with the education session. So we can arrange our time. In addition, we are also facing financial problems. If there is another meeting for carers like this [focus groups] we need transport costs to attend (5A, focus group 8)*

5.1.4.5.2. Improvement for information provision

Similar to the above findings related to ideas for emotional support improvement, the current information provision should be improved in terms of the strategy, time of delivery, place for group-based education, people involved, and anticipated barriers. A summary of the findings related to recommendations for service improvement is presented in Table 22.
### Table 22. Summary of findings about recommendations for service improvement sourced from the focus groups study

<table>
<thead>
<tr>
<th>Areas of improvement</th>
<th>Recommendations associated with group-based emotional support provision</th>
<th>Recommendations associated with information provision</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strategy</strong></td>
<td>• In conjunction with the group education provision</td>
<td>• More effective through face-to-face interaction than written information provision</td>
</tr>
<tr>
<td></td>
<td>• To exchange information about caregiving strategies, the progress of service users illness; and to express feelings associated with caregiving</td>
<td>• Individualised approach of information giving during consultation</td>
</tr>
<tr>
<td></td>
<td>• Organised by hospital</td>
<td>• Group-based education: delivering various and non-repetitive topics, using lay language, effective announcement, extra time for sharing thoughts and experiences</td>
</tr>
<tr>
<td><strong>Time of delivery</strong></td>
<td>• Once in a month for one hour</td>
<td>• At the beginning contact with health professionals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Group-based education: following the existing group education (i.e. once in a month from 10-12 am)</td>
</tr>
<tr>
<td><strong>Setting</strong></td>
<td>• Hospital</td>
<td>• Hospital</td>
</tr>
<tr>
<td><strong>People involved</strong></td>
<td>• 10 carers in one group</td>
<td>• 10-40 carers in one group</td>
</tr>
<tr>
<td></td>
<td>• Health professionals as the facilitator at start, then carer could replace</td>
<td></td>
</tr>
<tr>
<td><strong>Anticipated barriers</strong></td>
<td>• Time constraint</td>
<td>• Attrition issues</td>
</tr>
<tr>
<td></td>
<td>• Financial constraint</td>
<td></td>
</tr>
</tbody>
</table>

The above has provided a summary of the strategies emerging from the data to improve hospital-based support for carers in Indonesia. The scope of improvement was relatively narrow as the carer participants mainly discussed emotional and informational support provision. However, the ideas revealed were practical because they were derived from first-hand experience of using the hospital services in Indonesia. The suggestions has given an insight of how feasible it would be if the structured established family interventions were applied in the country, given that they are normally time consuming, costly and require highly trained professionals (Chakrabarti 2011). More importantly, the depicted expectations were sourced from those who became the target of the support development. Therefore, if the suggestions are implemented, the support developed will be more likely to become need-based services for Indonesian carers.

### 5.1.6. Summary

This section has described four main themes that emerged from the focus groups with carers and service users: Experiences in caregiving, carer needs from mental health hospital services, current
support for carers, and recommendations for service improvement. Each of the themes has been discussed and supported by the evidence sourced from the dynamic interactions among the participants. Obviously, as the smaller sample, the service users in this study gave less detail than carer participants. Nonetheless, the attained information from the service users has augmented evidence about carer needs from the perspective of people with serious mental illness in Indonesian context.

5.2. Section 2: Findings of qualitative interviews with health professionals

5.2.1. Introduction

This section presents the findings of individual interviews with health professionals exploring their perspectives about carer needs from mental health hospital-based services in Indonesia.

5.2.2. Study participants

The participants in this study were 24 health professionals, recruited from two mental health hospitals located in Jakarta, Indonesia (the procedures for recruiting the participants are detailed in Chapter Three). The majority of the participants were women (n=20), with an average length of employment of 7.54 years. Half of the sample were nurses (n=12), a quarter were psychiatrists (n=6) and the remaining participants included psychologists (n=2), social workers (n=2), a single occupational therapist and a single general practitioner. Thirteen of the 24 practitioners held managerial positions such as heads of ward or managers of hospital departments. The participants reported an average of 8.13 hours of contact with carers each week. A summary of the demographic data of the participants is displayed in Table 23.
Table 23. Demographic data of health professional participants

DS = Duren Sawit Mental Health Hospital, SH = Soeharto Heerdjan Mental Health Hospital; NA = Not available

<table>
<thead>
<tr>
<th>ID</th>
<th>Gender</th>
<th>Name of Mental Health Hospital</th>
<th>Occupation</th>
<th>Length of working time (in years)</th>
<th>Current managerial position</th>
<th>Length of time in current position (in year)</th>
<th>Time spent in contact with carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Female</td>
<td>SH</td>
<td>Nurse</td>
<td>13</td>
<td>Nurse Supervisor</td>
<td>0.5</td>
<td>4.5 hours/week</td>
</tr>
<tr>
<td>P2</td>
<td>Female</td>
<td>SH</td>
<td>Psychiatrist</td>
<td>8.5</td>
<td>The head of one unit care</td>
<td>2</td>
<td>24 hours/week</td>
</tr>
<tr>
<td>P3</td>
<td>Female</td>
<td>DS</td>
<td>Nurse</td>
<td>12</td>
<td>Head of ward</td>
<td>6</td>
<td>1.5 hours/week</td>
</tr>
<tr>
<td>P4</td>
<td>Female</td>
<td>DS</td>
<td>Psychologist</td>
<td>0.25</td>
<td>NA</td>
<td>0.25</td>
<td>3 hours/week</td>
</tr>
<tr>
<td>P5</td>
<td>Female</td>
<td>SH</td>
<td>Nurse</td>
<td>26</td>
<td>Head of ward</td>
<td>1</td>
<td>1.5 hours/week</td>
</tr>
<tr>
<td>P6</td>
<td>Female</td>
<td>SH</td>
<td>Psychiatrist</td>
<td>0.5</td>
<td>NA</td>
<td>0.5</td>
<td>20 hours/week</td>
</tr>
<tr>
<td>P7</td>
<td>Female</td>
<td>SH</td>
<td>Psychiatrist</td>
<td>8</td>
<td>Head of Verification Department</td>
<td>0.5</td>
<td>22 hours/week</td>
</tr>
<tr>
<td>P8</td>
<td>Female</td>
<td>SH</td>
<td>Nurse</td>
<td>8</td>
<td>Team leader of inpatient nurses</td>
<td>7</td>
<td>5.5 hours/week</td>
</tr>
<tr>
<td>P9</td>
<td>Female</td>
<td>DS</td>
<td>Nurse</td>
<td>10</td>
<td>Head of ward</td>
<td>6</td>
<td>0.4 hour/week</td>
</tr>
<tr>
<td>P10</td>
<td>Female</td>
<td>DS</td>
<td>Nurse</td>
<td>10</td>
<td>Head of ward</td>
<td>0.5</td>
<td>2.5 hours/week</td>
</tr>
<tr>
<td>P11</td>
<td>Female</td>
<td>DS</td>
<td>Nurse</td>
<td>10</td>
<td>Team leader of inpatient nurses</td>
<td>1.3</td>
<td>0.3 hour/week</td>
</tr>
<tr>
<td>P12</td>
<td>Female</td>
<td>DS</td>
<td>Nurse</td>
<td>9</td>
<td>NA</td>
<td>9</td>
<td>0.75 hour/week</td>
</tr>
<tr>
<td>P13</td>
<td>Female</td>
<td>DS</td>
<td>Social workers</td>
<td>4</td>
<td>NA</td>
<td>4</td>
<td>Undefined (incidental contacts)</td>
</tr>
<tr>
<td>P14</td>
<td>Female</td>
<td>DS</td>
<td>Nurse</td>
<td>10</td>
<td>Team leader of inpatient nurses</td>
<td>5</td>
<td>0.5 hour/week</td>
</tr>
<tr>
<td>P15</td>
<td>Female</td>
<td>SH</td>
<td>Nurse</td>
<td>8</td>
<td>Head of ward</td>
<td>0.5</td>
<td>1.5 hours/week</td>
</tr>
<tr>
<td>P16</td>
<td>Female</td>
<td>SH</td>
<td>Psychologist</td>
<td>3</td>
<td>NA</td>
<td>3</td>
<td>2 hours/ week</td>
</tr>
<tr>
<td>P17</td>
<td>Male</td>
<td>DS</td>
<td>Psychiatrist</td>
<td>3</td>
<td>NA</td>
<td>3</td>
<td>25 hours/week</td>
</tr>
<tr>
<td>P18</td>
<td>Male</td>
<td>SH</td>
<td>Nurse</td>
<td>8</td>
<td>Head of ward</td>
<td>2</td>
<td>3 hours/week</td>
</tr>
<tr>
<td>P19</td>
<td>Male</td>
<td>SH</td>
<td>GP</td>
<td>0.75</td>
<td>NA</td>
<td>0.75</td>
<td>21.5 hours/week</td>
</tr>
<tr>
<td>P20</td>
<td>Female</td>
<td>SH</td>
<td>Occupational therapist</td>
<td>3</td>
<td>NA</td>
<td>3</td>
<td>0.3 hour/week</td>
</tr>
<tr>
<td>P21</td>
<td>Female</td>
<td>SH</td>
<td>Nurse</td>
<td>18</td>
<td>Head of ward</td>
<td>2</td>
<td>2.5 hours/week</td>
</tr>
<tr>
<td>P22</td>
<td>Male</td>
<td>SH</td>
<td>Social worker</td>
<td>2</td>
<td>NA</td>
<td>2</td>
<td>1.6 hours/week</td>
</tr>
<tr>
<td>P23</td>
<td>Female</td>
<td>DS</td>
<td>Psychiatrist</td>
<td>3</td>
<td>NA</td>
<td>3</td>
<td>22.5 hours/week</td>
</tr>
<tr>
<td>P24</td>
<td>Female</td>
<td>DS</td>
<td>Psychiatrist</td>
<td>3</td>
<td>NA</td>
<td>3</td>
<td>21.25 hours/week</td>
</tr>
<tr>
<td>N= 24</td>
<td>Male= 4, Female= 20</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5.2.3. Themes identified

As described in Chapter Three, five key themes emerged from the application of framework analysis to the data of the interview study (Table 10 on page 108). A discussion of the themes as well as subthemes is presented subsequently.

5.2.3.1. Main theme 1: Why services should involve carers

This key theme focuses on revealing the professionals' justifications to involve carers in their services to people with mental illnesses. Recognition of these rationales is useful to understand the extent of carer involvement that has addressed carer aspirations from mental health hospital-based services.

5.2.3.1.1. Carers cause mental illness and relapse

Some professionals believed that carers caused their relatives' mental health problem as well as relapses. The mental health problems of service users were seen as a result of poor parenting or intense family arguments. As a result, the professionals thought that carers must be educated of how mental health problems could be attributed to the poor upbringing of children. Interestingly, the health professionals seemed to be wedded to psychosocial explanatory models as opposed to the medical model. The following quote illustrates the professionals' perspectives of their explanatory model:

It [carer involvement] is definitely needed because mental illness is related to what has been experienced by the sufferers in their family life... carers possibly have caused the illness. The illness might occur due to the maladaptive parenting which is not suitable for the sufferer... therefore there must be information given to the carers (P4).

Regarding the cause of relapses, some professionals believed that carers' emotions and attitudes contributed to the illness recurrence. A professional mentioned the concept of Expressed Emotion (EE), to emphasise that families who demonstrated one of the EE components exceedingly (i.e. emotional over involvement) could harm the service user. The professional criticised the families' over protectiveness such as showing pity and not allowing the service users to carry out day-to-day activities;
and that these might cause anxiety and frustration to the ill individuals. Some authors (Amaresha and Venkatasubramanian 2012), previously have supported this idea, emphasising that overprotectiveness might lead to over-dependence of service users on carers and finally hamper the recovery. Apparently the professional view was influenced by the concept of EE which is dominantly held by the western community. Kurihara et al. (2000) argues that the EE concept, especially in regard to over involvement, may not be appropriate for Asian culture that put involvement as the norm derived from a strong family bond. In contrast to many western countries, communal value from families in the countries is stronger than individual value (Kurihara et al. 2000). In addition, the description by the professional was given without any indication that other components of EE (i.e. critical comments and hostility) as well as outside factors (e.g. cultures and non-family environment) could also influence the relapse rates (McDonagh 2005):

We give the carers education, by teaching that what they are doing now; can trigger relapses. I often say to the carers: if they are too anxious, they can have high expressed emotions towards the service users (P7).

5.2.3.1.2. Medication adherence responsibility

For many professionals, carers were involved because they were primarily responsible for their relatives’ medication adherence. This medication responsibility was not only expressed by psychiatrist participants, but also the nurses, psychologists, and occupational therapists. This implied that the majority of professionals in this study held a medically oriented view in their contacts which is in direct contrast to their explanatory models described in the previous theme. To illustrate, more than half of nurses and all psychologists emphasised that it was the carers ‘duty’ to ensure medication adherence of service users. Moreover, the nurses disclosed that their consulting service (i.e. namely nursing consultation) was mainly intended to educate carers so they could support their relatives’ medication. For this reason, the carers were suggested to bring their loved ones in every visit to the psychiatrist as stated by a nurse below:

For the nursing consultation, the consumers are mostly carers who visit the psychiatrists without bringing their ill family member. Usually those are the target of our education because they must bring their ill relatives when visiting the doctors (P1)
Furthermore, some professionals expressed disappointment in carers who met physicians without the presence of service users during medication collection. This often occurred with the same carers even though they had been informed regarding the importance of service users being present in the prescription procedures. One psychiatrist divulged her disappointment in this way:

> Sometimes the upsetting situation is that, carers come to us without their ill relatives. For this reason, we give education like ‘Ma’am, please we are not shaman’. We are not a specialist who gives medicine when the service user is not around…’ I have explained it back and forth… I’m tired of giving the information…these carers do not want to work together with us...

(P23).

Clearly, the professionals believed that they need to educate carers about their role in medication collection, without any adequate exploration of why they could only see the doctors along without service users. It seemed that the professionals held beliefs which might have caused a situation of paternalistic partnership between carers and professional (i.e. beliefs that they know the best, they need to hold onto their power and maintain control on their interactions with carers) (Henderson 2003).

### 5.2.3.1.3. Carers as main support for service users

This subtheme emphasised that carers should be involved because they had the potential to support service users. The term ‘support’ was referred to assisting service users to control the illness symptoms, help them to perform daily activities, and provide funding assistance. According to the professionals, this assisting role was reasonable because a mentally ill person, as a member in a family system, should not be abandoned by their families. Rather, the main support for the service users should be sourced from the closest people who were commonly designated to the carers as expected by a nurse as follows:

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1. Shaman refers to a traditional healer, a person who has specialised cultural knowledge of healing people and practiced it through some activities such as special healing songs which cause him/her to enter into a trance-like condition and ‘diagnose’ and cure an illness (Singh, 1999).
The mentally ill person and his carers are a system in one family. That meant a mentally ill person is a part of his/her family. Moreover, the largest support system of individuals with mental illness should be sourced from their closest people...they are the carers. Therefore, it is highly expected that the carers are involved in mental health services (P1).

Perhaps the professionals reflected what has been highlighted by some authors (Ito et al. 2012) regarding carer involvement in Asia-Asian families, including Indonesian families, in which they have a strong commitment to be involved in providing care for people with health problems. Some researchers from Indonesia (Nurjannah et al. 2009) argue that such strong carer involvement is only relevant to families of people with physical illnesses but it is not always the case in mental health areas.

The current description seemed to reflect an encouraging view with respect to the value of carers as the closest people of service users. However, a deeper analysis showed that the carers were considered as those who must be educated about caring strategies. Many expressions tended to overlook possibilities in that the carers might have made great efforts to supporting the relatives, such as ‘the most important thing is teaching carers’, ‘carers should give great contribution in caring for their ill relatives’ and ‘carers should provide support’. In one interview, a health worker demanded carers to support their ill relatives to engage in meaningful activities. The way of the professional expressed her idea implied that the carers did not wish to give the best for their relatives. More interestingly, the idea of facilitating service users in meaningful activities was not meant involving them in programmes held by the existing services; rather, it was referred to activities designed by carers themselves as illustrated below:

I will say [to the carer]: ‘...at least he [service user] can do household activities, like sweeping or mopping the floor...The most important thing is that he has activities. Don’t let him stay at home without doing any activity and only day-dream. Eventually, the ill person is only smoking, drinking coffee, and smoking again. When he is day-dreaming, soon the whispering will start again’ … so this is what I say to carers. Overall, I want to say to the carers ... please help support the service user (P24)
5.2.3.1.4. Carers could help professional care

Some professionals thought that carers should be involved because they could assist professionals’ care during hospitalisation. According to nurse participants this was particularly appropriate to those service users who suffered from serious mental and physical problems. For example, one participant (nurse) described the difficulties of caring for service users with both mental and physical health problems and described the expectation that carers should assist the nurses in the same way that nursing assistants did:

Too often we take care of service users with B20 [schizophrenia and HIV AIDS] without any carer… We bathe them, help them for defecation and urination, and all of these duties are carried out by the nurses alone. No one accompanied these service users in the ward. … We really need the carers’ help to accompany their ill relatives (P15)

The hope for receiving help from carers did not end when their relatives completed their hospitalisation period. The carers were also expected to substitute certain professionals’ tasks at home like monitoring the relapse symptoms, even though initially they argued that carers could cause a relapse. In one interview, a nurse participant suggested carers to be just like her or become ‘a nurse for the ill person at home’, implying that nurses know best for service users. The statement also indicates that the nurses have positioned themselves as the most proficient people in caring for individuals with mental health problems. This finding seems to be congruent with the statement of some nurses in Australia, believed that they were experts in contrast to patients and families who lacked medical knowledge (Henderson 2003).

5.2.3.1.5. Supervisory activity

Contacts with carers were encouraged for the purpose of meeting the professionals’ need that was completing supervisory activities among nurse practitioners. The following is an affirmation from a head of ward, disclosing a fact that some communications between the nurse staff and carers were performed for supervisory reasons:
I will openly tell [my nurse staff], to please go to carers and do this and this... and then they have to do that. If they don’t do that, it will have an effect on their rewards. Let's say when they are supervised by me [as their manager], and then their performance(s) in interacting with carers is not satisfying, I would say to them... ‘That’s why I always tell you to see carers and that is actually for your own sake, not mine.’ After this, the nurse staffs usually become more serious in interacting with carers in the next supervision (P3).

In summarising this theme there were some interesting findings. None of the rationales of carer involvement was intended to enhance the carers’ own wellbeing. Instead, it was clear that the interactions between the professionals and carers were service user orientated. The findings also suggest that the professionals employed the psychosocial explanatory model in viewing the cause mental health problems (e.g. caused by poor parenting or continuous conflicts among family members); even though the model was not adopted consistently in contact with carers. In this sense, the professionals held a medical orientated view in that interactions with carers were aimed for supporting the carer duty of ensuring medication adherence. Other findings are related to the feature of professional-carer partnership in Indonesia where the carers’ expertise in caregiving was completely overlooked. The professionals have positioned themselves to be more knowledgeable than carers in caring for individuals with serious mental illnesses. Finally, it was found that some professionals involved carers for carrying out caregiving tasks in hospital; thus the involvement only took full advantage of the carers’ position as the closest people of the service users.

5.2.3.2. Main theme 2 : Professional views of what carers need for ill relatives

A key theme was professionals’ views of carer aspirations of service user’s wellbeing. Again, the service user-stance of the professionals was affirmed by the emergence of this theme, suggested that service users’ wellbeing is more important than their carers as reflected in the following statement:

The most important thing for carers is seeing that their relative is well... their relative is recovered… (P17)
5.2.3.2.1. Aftercare service engagement

Many professionals indicated that carers wanted their relatives to have a meaningful occupation following their hospitalisation. For this reason, the relatives were expected to be engaged in community-based services which could provide supported employment programmes including training, working skill development and sheltered work to prepare and then place the service users in a paid job. A nurse expressed this carer aspiration in this way:

_The service users should get activities. It would be better if the service users can be productive and having income [from the activities] and this is what the carers are expecting [from mental health services] (P1)._  

Furthermore, the involvement of service users in the services was considered as a way of reducing caregiver burden.

Some of the practitioners suggested that the need of aftercare services in Indonesia was prominent due to insufficient financial support from the government for individuals with mental illnesses. The issue of lacking aftercare services was not exclusive for developing countries like Indonesia, but it was also anticipated in countries like the UK where community mental health care has been well developed (Mairs et al, 2012). A psychiatrist in the current study detailed the need of aftercare services in Indonesia as follows:

_[Indonesia is] different from other countries where the government pays for [service users’] living cost in addition to their treatment. This includes facilities or places for them after they finish hospitalisation. I think this is less available in our country and has become a big issue for carers. You can imagine, people with mental illnesses are already stressed, disabled and moreover unable to contribute to their living cost, so of course it burdens their carers… the carers’ burden is massive, due to the illness, the symptoms, as well as their economic problems. So I think another need from the carer is access to a place to be productive for their relatives (P7)_
5.2.3.2.2. Recovery

A further aspiration that emerged was the recovery of service users. According to the professionals, carers wanted their relatives to recover which were characterised as being no longer exhibiting symptoms of mental illnesses, as illustrated in the following quotation:

Many carers have taken care of mentally ill relatives for 20 or 25 years, so they might not expect too much. If the service users do not show negative symptoms, this is enough! (P20)

It was clear that the professionals in this study tended to show a simple view about the concept of recovery in mental health problems: recovery is referred to individuals who have returned to their former state of health; characterised by remissions of symptoms, and remediation of deficits associated with the illness such as inabilities to carry out personal, social, and vocation functioning (Davidson et al. 2005). In fact, recovery in mental health problems has several other meanings which tend to be comprehensive and idiosyncratic. For example, recovery is defined as a personal process of changing one’s attitudes, values, feelings, goals, skills and roles (Slade et al. 2008). Recovery also refers to a person’s rights to self-determination and inclusion in community life despite continuing to suffer from mental illness (Davidson and Roe 2007).

To conclude, the description of this theme gives some context to the professionals’ views of what Indonesian carers want for service users. First, service users’ engagement in community aftercare services was deemed to be a fundamental need, even though the professionals acknowledged that meeting this need would be difficult because of the limitation of the government budgets in the field of mental health. Second, the description indicates an oversimplified perspective of the professionals regarding the concept of recovery in serious mental illnesses, which at the end might be harmful to service users and the carers. Defining recovery as no longer exhibiting symptoms of mental disorders could be stigmatising, because recovery in mental health problems does not always mean an end of a mental health state, but rather an individual process of changing attitudes, feelings and roles (Deegan 1996, Slade et al. 2008).
5.2.3.3. Main theme 3: Professional views of what carers need for own wellbeing

Professionals described their views about two main needs of carers in which their fulfilment might directly influence the carers' wellbeing.

5.2.3.3.1. Information

All professionals stated that carers of people with serious mental illnesses need a wide range of information about mental health. Overall, the information needed was general knowledge such as a definition of mental illness as well as its signs, symptoms and causes. The carers also need information about managing service users at home, medication and other treatments, individualised illness progress, services, and access to financial support. All of this information was uncovered throughout the interviews with nurse professionals. Moreover, the desirable information related to services and access to financial support did not emerge from any group of professionals (except nurses). The finding suggests that, nurses had adequate closeness with carers. Such close carer-nurse interactions were also reported in a qualitative study involving a wide range of mental health professionals (Jackson and Stevenson 2000). Given that nurses had more contacts with carers and service users, the psychologists and psychiatrists in the study relied upon the nurses to provide them information that would affect their professional judgement.

Another notable finding is that none of the required topics reflected what carers should know for maintaining their own wellbeing such as strategies in coping with caregiving distress. Perhaps the latter topic was unexplored or overlooked by the professionals in the current study. In one interview a physician did not indicate that knowledge about stress management was needed by carers. Instead, the professional urged carers to help service users to cope with stress:

*They [carers] have to know about stress... because the service user's ability to cope with stress is limited. Even when the service user is stable, they [carers] can support him to cope with daily stress. Finally, he will not relapse anymore (P2)*
5.2.3.3.2. Psychological support

The professionals acknowledged that the carers required support to maintain their mental health in caring for service users as asserted by one psychiatrist:

*Because they are taking care of mentally ill people...but actually they need places to vent. So we shouldn’t focus only on the service users but also on their carers* (P6)

Some professionals were empathetic to carers by giving recognition of burden entailing the implementation of caring roles. In the view of the professionals, the need of psychological support for carers referred to the need for catharsis or to express feelings towards health workers. For the same reason, it was perceived that Indonesian carers need opportunities for sharing feelings amongst peers. A senior nurse recognised this sharing need, based on her own experience in caring for service users in hospital:

*I think caring for people with serious mental illnesses is exhausting. This is what I feel sometimes, I am fed up...especially in treating a service user again and again without any progress...even for performing her activities of daily living it is difficult for this service user. I feel the burnout after providing the care for only 8 hours...You can imagine what the carers feel as they see the service user every day. Therefore, I think what they need is to gather with other carers so they can share information and minimise the burden of caring* (P8)

This is not a surprising fact providing that people tend to talk with those with similar circumstances (Kitzinger and Barbour 1999). Understandably, carers in some studies also disclosed the same motivation for joining peer groups that was to meet families with the same experiences in caring for individuals with mental health problems (Munn-Giddings and McVicar 2006, Nordy et al. 2010). Moreover, a number of previous studies also had provided evidence of the positive impact of peer group involvement for reducing caregiver burden and improving coping abilities (Biegel and Yamatami 1986, Medven and Krauss 1989, Cook et al. 1999).

Nonetheless, participants in this study had different views regarding the level of importance of psychological support for carers. Some professionals did not consider that psychological support was fully essential for carers’ welfare. Instead, it was anticipated that if carers were not supported
psychologically, they will give negative impacts on the service users’ wellbeing, as illustrated by a nurse practitioner as follows:

*I think it is [psychological support] important because if there is no psychological support, carers can get bored and they may not able to handle it. Finally the service users can be neglected because their carers are ‘ill’ as well (P19)*

The description of the second theme enlightens the current study that seemed to be successful in revealing the needs of carers of their own wellbeing. However, as mentioned earlier, the existing findings indicate that these carers’ needs were more directed towards the service users’ wellbeing than the carers’ themselves. The next section will focus on discussing the third theme of this study.

### 5.2.3.4. Main theme 4: Focus of current contact

This key theme represents essential information of current activities performed by the professionals during their interactions with carers. Each activity is detailed in the following sub-sections which signifies the emerging subthemes:

#### 5.2.3.4.1. Information provision

All professionals in the study claimed their existing contacts with carers involved information giving, even though it was performed simply and briefly. The contents of the information given were similar with the needed information depicted in the previous theme of what carers need for their own wellbeing (see section 5.2.3.3.1 on page 163). However, most of the information was surrounding medical treatment, which reflected upon the professionals’ medical orientation in the course of interactions with carers.

Furthermore, most of the professionals provided education to the carers, based on an assumption that they did not have adequate knowledge about mental illness and caring strategies. The professionals did not invite the carers to discuss their previous knowledge and experiences in caregiving; thus, it was unknown whether the given information had met the carers’ needs. Evidently, this approach of educating carers represented the deficit model of information described by Barrowclough and Tarrier (1997). The model assumes that a lack of information causes the carers to perform discouraging
behaviours towards their ill relative; hence providing relevant information is important to bring about positive changes to the carers’ behaviours. In one interview, a nurse illustrated her approach in educating carers which was advice orientated, and gave strict opportunities to talk about what the carers’ need from the information giving:

First, I asked carers about service users, especially the symptoms or condition when they were admitted here for the first time. And then, once I knew the symptoms, I explained to the carers, for example about hallucination, because perhaps they did not know about it. I explained what hallucination was, how to recognise it and care for people with that particular mental health problem (P11).

Whilst a majority depicted the straightforward approach, only one professional claimed that she always explored carers’ knowledge before being provided any information in which it fitted with the interaction model of information giving (Barrowclough and Tarrier 1997). The professional believed that the exploration was helpful to ensure that the informational needs of carers could be met:

With me, I usually ask before I start talking to carers. I ask whether they have any question. Then I explore to what extent they understand and I will focus on that. Finally, I always say if they have any complaint or questions, just tell them. If they don’t say anything, I do not know what they really need... especially with the limited time of interaction... So I will ask about what the carers need, to what extent do they know about the illness, what they want to know from me, what obstacles are there in caring for their relatives, and what has happened at home. [P6].

Lastly some of the professionals confirmed that they gave education to carers individually. A nurse participant confidently stated that she educated every carer distinctively based on the service users ‘mental health problems’ (here mental health problems referred to some main symptoms of mental illness: delusions, hallucinations, social isolation, low self-esteem and risk of violent behaviour). Unfortunately, a deeper analysis showed that the nurse did not really meet the informational needs of each carer uniquely. Regardless of the ‘mental health problem’, the information given only covered two components: its impacts and strategies to manage the ‘problem’. This restricted scope of information was definitely unparalleled with the large extent of informational needs identified in the earlier theme (see page 163).
Thus far it is clear from the discussion that endeavours of educating carers did exist, yet it appears that
the offered education was medically orientated. The application of traditional model of information giving
(Barrowclough and Terrier 1997) was evident which gave few opportunities to Indonesian carers to
express and elicit their lay view related to any issues, including what they needed from mental health
services.

5.2.3.4.2. Emotional support provision

The professionals in the study provided psychological support for carers by listening to their concerns,
even though it was only voiced by two nurses and an occupational therapist. Others provided emotional
support by allowing the carers to express feelings to the professionals, even though some of the
practitioners promoted the carers’ catharsis through non face-to-face interactions. For instance, a
physician maintained his contacts with certain carers via cellular messages:

So again, if I see carers who are really hopeless, then I would
give my mobile number so I can text them and they can reply to
me as well (P19).

Almost half of the participants maintained that the hospital services have offered opportunities for
‘sharing among carers’. In this sense, the sharing only referred to narrating caregiving experiences to
other carers for the purpose of problem solution; but not necessarily expressing emotional conditions
impacted by the caring performance:

After we delivered group education for carers, there was a
question and answer session, and followed with sharing among
carers. For example there was a carer who asked an issue and
other carers would respond. After that, we came to a conclusion
(P10).

Only nurse participants disclosed that the emotional support was also delivered by employing a spiritual
approach (i.e. advising carers to engage with religious activities). This implied that the professionals
viewed issues surrounding the carers more comprehensively, and respected the problems faced in their
cultural context (i.e. Indonesian people follow a religion, and the majority of them are Muslims). This
also implied the professionals’ understanding in that the emotional state of individuals was linked with
their spirituality. At last, only one of the 24 participants divulged that psychotherapy has been offered
for carers with emotional issues such as prolonged sadness and denial due to their relatives’ illness.
The above descriptions show that the current psychological support seemed to be various; as yet there is not a structured programme that has been offered to strengthen the carers’ mental health in general.

5.2.3.4.3. Gathering information about service users

A number of professionals reported that their contact with carers was merely to assess their ill relatives. The professionals openly stated that the assessing interactions were aimed for fulfilling their own needs as shown in the following quotation:

*Well, when we want to visit carers, we usually prepare a form… so it’s like…we really try to fill the form or seek information from the carers, and we have to get it. Afterwards, the following contacts will not be so important, because I have known the service user’s condition…so yes, this is for the professionals’ need. We need the information to plan our intervention to the service user (P22).*

Nevertheless, other health practitioners maintained that the assessment of service users also gave benefits to their carers. A psychologist tried to rationalise the assessing duty as an indirect strategy to fulfil the carers’ needs (i.e. the need of qualified treatment for service users):

*So far… based on my experience as a psychologist, carers are involved for my own need. So I need to know the data about the ill person from their carers. So it is true for my need, even though indirectly it is also for the carers’ need as they must desire good treatment for their ill relative (P4).*

The description of the key theme has shown that the professionals’ activities with carers have been dedicated more towards enhancing the service users’ wellbeing. It is doubtful whether the activities have met the carers’ needs and aspirations as described in the earlier themes two and three. The most striking finding is that the activities of educating carers were performed simply and briefly, without adequate exploration of what was really needed by the recipients. Over again, the professionals have positioned themselves as being experts in caring for mentally ill people; therefore they tend to provide advices in many of the interactions with carers. What follows is an account of the final key theme of this study.
5.2.3.5. Theme 5: Perspectives of support provision

The description of this key theme focuses on the professionals’ views regarding hospital-based support provision for carers of people with serious mental illness in Indonesia. The key theme consisted of two subthemes distinguishing the views between the existing and the potential support for the carers.

5.2.3.5.1. Views of current support provision

In general, this subtheme exemplifies the participants’ opinions regarding the merit of the existing education provision for carers.

Hospital endeavours for supporting carers

The majority of participants asserted that a number of attempts have been made for educating carers of people being treated in the mental health hospitals. The endeavours have been conducted through several programmes, including nursing consultation, health education for groups of carers (so-called as family gathering), and hotline services. Firstly, as mentioned briefly in the earlier sub-section (see page 154), the carers could receive individual nursing consultation(s). According to many participants, the service was important because it could help them overcome the insufficient information delivered by the psychiatrists, which showed the medical oriented stance of health worker when interacting with carers:

*I think it [the nursing consultation] can fulfil (the information need), because information from psychiatrists (like us) was only given for 10 minutes… it won’t be enough… so that [nursing consultation] is important. It really helps indeed (P6).*

Next, in the family gathering, a large group of carers were invited to have a two-hour-education session delivered by different professionals such as psychiatrists, nurses, psychologists and social workers. This programme has been offered once a month in the Soeharto Heerdjan hospital and at least twice a year in the Duren Sawit hospital. Finally, the carers could obtain information from the hospital on every occasion through a hotline service. Unfortunately, according to some interviewees the service was not well functioning due to insufficient funding for the operation.
Recurring data also emerged from the interviews detailing the hospital endeavours in order to increase the number of attendants of the carer group education (i.e. the family gathering). Various strategies reportedly have been employed to invite the potential carers, such as providing individual explanation regarding the gathering event and offering compensation for the costs of transportation and meals.

The above evidence is quite encouraging for showing a desire of the hospital services to educate carers as well as possible. Nonetheless, the endeavours have not necessarily fulfilled what the carers need as shown in the subsequent description.

**Have partly fulfilled the carers’ needs**

A few professionals considered that the existing education for carers, had completely met their needs as affirmed by a participant below:

> I think the information need of carers somehow has been fulfilled… I think, [the information provision has been] convenient or sufficient. Based on my experience, I can say that it’s been adequate because, beforehand; many carers didn’t know anything, and then by attending the group education [family gathering], they understood (P16).

More participants had different voices and claimed that the informational needs of carers had not been achieved through the offered educational programmes, as shown in the following quotations:

> Not all given by the hospital have fulfilled the carers’ needs… (P18).

> So far the information given is related to the problem of service users… such as the cause of their illness, their treatment, their medication obedience, and those all. I think carers need information on how to care for their relatives…So some of the carers’ needs have been fulfilled [through the existing education programme], but some of them haven’t (P11).

This view that health professionals were not fulfilling carers needs also highlighted the issue that there was only a limited impact of the support offered to service users and carers.
Limited impact of the current support to service users and carers

Some participants affirmed that the existing education programmes for carers focused on service users, but these have brought a limited impact on the service users' state - evidenced by numerous re-hospitalisation cases. One participant regretted seeing service users admitted to the hospital repeatedly, even though the carers have been given information about caregiving:

_The service users commonly were admitted here 3-4 times… on average… well, we have given the carers health education on how to care for their ill relatives at home, but the service users still come back here anyway. One time, I asked some carers ‘how many times has your ill relative been treated in this hospital?’ and they answered, ‘The last time? It was just a couple of days ago, nurse’… (P9)._  

In addition, some professionals perceived that the offered education has not brought significant improvement on the carers' understanding about mental illness as well as their attitudes towards the service users. Health Professionals were critical of carers who rarely visited their relatives in the hospital or provided incorrect information about the service users to medical and nursing staff. For example:

_In my opinion, if the group education programme [i.e. the family gathering] has been well conducted, then why do carers keep asking about how to take care of mentally ill people at home? Well, the carers should have understood more because they have been using the [education] support from this hospital [for a long time] (P21)._  

Improvement needed in current support for carers

As a final point, many participants agreed that improvement was needed, especially to educate carers adequately. A professional recognised that the current education has focused on informing what has been prepared by the professionals, without considering whether it was needed by the carers. Therefore, she recommended an improvement which was in line with the interaction model of information giving by Barrowclough and Tarrier (1997), allowing carers to talk about their needs before being given any information:

_Actually the programme can be used to give information for carers… It's really good… But, there should be information provision based on their needs as well… not based on what we can give. So far, what we have been doing is giving what we_
can give, without evaluation and knowing whether what we give, is what they need (P8)

In addition, the idea of improvement covered the area of emotional support for carers. Some professionals acknowledged that the hospitals did not have a programme or intervention which was specifically designed for reducing caregiving burden, as stated by a physician along these lines:

However there has not been a specific programme which focuses on reducing the carers’ burden. Well, we don’t have it yet (P19).

To summarise, despite the fact that the hospitals have offered several programmes to help carers, the professionals have a high level of aspiration for improvement. The following presents a more detailed explanation of how the existing support can be developed in the future.

5.2.3.5.2. Views of potential support for carers

The professionals uncovered some viewpoints surrounding potential support for Indonesian carers particularly with regard to the emphasis of the support provision, time delivered and anticipating barriers.

Firstly, the future support should be beyond the enhancement of carers’ knowledge about caregiving strategies (e.g. how to assist service users to perform daily activities and minimise relapses). The potential information provision can expectedly change the carers’ behaviours and attitudes so they are able and have a stronger willingness to care for service users:

Probably the biggest challenge is [how to increase] the ability of the carers… so the carers are able and willing to care for their ill relatives…so they don’t only know [the knowledge] but they want to care for the ill person… (P8).

Clearly the idea reinforces the notion that health education alone, without trainings about cognitive behavioural strategies, would limit the overall benefits of intervention to carers including the improvement carers’ abilities in dealing with problems associated with caregiving (e.g. problems in communicating with service users or managing caregiving stress) (Falloon 2003).
Secondly, professionals in both hospitals suggested an additional education which provided more opportunities for sharing about caregiving among carers. Nevertheless, the suggestion was more prevalent in the interviews with practitioners in the Soeharto Heerdjan Hospital, and only this group of participants expected this additional programme which was similar to the activities in the focus groups, as portrayed in the quotation below:

*It would be good if there is a kind of group therapy for carers…maybe like a focus group discussion or a group therapy but it is designed for carers…so they can share with other carers. I believe that they have their own problems in caring for the ill relatives… it would be very hard for them if they don’t share (P6).*

Next, the study also revealed data relating to the proposed time of the potential sharing group. Some professionals suggested that the sharing group to be conducted when carers accompanying service users in outpatient or after participating in the current family gathering. A less feasible suggestion was offered to invite carers to attend a 30-minute-sharing meeting when discharging their service users from inpatient care. In this context, the role of mental health workers should be less dominant than the carers, which was limited to observing the group process or facilitating every carer to express their thoughts. Perhaps, this idea intended to respond to what many carers want from the professional-carer partnerships (i.e. acknowledged as experts in caregiving) (Nordby et al. 2010, Thomas et al. 2010); yet it was clear from the following expression that professionals were still positioned to be more knowledgeable than the carers:

*Maybe it [the sharing group] can be conducted just like group activities for the service users treated in this hospital. There should be a leader of the sharing group. The leader can be one of the professionals. Otherwise, carers with enough experiences in caregiving can also become the leader. So the leader carer can start by saying, “This is what I have done in caring for my relative at home”. Then the professional can play a role as an observer or facilitator. For example, the professional can facilitate by saying, “when your relative relapses, what do you do?” (P21).*

The above discussion has covered the professionals’ viewpoints regarding potential support for carers which should be focused on service users’ wellbeing, not limited to information provision and added with opportunities for sharing among carers. The last viewpoint of the professionals’ was surrounding
the barriers in developing mental health hospital-based support for the carers. In general, the barriers were sourced from the carers, the hospitals, and the professionals.

**Health professionals views of the barriers encountered by carers**

According to the professionals, the first major obstacle for carers to participate in hospital-based support would be economic problems. This is particularly applicable for carers who were not capable of attending the family gathering programme due to the transportation cost issue. It was predicted that this financial problem would be prevailing if an additional support for carers to be applied, as explained by one professional in the following:

> If we conduct [a group intervention] specifically for carers, they may not come because they don’t have money for transportation... Once I asked some carers, ‘Why don’t you come to the [existing] family gathering?’ One said ‘I cannot come because that means I have to visit this hospital more often and I don’t have money for the transportation cost’. The transportation cost may not be a big issue for us, but it is for them… (P8).

Another obstacle was sourced from a stigmatised perception of mental illness among the general public (e.g. individuals with mental illnesses are considered as strange, unpredictable, aggressive and dangerous). The public assumption sometimes brought about unresponsive attitudes of the carers such as an unwillingness to accept mental illness or became inconsiderate to the hospital programmes designed for supporting the caring role. This view of professionals affirmed a notion in that people with mental illness in Indonesia, as in many countries, commonly experience stigmatisation in their community, and then results in families rejecting the service users (Lauber and Rossler 2007, Nurjannah et al. 2009). A participant attempted to illustrate the impact of the carers’ stigmatised thought about mental illness as follows:

> Maybe it's because of the stigma, the stigma from people out there. As a result, people who have been treated in a mental hospital also pose a problem for their families... how to make the family accepting the mentally ill relatives... maybe it's hard for the carers to accept them because they [service users] have been so destructive (P20).
The above barriers encountered by carers were consistent with the viewpoints of carers in other studies (Solomon 1999, McFarlane et al. 2003). Perhaps a distinctive finding of the current study was the perspective of the professionals who mentioned ‘uncooperative carers’ as significant obstacles, referred to families who were not obedient to the health workers’ decisions relating to treatment for service users. For example, the carers were labelled as ‘uncooperative’ because they were unwilling to pick up service users when they are ready for discharge from hospital, refusing to fulfil what the professionals’ requests for, and difficulty in being contacted by the professionals. A professional described ‘uncooperative carers’

> However, in some cases there are carers who don’t care about their ill relatives or they are not cooperative. They don’t come here when I want to talk to them. This becomes one of the obstacles in working with carers. (P17).

A nurse characterised ‘uncooperative’ for carers who reduced their visiting rate to re-hospitalised service users/attendance in group education without considered factors might contribute to the issue (e.g. Unaffordable transportation cost, time constraints):

> I notice the trend, if the relatives are new service users of this hospital; the carers are usually still attentive… they very often come to this hospital…several times in a week. But for service users who have had the illness for a long time…the re-hospitalised service users…. their carers only come to drop them….there were [also] carers who joined the group mental health education in the beginning, but later on many of them did not come anymore (P1).

**Barriers from hospital**

The hospital based barriers were generally classified into four areas: Standardisation, human resources, socialisation and issues surrounding approaches in providing the carer services. Respectively, each of the issues will be described in the subsequent passages.

First, standardisation issues were reported by all health professionals involved in the study. In this case the professionals regretted the lack of Standard Operating Procedures (SOP) in contact with carers. The SOP was a term which referred to a set of detailed and prescribed guidance to execute a specific work activity – in this case, activity of interacting with carers -- in order to achieve uniformity across all
eligible professionals. In Indonesia, government employees, including those working in health sectors, should carry out their working activity based on SOP issued by their institutions. With regard to the current study, the SOP would be helpful in delivering systematised education as well as representing inter-professional differences, as implied in the following quotations:

- There is no SOP for nursing consultation, so I give information based on my knowledge from nursing books. We also browse the internet to get the information and then we made leaflets on our own (P11).

- I have never seen written SOP in this hospital, but when we were studying our specialist in psychiatry we had been taught about what components should be given to carers (P23).

It seems that the above issue relating to standardisation has been already indicated in the policy review of Indonesian guidance relating to services for supporting carers of people with mental illnesses (see Chapter Two). The review pointed out a serious problem of accessibility of the policy documents among the health professionals, even though the guidance has been prepared for them. Predictably, this issue included the case of accessing the SOP for delivering carer education.

Next, a common obstacle in the course of information delivery for carers was also found that was lacking in human resources hired by the hospital (McFarlane et al. 2003). This was particularly relevant to the issue of lacking in practitioners in the outpatient services that eventually resulted in minimal contacts with carers who accompanied service users as described below:

- Actually, the ratio between the psychiatrist and the patient in this hospital is still very low. Here, 6 doctors must handle 200 patients (P7).

- The problem here is around the human resource...only 8 members of staff are available for nursing consultation...Sometimes there are many carers who want to use the consultation service, but then there is no counsellor at all and finally they are not underserved (P5).

The issue of human resources was also related to the problem of limited time for the professionals to interact with carers due to their excessive workloads. The obstacle was asserted by practitioners from all professions, as illustrated by a nurse and social worker as follows:
Maybe as a nurse I can deliver individual mental health education more optimally. But in this current condition? I am not sure... If I haven’t finished my report, it would be impossible for me to talk with you now. Moreover, I also have to see service users in this ward. I have to prepare their medication and manage their meals…I am not mentioning when there are service users that need to be fed… (P14).

So far as a social worker, I have double jobs because there are no administration staff in my work unit. Eventually, I have to do all things such as monthly report and others, including typing letters…almost all of these administrative tasks are completed by me. Honestly, I feel that my interaction with service users and the carers is lacking because of these duties (P22).

Another obstacle sourced from the hospital was the lacking of advertisement about the existing support for carers. The participants acknowledged that information about the current education programmes that have been broadcast to carers superficially, without sufficient details of the activities involved. One professional described this barrier which was applicable for the current group education for carers:

I think, maybe the problem [why are there not many carers attending the family gathering] is because the announcement is lacking…not all carers of service users treated in our ward know about the group education. Perhaps the announcement should be made wider, I meant it should be informed in both the inpatient and outpatient. And there is also a problem as we only give the invitation and say ‘Sir, please come tomorrow’, but the invited carers do not know whether it is free of charge or not. They don’t know what they can do during the education, either… so this kind of information is not given… (P18).

At last, the barriers were related to the inability of the hospital in finding optimal personnel for educating carers. Some professionals questioned the arrangement of educators for group of carers. These professionals commented on the speakers who delivered certain topics unsuitably as illustrated in the following quotation:

If the Keswamas [as the organiser of the family gathering] have a structured programme, the topics can be more varied and given by proper people. The Keswamas should be responsive to the most current trends and issues in mental health. For example, the topic about drug misuse that was given in the latest education was unsuitable. I think not all people coming there were drug misusers or having family members with drug misuse problems … (P18).
**Barriers from professionals**

These were the barriers in which to some extent replicated the findings of other studies in the same field (Falloon 2003, McFarlane et al. 2003). The participants, in large part, acknowledged that their support to carers was not adequate due to insufficient knowledge and skills of working with carers. Unfortunately, no training has been given on how to work with carers. Some professionals stated that the given trainings were mostly delivered to equip the professionals in working with service users, as illustrated by one participant below:

*So far the offered trainings focused only on the service users, and the knowledge about carers was inserted. For example, we have been trained on how to prepare interaction with service users, and a topic to prepare interaction with carers was inserted. But I think it [training about carers] needs to be explored more. So until now, there is not a specific training about carers… not yet (P10).*

In addition, some professionals acknowledged that lacking in empathy has become one of the causes of why the current support for carers has not been at its utmost, as reported (honestly) by one participant:

*Another thing is… the lack of care among health professionals, including me. If we are talking about time limitation, of course we do not have time… we have to do this and that… However, when we have time, we do not care about carers. We let the carers come to this hospital, but when they are here, we don’t really feel the need to talk to them… we only wait and talk to them until the service users are about to be discharged (P14).*

Finally, the lack of motivation from health professionals to interact with carers was acknowledged as a key barrier:

*In fact, they are bachelor nurses, but they do not have the motivation…I am very sad when they have already said that they don’t want to see carers…I think before offering training to the nurses about mental health education for carers, there should be training about customer service first… so they have motivation to serve. Once they have the motivation, whatever we give, it would be coherent… (P8)*

To summarise, the professional interviews brought important findings regarding their views about what Indonesian carers need and support provision for the carers. The discussion shows that the professionals held a service user orientated view. There is also evidence that the professionals held
medical orientated views in their contacts with carers, though the views were not apparent when describing the cause of mental health problems—here the professionals used a psychosocial explanatory model. Additionally, strong findings exist to show that the carers have been viewed as subordinate in their interactions with health professionals. This view might have impacted on how the professionals involved with the carers, which might have resulted in an insignificant influence on the carer’s knowledge and attitude towards mentally ill relatives. Some participants realised that the current support provision should be improved, particularly by introducing a more interactive education programme. However, the vast identified barriers should be taken into consideration to develop feasible support for Indonesian carers. The recommendations from the professionals might increase our understanding as to what extent, established family interventions are possible within the country.
CHAPTER SIX
SYNTHESIS OF THE QUALITATIVE STUDIES IN THE PhD

6.1. Introduction

This chapter provides a synthesis of the two studies: Focus groups and interviews exploring the needs of carers from mental health hospital services in Indonesia. It begins by describing the aims and method employed, followed by an explanation of the procedures of the synthesis. The result is presented in the last section of this chapter.

6.2. Aims

The aims of synthesising the focus group and interview studies were:

- To summarise findings from both studies concerning what was needed by carers from the services in Indonesia.
- To present new interpretations of the phenomena about the carers’ needs.

6.3. Method

There are a wide range of methods for synthesising qualitative research, including textual narrative which arranges studies into more homogenous groups with minor attention on interpretation; thematic synthesis which organises data according to themes and attempts to seek new interpretation; and meta study which requires a series of analyses on the studies’ findings, methods, and theories prior to synthesising (Dixon-Woods 2005, Thomas and Harden 2008, Barnett-Page and Thomas 2009).

The current synthesis applied a thematic approach because its aims were not only to describe and summarise their primary data [as it occurred in the textual narrative], but to also go beyond the original data for a new interpretation of the phenomena about carer needs in Indonesia. In thematic synthesis,
main findings are firstly organised into descriptive themes, and then interpreted to generate analytical themes (Barnett-Page and Thomas 2009). However, the present synthesis was not intended to produce complex analytical products - as expected from a meta-study. Rather, the synthesis was intended to yield applicable products to inform mental health policy and practice in the country. Although thematic synthesis has been criticised for its imprecise procedures (Dixon-Woods 2005), Harden and Thomas (2008) argue that a clear and replicable process of thematic is viable.

6.4. Procedures

The synthesis adopted two stages of the thematic synthesis outlined by Harden and Thomas (2008). Firstly, the development of descriptive themes to generate a summary of the main findings relating to what was required by the carers from mental health services in Indonesia. At first, all themes of the two studies which were relevant to the synthesis aims—which also reflect to the central aims of the PhD—were sorted out i.e. to explore what is needed by the carers and how services meet the needs. This procedure resulted in four themes about the needs of Indonesian carers, focus of current support for the carers, views about the current support and recommendations for improvement (Appendix 11). Other themes which were not directly associated with the synthesis aims were not included (e.g. experiences in caring for relatives with serious mental illnesses). The decision of data to be summarised was commonly made based on their relevance to the synthesis' outcomes (Harden and Thomas 2008, Bannet-Page and Thomas 2009).

It is worth pointing out that even though the studies involved carers, service users, and mental health professionals; the summary produced, was not to discriminate the findings from carers and service users. The reason is that the triangulation of these two sources of data, generated comparable results as shown in the previous chapter (see page 132). In the next section the term of ‘carers-service users’ is used to signify the similarity of the findings.

The second stage was the development of analytical themes to provide a new interpretation. This involved identification of similarities and differences on themes/subthemes resulting from the descriptive stage, and then arranging them into a hierarchical structure. At first, analogous themes/subthemes
were grouped into existing theme(s)/subtheme(s). To illustrate, the theme of views about current support provision was collapsed into an existing theme, namely current support for carers. Likewise, new subthemes emerged as the result of combining some comparable subthemes. For example, a subtheme of impact on carers’ knowledge, service users’ mental health and fulfilment of needs emerged after amalgamating three subthemes (i.e. Limited impact on service users ‘mental health and carers’ knowledge, knowledge improvement, and current support have partly fulfilled carer need).

A deeper re-examination to the key theme of what carers need for ill relatives, yielded a fact that the carer-service users and professionals were different in describing the feature of recovery of people with serious mental illnesses. While the carer-service users suggested idiosyncratic and comprehensive meaning of recovery, the professionals characterised recovery as no longer exhibiting symptoms. Furthermore, dissimilar the themes/subthemes were recorded to distinguish their source: carers-service users or mental health professionals. Such differences were then illustrated more clearly in charts as shown in the subsequent Figure 8.

This stage was continued to examine the recommendations for service improvements in the light of the emerging needs of carers. The examination was essential to answer the study question: how the services could meet the identified needs of carers?

6.5. Results

Four major themes and subthemes were revealed to describe what was needed by Indonesian carers and how mental health hospital services could be improved in meeting those needs (Table 24).
Table 24. Themes from the synthesis of the qualitative studies in the PhD

<table>
<thead>
<tr>
<th>No</th>
<th>Main Themes</th>
<th>Subthemes</th>
</tr>
</thead>
</table>
| 1  | Carer needs for own wellbeing | • Information  
• Emotional support  
• Financial support *  
• Professionalism in contact with carers* |
| 2  | Carer needs for ill relatives | • Professionalism in contact with service users *  
• Follow-up activities after hospitalisation ** |
| 3  | Current support for carers | • Supporting carers through information provision and emotional support  
• Supporting service user medication **  
• Supporting professionals for data exploration relating to service users **  
• Impacts on carers’ knowledge, service users’ mental health **, and the fulfilment of carer needs** |
| 4  | Recommendations for improvement | • Improvement for information provision:  
✓ Strategy : face-to-face, individualised approach*, or group based-education with various, non-repetitive topics* and extra sharing among carers  
✓ Time delivery : Initial contact with professionals* or monthly after current education.  
✓ Setting * : hospital  
✓ People involved * : 10-40 carers in one group*  

• Group-based emotional support *  
✓ Strategy : activities to exchange information and express feelings; organised by hospital  
✓ Time delivery : monthly in conjunction with group-based education  
✓ Setting : hospital  
✓ People involved * : 10 carers in a group, facilitator from professionals at the start  

• Anticipated barriers  
✓ Encountered by carers : transport cost, stigmatised thoughts from general public **, ‘uncooperative carers’ **  
✓ From hospital : lack of standardisation *, socialisation **, and human resources (relating to limited time and excessive workload),  
✓ From professionals** : insufficient knowledge and skills, lack of empathy and motivation |

* Findings revealed only by carer-service user participants  
** Findings revealed only by professionals  
Without asterisk: similar findings revealed by carer-service users; and professionals
Figure 8a. Comparison of data sourced from carer-service users and professionals under the key theme of what carers need for own wellbeing.

Carers-Service users

- Information
- Emotional support

Professionals

- Financial support
- Professionalism in contact with carers

Not available

Figure 8b. Comparison of data sourced from carer-service users and professionals under the key theme of carer needs for ill relatives.

Carers-Service users

- Follow-up activities after hospitalisation
- Recovery of ill person: individualised and comprehensive

Professionals

- Professionalism in contact with service users
- Recovery of ill person: no symptoms of illness

Similar findings revealed by carer-service users, and professionals
Figure 8c. Comparison of data sourced from carer-service users and professionals under the key theme current support for carers.

Figure 8d. Comparison of data sourced from carer-service users and professionals under the key theme recommendations for improvement.

Similar findings revealed by carer-service users, and professionals
As mentioned earlier, the above figures could illustrate the difference of findings sourced from the carers-service users and professionals. The figures could indicate the extent to which the study participants have exposed data for each key theme, and at the end reflect to their emphasis when conversing about carer needs. As shown in Figure 8a with regard to the first theme, the professionals highlighted the importance of after-care activities, however this was not emerging in the conversations amongst carers-service users. Likewise, financial support was considered as the most required need by the carer-service user participants, but such a demand did not yield in the professional groups. Discrepancy also emerged in the conversions of suggestions for service improvement. The professionals seemed to show less attention on the ideas about group-based emotional support. Instead of offering thorough suggestions as given by the carers-service users, the professionals detailed barriers if services for carers were improved.

Finally, the examination of the relationship between the identified needs and recommendations for service improvement resulted in a notion: the recommendations were responding to some of the needs for carers' own wellbeing i.e. information and emotional support. The recommendations seemed to be feasible as barriers when the services were improved were taken into account. This relationship is illustrated in the following Figure 9,
# Recommendations of a need-based support for Indonesian carers

## The carers’ needs

- **Information**
  - General knowledge of mental illness, mental health problem, service users’ progress, medication, other treatments, hospital regulation, caregiving strategies and services offered
- **Emotional support**
  - Catharsis to health workers, sharing feeling among peers and talking to other family members
- **Financial support**
- **Professionalism** in contact with carers and service users
- **Recovery**
- **Follow up/ activities aftercare**

## Recommendations

### Improvement required

### Anticipated barriers
- Carers
- Hospital
- Professionals

### Aims:
- To address informational needs
- To address the impact of caregiving on carers’ wellbeing
- To maximise non-distressful environment in the family (which at the end may reduce high EE-criticism)

### Objectives:
- To provide relevant and needed information
- To provide emotional support
- To teach skills required for caring role
- To offer social support

### Strategy:
- Face to face
- Group-based (multi-family groups)
- Extra sharing of feelings and experiences
- IP in conjunction with ESP-SA, at one time
- IP first in a big group then ESP-SA in smaller groups

### Content:
- Education provision
- Skills acquisition (problem solving, crisis intervention, relapse prevention, effective communication and coping skills)

### Setting:
- Hospital

### Time:
- Monthly, for 2-3 hours (minimum months not identified, but may consider the NICE guidelines in 2014: between 3-12 months)
- Start with IP, followed with ESP-SA

### People involved:
- 40 carers in EP
- 10 carers in ESP-SA
- Facilitated by professional in the beginning

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**IP**: Information provision

**ESP-SA**: Emotional support provision-Skills Acquisition
6.6. Summary

This chapter has presented a synthesis of two qualitative studies in the PhD. The results of the synthesis provide a summary about what carer needs from mental health services in Indonesia and how services could meet the needs. It also suggests for new interpretations relating to the emphasis of the participant groups in revealing data for every theme, and how the identified needs were linked to the recommendations for service improvement. The next chapter will discuss the main finding of the qualitative studies as well as their strength and weaknesses.
CHAPTER SEVEN
DISCUSSION

7.1. Introduction

The PhD study aims to explore the views of carers, service users and professionals about the needs of carers from mental health hospital services in Indonesia. To achieve this aim, three stages were conducted: (1) A review of relevant literature about the carer needs (2) Focus groups with carers and service users and (3) Individual interviews with health professionals.

This final chapter presents an overview of the principal findings, recognises the strengths and limitations of the overall study, considers the implication on policy development, future research and practice, and ends with a conclusion.

7.2. Principal findings

7.2.1. Study one: A literature review relating to carer needs

Two reviews were completed. Firstly, a review of 40 studies eliciting the needs of carers from mental health services. The synthesis of the reviewed studies identified four major needs of carers: holistic wellbeing of service users, holistic wellbeing of carers, supportive attitudes of professionals, and carer involvement. Further analysis showed that these carer needs were eventually directed to the service users’ wellbeing instead of the carer’s own welfare. Nevertheless, the review could not provide adequate information of carer needs which were suitable to an Indonesian context. Therefore, reviewing additional literature such as policy documents relating to carers in the country was essential.

Secondly, a review of 15 policy documents relating to the contribution of carers within mental health services in Indonesia. The need of involving carers in the services was acknowledged. However, there has not been clear and strong political endorsement ensuring the carers to receive adequate
supports based on their own needs and for their own wellbeing. Problems to access these documents also existed.

The results of the two reviews directed the focus group and interview schedules for the next stage of the PhD).

7.2.2. Study two: Focus groups with carers and service users

The purpose of the focus groups was to explore the needs of Indonesian carers and how mental health hospital services could help to meet those needs. In total, 9 focus groups were conducted, seven with carers and two with service users. All carer and service user participants were recruited from two government mental health hospitals in the capital city of Indonesia. The data were analysed using framework analysis (Ritchie and Spencer 1994). A triangulation of findings from the two sources resulted in four combined themes as presented as follows:

(1) Experiences in caregiving.

The participants reported a wide-range of negative emotional responses that resulted from caregiving. These included the feelings of shame, stigmatisation, sadness, distress, frustration, and tiredness. A few positive responses were also exposed such as gratefulness, a sense of caring and compassion for service users; suggested that taking care of individuals with serious mental illnesses could also be rewarding. Some coping strategies which seemed to be harmful to service users were identified (e.g. protecting them from social life); in addition to endeavours which indicated carers’ attention to ill relatives (e.g. detecting the illness and managing the symptoms).

The focus groups exposed the main source of burden of Indonesian carers, which was problems relating to caregiving cost. Apparently, the carers’ cultural values have influenced their caring activities, especially in seeking help from traditional healers.
(2) Carer needs from mental health hospital services

Five needs were identified: information, emotional support, financial support, recovery for service users and professionalism in contact with service users and the carers.

The carer and service user groups had similar views regarding the needs of emotional and financial supports as well as recovery of mental illness. In addition, both samples deemed the focus group discussions as a proper method for supporting carers emotionally.

A slight discrepancy was uncovered with respect to the needs of information and professionalism of health workers in contact with carers. The carer groups required information about strategies to communicate with their ill relatives. In the views of service user groups, information in that topic was not sufficient thus expected behavioural change for their caregivers. In addition, while the carer groups suggested health workers to demonstrate sympathetic communication to their loved ones, the service user groups demanded that such good communication should also be offered to families.

(3) Current support for carers

The theme emphasised hospital endeavours in supporting Indonesian carers, especially through education provision. One positive view was revealed i.e. improvement of carer knowledge about mental illness; yet incomparable with a number of limitations i.e. difficulties to access the offered information, insufficient and similar unneeded information given.

(4) Recommendations for service improvement.

The supporting data were mainly exposed within the carer groups to address the needs of information and emotional support. The suggested improvement was discussed in terms of the strategy, time of delivery, setting, people involved and anticipated barriers (details in page 262).

The findings clearly exposed what the carers and services users expected from the hospital services, including the personnel, in order to meet the identified needs. Hence, the findings directed to a further exploration surrounding the carer needs from the perspective of health professionals.
7.2.3. Study three: individual interviews with health professionals

The objectives of interviewing the professionals were to explore their views of (1) what Indonesian carers need from the mental health hospital services, (2) the extent to which the current services have met the needs, and (3) ideas for service improvements. The study involved 24 health professionals comprising of nurses, psychiatrists, psychologists, social workers and occupational therapist. The entire professionals were recruited from the hospitals where the earlier focus groups were conducted. Each participant was interviewed by the researcher. Framework data analysis was adopted and produced five major themes as follow.

(1) Professional views of why services should involve carers

Health professionals viewed carers as the main cause of service users’ mental illness and their subsequent relapses, viewed them as responsible for service users’ adherence in medication treatment; and to support health professionals in caring for those with physical and mental health difficulties. The professionals also considered carers as the main support of service users, and able to help professional care as well as support the professionals’ supervisory activities.

Of significant note is that none of the health professionals raised the issue associated with the carers’ own wellbeing. In addition, the professionals employed the psychosocial explanatory model, viewing that carers could cause mental health problems, though the opposite medical model was used in their interactions with the carers. Finally, there was consistency in the view of health professionals that they were the experts and that carers had insufficient knowledge and skills in caregiving.

(2) Professional views of what carers need for ill relatives

The theme detailed the carers’ expectation for their ill relatives including their engagement in aftercare services and recovery from mental illness.

(3) Professional views of what carers need for own wellbeing
The professionals identified the needs of information and emotional support in which their fulfilment might directly influence carers’ wellbeing. Unfortunately, a deeper examination indicated that these needs were more intended to service users’ wellbeing than the carers’ themselves. To clarify, none of the required information covered strategies for maintaining carers’ wellbeing. Furthermore, some professionals believed carers should be supported psychologically so they would not give a negative impact on the service users’ wellbeing.

(4) Focus of current contact

The theme focused on current activities in the course of professional-carer interactions, comprising of information provision, emotional support provision, and gathering information of service users. Most of the activities were offered for the service users’ wellbeing. The psychological support was delivered without a structured programme. The carer education was provided simply and briefly without exploration of what was needed by the recipients. Again, the professionals positioned themselves as being experts; therefore they tended to provide advices about caregiving in many of their interactions with carers.

(5) Perspectives of support provision

The professionals maintained that several programmes have been offered to help Indonesian carers, but they have partly fulfilled the carers’ needs and brought limited impact on service users’ mental health and the carers’ knowledge. Therefore, the professionals suggested for improvement which should focus on the service users’ wellbeing, not limited to information provision but extra sharing among carers. Finally, the professionals expressed their views about barriers in developing carer support, sourced from carers, hospitals, and professionals.

7.2.4. Synthesis of focus groups and interview studies

A synthesis was completed to present the overall findings sourced from the focus groups with carers and service user and professional interviews. A thematic approach was adopted and resulted in four unified themes specifying what Indonesian carers need from mental health hospital services and how
the services could help to fulfil the needs. These themes as well as the subthemes had been presented in the previous chapter (Table 24 on page 181).

The synthesis could identify similarities and differences between the groups of carer, service user and professional participants in viewing the needs of Indonesian carers. The most obvious similarity was the view that Indonesian carers require information and emotional support for their own wellbeing. All group participants also agreed that the current information and emotional support provision have not met the carers’ needs. Therefore, improvement in those fields was crucial. Interestingly, even though the exploration could identify what Indonesian carers need for their own wellbeing, all participants exposed data which reflected their service user orientation stance. Another significant similarity was the view that the carers’ involvement in peer groups could support them emotionally. All group participants affirmed the benefit of the carer focus groups for sharing thoughts, experiences, and feelings associated with caregiving. The carer and service user groups reflected their positive experiences in the focus groups, and anticipated that they could be continued in the future carer support provision.

The identified discrepancies reflected the group participants’ emphasis when conversing about the carer needs. The views between the carer-service user and professional groups about what carers want for ill relatives were clearly incomparable. A re-examination which focused on the need of recovery of ill person revealed a significant gap. While the carers and service users gave an individual and comprehensive meaning, the professionals tended to have an oversimplified view about recovery of people with serious mental illness. Likewise, while carer-service user groups emphasised financial support as the most essential need, such a demand did not emerge in the professional groups.

Finally, the synthesis resulted an explanation of the link between the identified needs and recommendations for service improvement (page 185). Clearly, the recommendations were answering the needs of carers for their own wellbeing i.e. information and emotional support. Bear in mind, the findings suggest that the adoption of the established family interventions in Indonesia might be problematic. The feature of the structured interventions that normally require long-term and continuous sessions, high cost, and highly trained personnel could be challenging. As shown in the study, skilled professionals in working with carers were scarce and the mental health services were inadequate.
Nevertheless, the recommendations presented were relatively practical because they attempted to respond to the anticipated barriers.

A summary of these principal findings is illustrated in the following Figure 10

**Figure 10**  
Summary of the principal findings

- **Literature review of carer needs and methods of exploring the needs**
  - 4 carer needs identified
  - The needs were intended for service users’ well being
  - Focus groups as a proper method of exploring the needs from carers.

- **Indonesian policy review related to supporting carers**
  - No reference to carers own well being
  - Access issue

- **Focus groups with carers and service users to explore Indonesian carer needs and how mental health hospital services could meet the needs**
  - 4 combined themes
  - *Yielded participants expectation to health workers (e.g. professionalism in contact with carers)*

- **Professional interviews to explore Indonesian carer needs, the extent to which current services have met the needs and ideas for service improvement**
  - 5 key themes identified

- **Synthesis of studies 2 and 3**

**4 Unified themes:**
- Carer needs for own wellbeing
- Carer needs for ill relatives
- Current support for carers
- Recommendations for improvement

**Different and similar views between carer-service user and professional participants**

**Relationship between the identified needs and recommendations**
Recommendations responding to the needs of carers for own wellbeing as well as anticipated barriers
7.3. Strengths and limitations

7.3.1. The strengths of the study

The main strength of the PhD study is that it addressed a gap of knowledge relating to the needs of carers from Indonesian mental health services. There have been no published studies exploring the carer needs in an Indonesian context. Although, a few studies that involved Asian carers have been conducted, they are principally surveys with a small sample size, and only represented a Chinese cultural background (Sung et al, 2004; Chien and Norman, 2003; Tung and Beck, 2007). The majority of qualitative studies exploring carer needs have been mainly conducted in the western countries which are culturally different from Asian countries (Askey et al, 2009; McAuliffe et al, 2010; Van der Voort et al, 2009).

In addition, the study captured the phenomenon of the needs of carers comprehensively. It was not limited to identify the carer needs but also explored how services could meet the identified needs. Some recommendations were revealed, clearly to address the needs of carers for their own wellbeing. Although the recommendations mostly arose in the carer-service user groups, they were relatively practical due to consideration of barriers anticipated by all stakeholders, including the health professionals.

The study was also valuable because it attempts to offer straightforward information of what carers need for their own wellbeing – the label of the first unified theme clearly addresses the need. As indicated in the literature review, many studies failed to acknowledge that carers and service users have individual needs (McFayden and Farrington 1997, Kuiper et al 2010).

Another strength is related to the chosen data collection method. The study adopted focus groups with carers and service users which have elicited rich information about carer needs. The dynamic nature of the focus groups encouraged the participants to speak and discuss mental health topics openly. Conversations about mental health in other circumstances such as individual interviews might be difficult because of stigma or giving no opportunity to the carers and service users to compare and
share feelings about caregiving (McAuliffe et al. 2009). Unsurprisingly, most of the carers associated their involvement in the focus groups to reducing their level of stress and recommended similar gatherings for the hospital-based emotional support.

The use of multiple sources in the study i.e. reviews of studies and Indonesian policy relating to carer needs, focus groups with carers and service users, and interviews with a wide-ranging health professional has served to strengthen the credibility of the findings. The researcher could draw upon multiple perspectives, to ensure the interpretation was based on the data and represented the situation being researched rather than opinions or biases from the investigator (Tobin and Begley 2004, Morrow 2005). A viewpoint of one group cannot be considered as the only truth about the topic under investigation (Mays and Pope 2000).

The adoption of framework analysis also enhanced the credibility of the findings. The method allowed the researcher to work in a series of interconnected stages to elicit and manage data systematically (Spencer et al. 2003, Spencer et al, 2014). For the purpose of transparency, the use of charting allowed non-researchers to track the decisions that have been made in the stages, thus ensuring the link between the original data and the findings (Smith and Firth 2011, Spencer el al. 2014, Ward et al. 2011).

Lastly, the researcher as the sole moderator in the focus groups and interviewer in the interviews increased the consistency of the data collecting process. This advantage might threaten a neutral stance of the data collector; but it was dealt with reflexivity where the researcher acknowledged honestly that she had the potential to introduce bias and subjectivity into the data collected (Sim and Snell 1996, Ezzy 2002, Morrow 2005). Discussions with supervisors and documenting emotions during the data collection in field notes were also helpful to maintain a more neutral stance towards the study participants (Sword 1999).
7.3.2. The limitations of the study

There are limitations to the study with respect to generalizability. Sampling for both qualitative studies was collected from two government mental health hospitals in the capital city of Indonesia, thus it cannot be assumed that the views expressed are representative to carers, service users, and health professionals in the country. It is possible that identifications of what carer needs from services and recommendations for the improvement would have been diverse if the study was conducted in rural settings. However, generalising is not the primary concern in a qualitative inquiry, yet its strength lies in the extent to which others can utilise the findings in their own context (Lincoln and Guba 1985, Ezzy 2002, Morrow 2005).

The carers in the study were not a representative sample of relatives of people with serious mental illness in Indonesia. The carer participants were predominantly female, typically mothers or sisters of the ill persons. Understandably, female carers are recognised to be more responsible and motivated in activities relating to caregiving (Wahid 2009, Mizuno et al. 2013). Nevertheless, involving more fathers, male siblings/children or significant others in the study would have maximised the heterogeneity of the carer participants. Likewise, the mental health problem suffered by the relatives of the carer participants was mainly schizophrenia. Carers of people with other serious mental health problems e.g. bipolar disorders, and chronic or persistent depression (Levine and Legenza 2002); may have had exclusive needs and preference about the services.

It is important to acknowledge the differences between the richness of the data collected amongst the three groups. As expected, less data were revealed from two service user groups in contrast to those sourced from seven carer groups. While the service users could maintain their participation for no longer than one hour, the carers could engage in intense discussions for up to two hours. Likewise, the professionals did not provide rich data of recommendations for service improvement, in contrast to those expressed by the carers and service users. However, the overall data gathered in the study were valuable for capturing the phenomena about carer needs from non-carer perspectives.
The use of stratified purposive sampling for capturing the variations in the manifestation of a phenomenon would have been better and more rigorous than convenience sampling (Patton 2002). Nevertheless, the adoption of convenience method was appropriate because of time and budget restrictions for data collection on the research sites. Although the sample was selected because they were readily available and easy to contact (Koerber and McMichael 2008), some efforts were involved in reaching and recruiting the participants e.g. identified potential participants based on the established criteria, provided them information about the research, and consented them by referring to the ethics approval.

External professional translators would have back translated all Indonesian transcripts to enhance the validity of the translation. Time and financial constraints inhibited this process, thus allowing the researcher as the single translator. The researcher was a suitable person for cross language data analysis for her capability of translating from Indonesian into English (Temple and Young 2004). The accuracy of the translation, however, was enhanced by two Indonesian speaking researchers who checked some of the translated transcripts against the original language. Discussions of doubtful words or phrases with the reviewers were maintained throughout the study process.

7.4. Implications

7.4.1. Implications for policy

The policy review highlighted the importance of written governmental support for strengthening the role of carers in helping persons with mental illnesses in Indonesia. The review did not negate current endeavours for recognising the carers’ potential. The message is that the policy enforcement should be enhanced, from concentrating on service users’ wellbeing, move onto addressing the carers’ own needs and fulfilling the needs as possible. This is a challenging task providing that countries which have been equipped with national acts for carers are subject to critics for insufficient attention to the carers own needs (Kuipers 2010). The situation should not be put on a pessimistic outlook. Rather, it is a stimulus to develop legal recognition for Indonesian carers by taking their own needs into consideration. Perhaps the most important step at this time is producing a specific guidance of how supporting
Indonesian carers for the sake of their own wellbeing. The recommendations from this study are significant resources because they were sourced from those who became the target of the policy development.

Equally important is that a policy dedicated to professionals for the enhancement of competencies in working with carers. The existing directives have supported carer involvement in services, but no clear programme to equip the professionals with relevant knowledge and skills. The focus groups and interviews clearly indicated that what carers want from the services were complex, but the professionals recognised their insufficient knowledge and skills have limited their optimal service for the carers.

How to access the policy documents is another issue. The available directives, even minimal, could not be utilised optimally by the stakeholders in mental health services. Ensuring carers and service users are well informed through computer-based facilities is a challenge, given that no specific, simple and straightforward guidance about caregiving has been offered. Likewise, concentrating the printed documents on certain inaccessible locations might have amplified the lack of information among carers and professionals. The focus group and interview studies in the PhD clearly exposed that the carers, service users, and health professionals demanded information about caregiving was readily available in the mental health hospitals.

7.4.2. Implications for research

The findings of the study serve as relevant evidence of what is available and what Indonesian carers require from mental health hospital services. Using the Medical Research Council (MRC) framework, the findings were valuable for developing a need-based and culturally adaptable support for carers in Indonesia. It is located in the development phase involving identification of the best available evidence and appropriate theory behind an intervention prior to an in-depth evaluation (MRC, 2008).

Given the limitations of the study, it would be helpful to strengthen the evidence through similar qualitative research reaching out to other regions of the country, involving wide-ranging carers, and
adopting a purposeful method of sampling. Alternatively, a large-scale survey would also be helpful to maximise the coverage of participants across the country.

The findings of recommendations for service improvement only targeted two needs of carers, namely information and emotional support. Although the recommendations were described exhaustively, they did not capture ideas for meeting another major need of Indonesian carers that was financial needs. Thus, a further exploration is necessary to explore the subject from the views of all stakeholders.

7.4.3. Implications for practice

Given the early stage of development of an intervention for Indonesian carers, it would be premature to make recommendations for practice, even though findings of this study relating to suggestions for service improvement are worthy of attention. The carer participants expected information provision was encouraging for express feelings, needs, and experience of caregiving towards health workers. Unfortunately, the interview study indicated that, to an extent, such an interactive carer-professional relationship did not appear. The findings of this study could be a helpful source for considering an interaction model of information giving by Barrowclough and Terrier (1997), which allows mutual sharing of knowledge and experience to occur, and carers talk about their needs before being given any information by practitioners.

It is also worth noting that some of the recommendations for service improvement are parallel with the values of the existing family interventions in regard to the aims, contents, strategy/format, and setting (see Figure 9). This delivers a message in that, in order to develop a need-based intervention for Indonesian carers, considering some of the general features of the established family interventions may be relevant. For example, some researchers (Barbato and Avonzo 2000, Kuipers et al. 2010) have confirmed that education alone without the inclusion of behavioural components is not an effective approach in working with people with serious mental illnesses. Likewise, the service user participants in the focus groups stated that the future carer interventions should not be only aimed for education provision; but also for bringing behavioural changes into a more supportive and non-judgemental caregiving. Understandably, a number of skill acquisitions that have been offered in the established
family interventions (e.g. problem solving, communication and coping skills) are also demanded by the participants of this study. In addition, while some researchers (Dyck et al. 2000) have found the effectiveness of group-based family interventions, all groups of participants in the present study also concurred that the future interventions for Indonesian carers should be delivered in a group format which consist of 4-10 families (e.g. multi-family interventions).

Nevertheless, the development of carer interventions for practice needs to consider the facilitators as well as the barriers as informed by the data from the PhD study. First, as yielded in the focus groups, Indonesian carers have strong spiritual beliefs which influence their positive outlook about recovery of people with serious mental illnesses. The carers’ view that mental illness can be cured by God is beneficial so efforts to communicate such a hopeful recovery concept as the foundation of family works may be not too difficult. Further, Indonesian carers evidently have a belief that mental health problems are caused by a supernatural power, and this has led to some common supportive attitudes such as not blaming service users nor the carer themselves for the presence of problems and having strong willingness to help through the traditional healers. These Indonesian carers’ responses to their ill relative give the impression that the carers have demonstrated what have been expected from family works that is family is able to demonstrate and maintain supportive relationships with service users (i.e. showing empathy, non-judgemental, and non-blaming approaches). However, according to the professional participants in this study, education about medication is vital. It is implied that holding the supernatural belief alone –without helping the ill relatives with medication- can harm the service users; thus developing intervention for Indonesian carers means including educating carers about medication.

Some barriers in developing interventions for Indonesian carers have been discussed in the previous chapters. In Chapter Five, participants in the focus groups anticipated some barriers if the development of interventions for Indonesian carers to be implemented such as time and financial constraints (e.g. busy carers, limited transportation costs) and attrition issues (e.g. inability to continue the engagement in the intervention). Similarly, in Chapter Six, the participants in the professional interviews described three sources of obstacles to develop interventions for carers in the country: 1) Obstacles encountered by carers: limited transport cost, stigmatised thoughts about mental illness from general public and ‘uncooperative carers’; 2) Obstacles from hospital: lack of standardisation, socialisation and human
resources (relating to limited time and excessive workload); 3) Obstacles from professionals: insufficient knowledge and skills for working with carers, and lack of empathy and motivation.

It is necessary to include some barriers informed by the policy review relating to support for carers in Indonesia. The findings of the policy review suggest that there are significant challenges for mental health services in the country to support the carers through the development of a need-based family intervention. There is no specific act which acknowledges the contribution of carers in helping people with mental illnesses nor guidance dedicated to the carers supporting their own needs and for the sake of their wellbeing. Moreover, even though there have even been policies that should be useful to professionals, carers and service users; problems to access these documents exist. It is expected, therefore, once an intervention for carers is developed (i.e. tested and implemented), its duplication across the country may be hindered due to insufficient policy support and issues of accessibility.

Given the above discussion related to the barriers and facilitators, it is clear that there are many challenges ahead to implement the recommendations from the PhD into mental health practice in Indonesia regarding suitable interventions for the carers. Nevertheless, the recommendations definitely inform to the practice what intervention for Indonesian carers should look like in the future.

7.5. Conclusion and recommendations

7.5.1. Conclusion

The study was intended to explore the needs of carers from mental health hospital services in Indonesia from the perspectives of carers, service users and professionals. It consisted of three stages: (1) reviews of the literature of carer needs from mental health services and policies relating to carers contribution in the services, (2) focus groups with carers and service users, and (3) individual interviews with professionals.

The exploration resulted in identifications of the needs of carers for own wellbeing as well as for ill persons, current support provision the carers and recommendations for service improvement within an
Indonesian context. Even though the study had a number of limitations, the findings were valuable resources to aid in the design of a need-based and culturally sensitive intervention for carers in the country.

7.5.2. Recommendations

- Policy makers should legally acknowledge the contribution of carers in helping people with mental illness, and position the carers' wellbeing strategically.
- Policy makers should consider programmes for enhancing professionals’ skill and knowledge for working with carers.
- Access to policy documents should be improved ensuring all stakeholders to receive sufficient written and interned-based information of supporting carers.
- Further explorative research should be conducted to capture the phenomena of carer needs in a larger and more wide-ranging sample of participants.
- An investigation should be undertaken to explore the views of all mental health stakeholders about strategies to meet the entire needs of carers.
- The practitioners should consider an interactive approach in their contact with carers, allowing them to express feelings, share knowledge and experience of caregiving, and express their needs before being given any information.
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Protocol of approved ethical application for focus group study

UNIVERSITY OF MANCHESTER
COMMITTEE ON THE ETHICS OF RESEARCH
ON HUMAN BEINGS
Application form for approval of a research project

This form should be completed by the Chief Investigator(s), after reading the guidance notes.

1. Title of the research

Full title:
Understanding the needs of carers of people with serious mental illnesses from mental health services in Indonesia

2. Chief Investigator

Title: Ms
Forename/Initials: Herni
Surname: Susanti
Post: Postgraduate

Qualifications: Master of Science in Nursing
School/Unit: School of Nursing, Midwifery, and Social Work, The University of Manchester, UK
E-mail: herni.susanti @postgrad.manchester.ac.uk
Telephone: +447845580854/+441613129830/+6281317522054
3. Details of Project

3.1 Proposed study dates and duration

Start date: 2 May 2012

End date: 1 August 2013

3.2 Is this a student project?

Yes, this is a PhD project

3.3. What is the principal research question/objective? (Must be in language comprehensible to a lay person.)

The objectives of this study are:

1. To explore carers’ perspectives of what they need from mental health services in Indonesia

2. To explore service users’ perspectives of what their carers need from mental health services in Indonesia

3.4. What is the scientific justification for the research? What is the background? Why is this an area of importance / has any similar research been done? (Must be in language comprehensible to a lay person.)

Serious mental illnesses not only affect the individual experiencing the illness but also their families who are caring for them. The impact of caring has been well documented and it shows that the increased level of stress arising from diagnostic uncertainty results in difficulties in coping with symptoms of mental disorder, contact with police during crises, stigma of mental illness and loss of the loved one (Glendy and Mackenzie 1998, Paterson et al. 2005, Barton and Jackson 2008, Kuipers 2010, van de Bovenkamp and Trappenburg 2010).

Mental health services in many countries including the UK have placed increasing emphasis on meeting the needs of carers and this is enshrined in many mental health policy documents. However, despite such advances there is still further work needed to ensure that carers’ needs are being met. Moreover, much of this work has been completed in developed countries and much less work has been focused on carers in developing countries. How the results from developed countries can be translated or whether such needs of carers are similar is yet to be determined (Mcleod et al. 2011).

Indonesia is a developing country which has basic and limited services for carers of people with serious mental illnesses. There is no literature to suggest that carers needs have either been identified or met. The proposed study aims are to explore the perspectives of carers and people with serious mental illnesses about what carers need from mental health services in Indonesia. This is a preliminary investigation of carer needs to inform the design of an intervention to support carers of people with serious mental illnesses in the country. Prior to determining any appropriate approach for the service, identification of what the carers needs is fundamental. In the UK, Medical Research Council (Craig et al. 2008) emphasises that any development of
intervention in health field should be based on scientific identification from the users’ perspective.

3.5. How has the scientific quality of the research been assessed? *(Tick as appropriate)*

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Internal review (e.g. involving colleagues, academic supervisor)
- None external to the investigator
- Other, e.g. methodological guidelines *(give details below)*

*If relevant, describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review.*

This study had been developed under the supervision of Prof. Karina Lovell and Dr. Hilary Mairs as they are the academic supervisors of the student.

3.6. Give a full summary of the purpose, design and methodology of the planned research, including a brief explanation of the theoretical framework that informs it. It should be clear exactly what will happen to the research participant, how many times and in what order. Describe any involvement of research participants, patient groups or communities in the design of the research. *(This section must be completed in language comprehensible to the lay person.)*

This study will use a qualitative methodology using Focus Group Discussion (FGD). This methodology is appropriate to the aim of this study i.e. exploring the perspectives of carers’ and service users about the needs of carers from mental health services in Indonesia. This qualitative study will be grounded in applied research by running focus group discussions with groups of carers and users. The group interaction between participants in this study (carers and service users) is expected to provide rich and detailed information related to the needs of carers *(Askey et al. 2009)*. However, participants who show their lack of preference to take part in group meetings will be offered with individual interviews. The use of group as well as individual interviews have been demonstrated when the researchers found difficulties to achieve adequate participants through group meetings *(Richard et al. 2006)*.

3.6.1. Has the protocol submitted with this application been the subject of review by a statistician independent of the research team?

This study is a qualitative study and no statistical advice required.

3.6.2. If relevant, specify the specific statistical experimental design, and why it was chosen?

- Yes – copy of review enclosed
- Yes details of review available from the following individual or organisation *(Give contact details below)*
- No – justify below
This study is a qualitative study and no statistical advice required.

3.6.3. How many participants will be recruited?

*If there is more than one group, state how many participants will be recruited in each group? For international studies, say how many participants will be recruited in the UK and in total.*

The aim is to run 6 groups (4 with carers, 8 participants per group and 2 with service users, 8 participants per group). Thus there will be 48 participants in total.

3.6.4. How was the number of participants decided upon?

*If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

It has been suggested that a sample of 48 participants is generally sufficient in order to achieve data saturation (Morse 2000). Therefore it is proposed to recruit a total sample of 48 participants to include 32 carers and 16 service users. Such numbers would be sufficient for four carer and two service user focus group discussions.

3.6.5. Describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

The group interviews will be recorded by digital video facilities and transcribed verbatim. Data analysis for this study will use framework analysis described by Ritchie and Spencer (1994). Framework analysis has been selected for several reasons. Firstly, the analysis is systematic in that it allows a logical and step by step approach to analysis. Further, framework analysis allows practitioners, stakeholders and policymakers to understand and access its systematic process. (Ritchie and Spencer 1994).

3.7. Where will the research take place?

This study will be conducted in two government mental hospitals in Jakarta, Indonesia. The setting for FGD has been suggested to be held in a neutral place e.g. outside of hospitals (Powell and Single 1996). However, this may not be feasible for users and carers as they may prefer to meet in a hospital setting in which participants are familiar. Thus potential participants will be asked their preference on either a neutral but safe setting (e.g. a community based venue) or a hospital setting. If preferences are mixed then focus groups will be conducted in both settings.

3.8. Names of other staff involved.

1. Professor Karina Lovell (main supervisor)
2. Dr Hilary Mairs (second supervisor)
3.9. What do you consider to be the main ethical issues which may arise with the proposed study and what steps will be taken to address these?

One of major ethical issues is that this study will involve discussing carers’ and users’ experience in using services in which might be distressing and uncomfortable for some of them. For this reason, the chief investigator who will also facilitate the groups will be mindful of the potential distress. At the beginning of the focus group the facilitator will discuss the possibility of potential distress and participants will be informed that they can withdraw from the discussion if distress is experienced. The facilitator is an experienced mental health nurse with significant expertise in managing distress. If participants do become distressed the facilitator will speak to the individuals and offering time for them to leave the room accompanied by the co-facilitator. This will allow the participants to continue with the focus group but allow the distressed participant to have some individual time with the co-facilitator. The facilitator will also emphasise the right to withdraw from the discussion at any time (as also stated on the participant information sheet), and this withdrawal will not affect the services that they are usually received from the hospital. The participants who withdraw will be offered time to debrief afterwards to a designed person e.g. a nurse practitioner working as head of ward/team leader in the hospital. Alternatively, if the participants want to talk to the facilitator after the FGD finishes, information about stress management will be provided on the basis of guidance/leaflet from the hospital. Similar procedures will be applied to participants with potential aggression i.e. the facilitator will attempt to calm them and offering time to leave the room. However, if the participants are uncontrollable, the facilitator will ask help from the designed nurse practitioner who will stay outside the room during the discussion. As a head of ward/team leader in the hospital, the designed nurse is experienced in managing people with distress or aggression. If further intervention is required, the participants can be referred to GP then psychiatrist/psychologist as necessary.

Another consideration is that ensuring the principles of autonomy and fairness are applied to people with serious mental illnesses who are included as vulnerable groups. For these people, the researcher will conduct all procedures of research similarly to the carers such as providing clear information about the study, informing that with or without their participation they will receive similar treatment/care from the hospital, providing enough time to determine their participation, guiding them so they have enough time and chance to talk freely during a discussion, protecting their confidentiality by concealing their identity to mental health practitioners as much as possible, and inviting them so the researchers can clarify data gathered from the FGD.

In relation to FGD, one issue that may arise is about how to protect confidentiality for all members of groups (Gibbs 1997). The researcher will explain (on the information sheet and verbally prior to a discussion) that information from one participant will shared with other members as well as the facilitator and co-facilitator. However, all participants will be advised to keep what they hear during the meeting confidential. The participants will be also advised that quotes may be used in the presentation of the thesis and any publications but that these will be anonymised.

In addition, this study will also consider health and safety aspects of the researcher, since it will require travelling to reach the participants. For this reason, the researcher will provide consistent information about the research progress to the University (through main supervisor and second supervisor) and local research ethic board (Broom 2006). In addition, in reaching
the participants (particularly the carers), the researcher will ask support from the hospitals as they have a policy related home visiting. In this case, transportation facility will be advised.

3.9.1. Will any intervention or procedure, which would normally be considered a part of routine care, be withheld from the research participants?

☐ Yes ☑ No

4. Details of Subjects.

4.1. Total Number

- Carers: 32 carers, divided into 4 groups, thus 8 people for each group
- Users: 16 users, divided into 2 groups, thus 8 people for each group

4.2 Sex and Age Range

The sample can be women and men, with a range of age between 18 years and above

4.3. Type

The participants will be carers of people with serious mental illnesses and service users of mental health services in Indonesia.

4.4. What are the principal inclusion criteria? (Please justify)

- Criteria for the carers:
  - Adult carers aged 18 years and over, who have a relative with a serious mental illness.

  This study requires information from adult people who are responsible in caring for a seriously mentally ill person on daily basis. The information should be sourced from those who have adequate experience in this field and able to express it with clarity.

  - Presently in contact with one of the government mental hospital in Jakarta.

  This is a pragmatic rationale for recruiting carers as the chief investigator does not have the financial resources to travel around Indonesia.

- Criteria for users:
  - Adult people (aged 18 years and over) who are registered as service users at the local hospital with a serious mental illness
The participant users of this study are those who have had hospital admission for a serious mental illness e.g. having one of medical diagnosis of schizophrenia or schizoaffective disorders, bipolar disorders, and chronic or persistent depression.

4.5. What are the principal exclusion criteria? *(Please justify)*

- **Carers**
  - Carers or service users under the age of 18 years
  - Having a serious problem in communication (problems in speech, language and hearing)

  The participants of this study will be involved in FGD and thus require people who can speak clearly so that their responses are understandable to the rest of the focus group.

- **Paid carers**

  This research seeks information about the needs of carers from those who are directly impacted from their caregiving role physically, emotionally, and financially. Paid carers do not have such direct connectivity to the mentally ill person.

- **Users**
  - People who have a serious problem of perception for reality, aggressive behaviour, and depressed emotion.

  This study will collect data through FGD that requires active participation and conducive atmosphere from its members, thus the participants should have adequate capacity in involving in a discussion for 1.5 - 2 hours.

4.6. Will the participants be from any of the following groups? *(Tick as appropriate)*

- Children under 16
- Adults with learning difficulties
- Adults who are unconscious or very severely ill
- Adults who have a terminal illness
- Adults in emergency situations
- Adults with mental illness (particularly if detained under mental health legislation)
- Adults with dementia
- Prisoners
- Young offenders
- Adults in Scotland who are unable to consent for themselves
- Healthy volunteers
- Those who could be considered to have a particularly dependent relationship with the investigator e.g. those in care homes, medical students.
- Other vulnerable groups
Justify their inclusion

People with serious mental illnesses are involved as participants because they are stakeholders that cannot be separated from mental health system. The ultimate aim of this study is to give inputs so carers can be adequate helpers for their ill relatives. Therefore, appropriate services for the carers should also consider the view of the users.

4.7. Will any research participants be recruited who are involved in existing research or have recently been involved in any research prior to recruitment?

☐ Yes ☐ No ☑ not known

If yes, give details and justify their inclusion. If Not known, what steps will you take to find out?

I will ask the head of wards about carers and users involved in research. When there is research being conducted in the hospitals, this study will not recruit anyone who is already involved in the research unless this will impact upon recruitment to FGDs e.g. the number of participants is too small to conduct FGDs. However, this study does not involve clinical intervention and conducted in a short period of time. It is expected therefore any involvement has relatively low burden on study participants.

4.8 How will potential participants in the study be (I) identified, (ii) approached and (iii) recruited?

Where research participants will be recruited via advertisement, please append a copy to this application

The initial process of recruitment will be conducted on a formal basis with managers of the mental hospitals that are responsible for research activities. As soon as ethical approval is achieved from Indonesian Nursing Ethic committee with a supporting letter from the University of Manchester, a letter of permission will be delivered to the Directors of the mental hospitals for data collection. After the permission for research is completed, the chief investigator will talk to each head of ward within the two hospitals via telephone to discuss the study and generate a list of people currently on the ward who meet the inclusion criteria. A research assistant will distribute the information sheet about the study to potential participants. The chief investigator will then meet with each potential participant to discuss the study and ask whether (I) they would be interested in taking part and (ii) whether they consent the chief investigator to include their relatives as the carers participants in this study. Where they consent to the latter, service users will be asked to identify the members of the family they can contact and give the information sheet.

Service users will be given 48 hours to decide whether (I) they wish to take part and/or (ii) they would contact their family and give them the information sheet related to the study. Those who agree to participate will be asked to sign a consent form and invited to either a focus group discussion or individual interview.

Where service users have contacted their family and given the information sheet, they will be contacted by the chief investigator for their decision of participation. The chief investigator
will give time for the potential carers to decide their participation up to 48 hours after the information distributed. Those who agree to participate will be met and asked to sign a consent form and invited to either a focus group meeting or in individual interview.

4.9 Will individual research participants receive reimbursement of expenses or any other incentives or benefits for taking part in this research?

☐ √Yes ☐ No

Each person who agrees to participate will be paid expenses to cover his/her travel to the focus groups (equivalent of 8 GBP).

5 Details of risks

5.1 Drugs and other substances to be administered

*Indicate status, e.g. full product licence, CTC, CTX. Attach: evidence of status of any unlicensed product; and Martindale’s Pharmacopoeia details for licensed products*

DRUG STATUS DOSAGE/FREQUENCY/ROUTE

5.2 Procedures to be undertaken

*Details of any invasive procedures, and any samples or measurements to be taken. Include any questionnaires, psychological tests etc. What is the experience of those administering the procedures?*

There will be no drug or other substances to be administered to participants in this study.

5.3 Or Activities to be undertaken

*Please list the activities to be undertaken by participants and the likely duration of each*

Every participant will involve in a group to discuss about the needs of carers from mental health services in Indonesia for 1.5-2 hours. However, flexibility will be employed as necessary, as the duration is determined by the number of participants in a group as well as their complexity (Powell and Single 1996).

5.4 What are the potential adverse effects, risks or hazards for research participants, including potential for pain, discomfort, distress, inconvenience or changes to lifestyle for research participants?

This study will not involve changes to the carers’ and the users’ standard of service and there are no clinical risks to them. It will involve discussing their experience in using services for caring for a person with a serious mental illness. This may be distressing for some participants. If there is any participant who is uncomfortable with a particular issues rising in a discussion, the facilitator will inform that he/she does not have to give any comment. Also, leaving the meeting will be allowed, if the participant wishes to withdraw from the discussion at any point. The next anticipation will follow the procedures that have been explained in the previous section related ethical issues.
5.5 Will individual or group interviews/questionnaires discuss any topics or issues that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could take place during the study (e.g. during interviews/group discussions, or use of screening tests for drugs)?

☐ □ Yes ☐ No

*If yes, give details of procedures in place to deal with these issues:*

As stated previously, during the discussion issues surrounding carers and users' experience in utilizing the existing services can be upsetting for some people. Anticipation for this issue has been provided in the previous section (3.9).

5.6 What is the expected total duration of participation in the study for each participant?

The total duration of participation for this study will be around 1.5-2 hours for discussion. However, time for reading information about this study, deciding the participation and travelling to the hospital is not included in this estimation; as it is very individual.

5.7 What is the potential benefit to research participants?

There are no direct immediate benefits to taking part in this study. However, it is expected that by undertaking this research might have a better understanding about the needs of carers from mental health services in Indonesia. In addition, the study may help to influence policy makers and mental health professionals to develop services for carers in the future. However, it is important to inform the participants that there is no guarantee the policy makers and mental health professionals will utilise of the information from the study.

5.8 What is the potential for adverse effects, risks or hazards, pain, discomfort, distress, or inconvenience to the researchers themselves?

There will be no specific risks for the researchers of this study. However, it is important to consider health and safety aspects of the chief investigator, since it will require travelling out of the UK to reach the participants. Also, it is essential to recognise the safety issue of the chief investigator in handling participants with potential aggression.

6. Safeguards

6.1 What precautions have been taken to minimise or mitigate the risks identified above?

The chief investigator will provide consistent information about the research progress to the University (via main supervisor and supervisor) and local research ethic board (Broom 2006). Detail anticipation in managing participants with potential aggression has been described in section 3.9 (ethical issues).

6.2 Will informed consent be obtained from the research participants?

☐ □ Yes ☐ No
If yes, give details of who will take consent and how it will be done. Give details of the experience in taking consent and of any particular steps to provide information (in addition to a written information sheet) e.g. videos, interactive material.

If participants are to be recruited from any of the potentially vulnerable groups listed in Question 4.6, give details of extra steps taken to assure their protection. Describe any arrangements to be made for obtaining consent from a legal representative.

If consent is not to be obtained, please explain why not.

Where relevant the committee must have a copy of the information sheet and consent form.

Participant Information Sheet (PIS) and written consent will be provided for both carers and users. For the users, the procedure will be started by seeking information from nurses as head of ward about potential participants who meet the criteria. Once identified, every potential user will be contacted and will be informed about the research. In addition, PIS and consent form will be provided. After giving 48 hours to make a decision, the researcher will come back to the informed users (those who have been given PIS) to ask their confirmation in joining the study. The users who agree to participate will be suggested to sign the written consent. Two copies of consent need to be signed by both the user participant and the researcher, and each of them will keep one copy. The consent sign will be performed by the users without someone e.g. nurse or carer will be their representatives.

Similarly, a written consent will be provided to carer participants. Information about potential carers will be gathered from the users who have agreed to be involved. The same procedures with the users will be employed in terms of giving clear information about the study, allowing them to think prior to making a decision for 48 hours, and asking them to sign consent if they agree for participation. Each carer should also keep one copy of consent as the researcher does.

6.3 Will a signed record of consent be obtained?

☐ □ Yes □ No

If not, please explain why not.

6.4 How long will the participant have to decide whether to take part in the research?

Each participant will be given 48 hours to decide whether to participate or not. This should be enough time to go and speak to family members or friends about their decision.

6.5 What arrangements have been made for participants who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (E.g. translation, use of interpreters etc.)

It is expected that there will be no special needs of communication for participants in this study. All processes of the study will be provided in local language (Bahama Indonesia). The carers and the users will be selected for those who do not have problems in understanding verbal explanation and written information. Similarly, for the purpose of FGD, the participants of this study should not have difficulties in verbal communication. In relation to written communication, this study will not exclude people who are unable to read and write. However,
if participants are not able to read or write the chief investigator will read aloud the information sheet and the consent form. Particular care will be taken to ensure that the participants are clear about the study and the researcher will check this by asking participants to verbally feedback what the chief investigator has told them.

Information about the capacities (verbal and written communication) of the users will be attained from health personnel who are providing direct care on daily basis. Information about the capacities of the carers will be obtained from service users who have been asked their consent to the researcher contacting their family member.

6.6 What arrangements are in place to ensure participants receive any information that becomes available during the course of the research that may be relevant to their continued participation?

The participants will be given opportunities to ask and clarify information about their participation. Contact details of the researchers will be included in the information sheet. The details contain office address in Indonesia and in the University of Manchester, office phone numbers, and office email addresses.

6.7 Will the research participants' General Practitioner be informed that they are taking part in the study?

☐ Yes ☐ No

If no explain why not

The GP system is not implemented in Indonesia. The system there is different than the one implemented in UK. Mental health professionals who would know about carers and users participation are nurses as a head of ward or a head of team (note: in a ward, services are delivered on team management basis) and the psychiatrist. However, because the nature of the information that this study seeking is sensitive e.g. carers needs from mental health service, thus the participants will not be advised to ask any clinician regarding the study.

6.8 Will permission be sought from the research participants to inform their GP before this is done?

☐ Yes ☐ No

If no explain why not

As noted previously, head of ward and/or head of team would know about the users’ and carers' participation, but not necessarily the GP. However, the researchers of this study will emphasise to the participants that whether they will not participate, their decision will not effect on the services they receive.

6.9 What arrangements have been made to provide indemnity and/or compensation in the event of a claim by, or on behalf of, participants for (a) negligent harm and (b) non-negligent harm?
As previously stated, this study will not result in physical harm. Therefore insurance coverage for this matter will be unnecessary. In relation to psychological distress that may arise during or after discussing a sensitive issue of mental illnesses, designed nurse practitioners e.g. particularly who are responsible to the participants’ care will provide help. If further intervention is needed, usual procedures in Indonesia will be implemented. The basic government health insurance for users and carers can be utilised to cover expenses of visiting GP then can be referred to psychologists or psychiatrists as necessary.

7. Data Protection and Confidentiality

7.1 Will the research involve any of the following activities at any stage (including identification of potential research participants)? *(Tick as appropriate)*

Further details:

- Examination of medical records by those outside the NHS, or within the NHS by those who would not normally have access
- Electronic transfer by magnetic or optical media, e-mail or computer networks
- Sharing of data with other organisations
- Export of data outside the European Union
- Use of personal addresses, postcodes, faxes, e-mails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
  - Manual files including X-rays
  - NHS computers
  - Home or other personal computers
  - University computers
  - Private company computers
  - Laptop computers

The participants of FGD in this study will be informed that the researchers intend to use quotes but they will not be attributed to anyone.

7.2 What measures have been put in place to ensure confidentiality of personal data?

*Give details of whether any encryption or other anonymisation procedures have been used and at what stage?*

Data e.g. hardcopies/papers/digital video recorded materials will be stored in a locked cabinet at the researcher’s office at the Faculty of Nursing University of Indonesia or the University of Manchester. Data in soft copies in computer can be only accessed with password (in the protected server from The University of Manchester). The use of USB stick will be avoided unless it has been encrypted. The data can be also stored in the researcher’s personal encrypted laptop equipped with password. All data can be only accessed by the researcher members with the permission of the chief investigator. Information through emails between the chief investigator and the supervisors cannot be avoided due to the long distance. However, the researchers will enhance the confidentiality of participants by giving no name for any participant in any writing reports as a part of the study. The researchers will give false names
and remove any information that could identify the participants. Due to their involvement in FGD, the chief investigator will advise that as much as possible every participant should keep the information gathered from a discussion only for the members.

7.3. Where will the analysis of the data from the study take place and by whom will it be undertaken?

Data analysis will be undertaken by the chief investigator in two places e.g. at the office of the chief investigator in Indonesia and the University of Manchester, UK. During this process, the supervisors will be oriented with the analysis procedures and primary findings.

7.4 Who will have control of and act as the custodian for the data generated by the study?

The chief investigator will control and keep all data gathered from the study

7.5 Who will have access to the data generated by the study?

The chief investigator and the supervisors.

7.6 For how long will data from the study be stored?

Five years after the PhD project ends, unless the DVD recording materials that will stored one year after the project completion.

Give details of where they will be stored, who will have access and the custodial arrangement s for the data.

This period should be enough time so that the researchers are able to go back to the data for dissemination purposes. The data of hard copies will be stored in a locked cabinet at the chief investigator's office in Indonesia as well as at the University of Manchester’s research data storage. Only the chief investigator could access them but a spare key will be provided to the supervisors in the UK.

The data of soft copies e.g. scanned transcripts of interviews will be stored in a password-protected drive on the University of Manchester server. Therefore the data can be only accessed by the chief investigators and the supervisors. The data can be also kept in the chief investigator’s laptop equipped with password, and only she could access them. After 5 years the PhD completion all data will be destroyed (unless the DVD recoding materials that will be destroyed 1 year after the project completion).

8. Reporting Arrangements

8.1. Please confirm that any adverse event will be reported to the Committee

By using standardised reporting, the chief investigator will report to Ethical Committee at The University of Manchester for any adverse event arising in this study such as unexpected occurrence from the designed protocol. In addition, such report will be also provided to Nursing Ethical Committee in the country.
8.2. How is it intended the results of the study will be reported and disseminated?

(Tick as appropriate)

- [ ] Peer reviewed scientific journals
- [ ] Internal report
- [ ] Conference presentation
- [ ] Thesis/dissertation
- [ ] Written feedback to research participants
- [ ] Presentation to participants or relevant community groups
- [ ] Other/none e.g. Cochrane Review, University Library, report to the student’s sponsorship

8.3 How will the results of research be made available to research participants and communities from which they are drawn?

From the given addresses, the chief investigator will provide a summary of the research findings to carers and users via post. In addition, the chief investigator will disseminate the research findings to staff who are in charge in activities of education and research in the mental hospital. In this occasion, it is also necessary to invite mental health personnel who are relevant to services for the carers.

8.4 Has this or a similar application been previously considered by a Research Ethics Committee in the UK, the European Union or the European Economic Area?

- [ ] Yes  - [ ] No

If yes give details of each application considered, including:

Name of Research Ethics Committee or regulatory authority:
Decision and date taken:
Research ethics committee reference number

8.5 What arrangements are in place for monitoring and auditing the conduct of the research?

The chief investigator will have regular and frequent contact with the supervisors during data collection. A report explaining the undertaken research procedures will be produced and submitted to the supervisors. Frequent monitoring via the University of Manchester eProg will occur during data collection. The chief investigator will also have regular contacts with Indonesian Nursing Ethic committee who are responsible for the technical and administrative supervision of the research conduction in the country.
8.6. Will a data monitoring committee be convened?

☐ Yes ☐ No

8.7. What are the criteria for electively stopping the trial or other research prematurely?

The research activities can be stopped for dramatic reasons such as national/local disaster that affecting the country/the city/the sites of studies for a long time e.g. more than 6 months.

9. Funding and Sponsorship

9.1 Has external funding for the research been secured?

☐ Yes ☐ No

If yes, give details of funding organisation(s) and amount secured and duration:

Organisation: Indonesian government scholarship e.g. Directorate of Higher Education, Ministry of Education, Republic of Indonesia

UK contact: Indonesian Embassy 38 Grosvenor Square London W1K 2HW
Phone: 020 7499 7661/ 020 7499 766, Website:
www.indonesianembassy.org.uk

Amount (£): 60,150 during the study (allowance + PhD programme fees)

Duration: 36 Months

9.2 Has the external funder of the research agreed to act as sponsor as set out in the Research Governance Framework?

☐ Yes ☐ No ☐ Not Applicable

9.3 Has the employer of the Chief Investigator agreed to act as sponsor of the research?

☐ Yes ☐ No

Because the chief investigator is a PhD student sponsored by the University of Manchester.

Sponsor

The sponsor for this research is The University of Manchester...

10. Conflict of interest

10.1 Will individual researchers receive any personal payment over and above normal salary and reimbursement of expenses for undertaking this research?

☐ Yes ☐ No
If yes, indicate how much and on what basis this has been decided:

10.2 Will the host organisation or the researcher's department(s) or institution(s) receive any payment of benefits in excess of the costs of undertaking the research?

☐ Yes ☐ No

10.3 Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share-holding, personal relationship etc.) in the organisation sponsoring or funding the research that may give rise to a possible conflict of interest?

☐ Yes ☐ No

If yes, give details:

11. Signatures of applicant(s)

.................................................................................................................. .................

Signed Date

12 Signature by or on behalf of the Head of School

The Committee expects each School to have a pre-screening process for all applications for an ethical opinion on research projects. The purpose of this pre-screening is to ensure that projects are scientifically sound, have been assessed to see if they need ethics approval and, if so, go to the relevant ethics committee. It is not to undertake ethical review itself, which must be undertaken by a formal research ethics committee.

The form must therefore be counter-signed by or on behalf of the Head of School to signify that this pre-screening process has been undertaken

I approve the submission of this application

.................................................................................................................. .................

Signed by or on behalf of the Head of School Date
Duration: 36 Months

9.2 Has the external funder of the research agreed to act as sponsor as set out in the Research Governance Framework?
  □ Yes □ No □ Not Applicable

9.3 Has the employer of the Chief Investigator agreed to act as sponsor of the research?
  □ Yes □ No

Because the chief investigator is a PhD student sponsored by the University of Manchester.

Sponsor

The sponsor for this research is the University of Manchester.

10. Conflict of interest

10.1 Will individual researchers receive any personal payment over and above normal salary and reimbursement of expenses for undertaking this research?
  □ Yes □ No

If Yes, indicate how much and on what basis this has been decided:

10.2 Will the host organisation or the researcher's department(s) or institution(s) receive any payment of benefits in excess of the costs of undertaking the research?
  □ Yes □ No

10.3 Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share-holding, personal relationship etc.) in the organisation sponsoring or funding the research that may give rise to a possible conflict of interest?
  □ Yes □ No

If Yes, give details:

11. Signatures of applicant(s)

[Signature]

Signed Date
2 May 2012
12 Signature by or on behalf of the Head of School

The Committee expects each School to have a pre-screening process for all applications for an ethical opinion on research projects. The purpose of this pre-screening is to ensure that projects are scientifically sound, have been assessed to see if they need ethics approval and, if so, go to the relevant ethics committee. It is not to undertake ethical review itself, which must be undertaken by a formal research ethics committee.

The form must therefore be counter-signed by or on behalf of the Head of School to signify that this pre-screening process has been undertaken.

I approve the submission of this application:

[Signature] 2/5/20[...]

Signed by or on behalf of the Head of School  Date

Document E
Ms Heni Susanti,
c/o Dr Hilary Mairs,
School of Nursing, Midwifery and Social Care,
Jean McFarlane Building 6.317
14th June 2012

Dear Heni,

Research Ethics Committee I
Susanti: Understanding the needs of carers of people with serious mental illness from mental health services in Indonesia (ref 12047)

I write to thank you for attending the meeting on 24th May and to confirm that the amended documents set out in your email of 7th and 13th June satisfy the concerns of the Committee and that the project has been given 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 May 2013.

Yours sincerely

Timothy Jollands
Dr T P C Jollands
Secretary to the University Research Ethics Committee

Enclosed: Report form
You are being invited to take part in a research study as part of a PhD project to explore the needs of carers of people with mental health problems in Indonesia.

Before you decide whether to take part 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?
Herni Susanti as the PhD student as well as the lead researcher under the supervision of Professor Karina Lovell and Dr Hilary Mairs in the School of Nursing, Midwifery, and Social Work, The University of Manchester, UK.

Title of the Research
Understanding the needs of carers of people with serious mental illnesses from mental health services in Indonesia

What is the aim of the research?
The purpose of the study is to try to find out what carers need from mental health services so that we can design an intervention to support carers in Indonesia.

Why have I been chosen?
You are being given this letter because you are an adult service user who is being using a government service in Jakarta Indonesia. We would like to talk to you and other service users to find out what you think carers need from mental health services and how the services might best supporting them.

What would I be asked to do if I took part?
If you agree to take part you will be invited to a focus group discussion, where you will meet up to 8 and other service users and be asked to discuss what you think carers need from mental health services in Indonesia. The lead researcher will facilitate the discussion and will
be helped by a co-facilitator. Hopefully, the discussion will last for no longer than 2 hours. The discussion will be DVD-taped with your permission. If you do not agree to be DVD-taped, we would interview you individually and this will not be recorded.

This study *does not* involve changes to your standard of care, and there are no clinical risks to you. It will involve discussing your and your carer’s experience in using services for caring for a person with a serious mental illness. This may be distressing and uncomfortable for some people, although please be reassured that the researcher has experience of talking to people who need to express their feelings. If you take part and are uncomfortable with a particular issues rising in a discussion, you do not have to give any comment. Also, if you take part and wish to stop the interview at any point, you could tell the lead researcher and you can to leave the meeting. The researcher will not be upset if you change your mind. However, you will be offered time for talking about your feeling to a nurse working in the hospital. You could also wait for the lead researcher until she finishes facilitating the discussion, and she will give support to you based on guidance/leaflet from the hospital. If more help is needed the nurses or the lead researcher will advise you to go to GP/psychiatrist/psychologist as necessary.

**What happens to the data collected?**

The results of the group discussion will be then written down word for word and looked at to identify common ideas that might arise during the discussions. It is important to know that once data from discussion written, you could not withdraw from this study as we will not be able to identify people who gave the information.

**How is confidentiality maintained?**

Every participant in this study will be advised to keep the information gathered from a discussion only for the members.

All information collected about you during the research will be kept strictly confidential. For the purpose of data analysis, a very few people in addition to the principal investigator may access the information gathered i.e. two supervisors, co-moderator, and two people for transcription and checking the translation. Any information about you will be stored in a locked cabinet at the researcher’s office in Indonesia and at the University of Manchester or on an encrypted computer. We will not name anyone in reports we write up. You will be allocated a false name and any information that could identify you will be removed. Health care professionals responsible for you and your relative’s care might be informed that you have taken part for policy reasons of the hospital. The DVD taping materials will be stored 1 year after the PhD project finishes as we might need to go back to analyse. Other data will be stored for 5 years after the PhD project ends so we can return to the data for dissemination purposes. After this, all data will be destroyed.

**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 after 48 hours. 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?**

We can provide a small amount of money to cover your travel and meal expenses.
What is the duration of the research?
The study will last for about 15 months, although your involvement will only be taking part in one focus group discussion, each lasting for between 1.5 - 2 hours.

Where will the research be conducted?
The discussion will be conducted in the mental hospital in a private room.

Will the outcomes of the research be published?
So that others can learn from our study, we will write articles for nursing and other health and social journals and give presentations at health-related conferences. We will be careful to ensure that it is not possible to identify you individually in any reports, papers or presentations. If you take part, we will send you a summary of the results when we have completed the research.

Contact for further information
If you need more information you can contact the lead researcher at the School of Nursing, Midwifery and Social Work University of Manchester, University Place Oxford Road Manchester M13 9P phone: +44 (0)161 306 7614 or Faculty of Nursing University of Indonesia, Kampus UI Depok Indonesia, phone +6221788491120 or write email to herni.susanti@postgrad.manchester.ac.uk (to contact Herni Susanti only). Contact details for supervisors: Professor Karina Lovell, Room 6.322.a. Jean McFarlane Building University of ManchesterM13 9PL, phone +44 (0) 161 306 67853, email Karina.Lovell@manchester.ac.uk and Dr Hilary Mairs, Room 6.317 Jean McFarlane Building University of ManchesterM13 9PL, phone +44 (0) 161 306 7842, email Hilary.Mairs@manchester.ac.uk

What if something goes wrong?
We do not anticipate that taking part in the study will cause you problems. If, however, you are unhappy with any aspect of the way that you are treated, you should inform the lead researcher. Any complaint or question you make will be taken very seriously. If the lead researcher cannot satisfy your question or comment, you could contact her supervisors.

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 Practice and Governance Coordinator by either writing to 'The Research Practice and Governance Coordinator, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester M13 9PL', by emailing: Research-Governance@manchester.ac.uk, or by telephoning +44 161 275 7583 or 275 8093.

If you are interested in taking part in the research, you should complete the attached contact and personal data form and sign the consent form enclosed with this letter. The researcher will contact you to pick up the document as well as to arrange time, venue and date that is best for a discussion.

Thank you for taking the time to read this information
You are being invited to take part in a research study as part of a PhD project to explore the needs of carers from mental health services in Indonesia. In particular we are interested in talking to a family member/friend/neighbor who now has responsibility for caring for a person with a severe mental health problem. The person you care for could have been given a diagnosis which may include schizophrenia or schizoaffective disorders, bipolar disorders, and chronic or persistent depression.

Before you decide whether to take part 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?
Herni Susanti as the PhD student as well as the lead researcher under the supervision of Professor Karina Lovell and Dr Hilary Mairs in the School of Nursing, Midwifery, and Social Work, The University of Manchester, UK.

Title of the Research
Understanding the needs of carers of people with serious mental illnesses from mental health services in Indonesia

What is the aim of the research?
The purpose of the study is to try to find out what carers need from mental health services so that we can design an intervention to support carers in Indonesia.

Why have I been chosen?
You are being given this letter because you are an adult carer of a person with severe mental health problem and the person is currently being treated in a government service in Jakarta, Indonesia. We would like to talk to you and other carers to find out what you think your needs from mental health services and how the services might best supporting you.

What would I be asked to do if I took part?
If you agree to take part you will be invited to a focus group discussion, where you will meet up to 8 other carers and be asked to discuss what you think carers need from mental health services in Indonesia. The lead researcher will facilitate the discussion and will be helped by a co-facilitator. Hopefully, the discussion will last no longer than 2 hours. The discussion will be DVD-taped with your permission. If you do not agree to be DVD-taped, we would interview...
you individually and this will not be recorded.

This study does not involve changes to you and your relatives’ standard of service, and there are no clinical risks to you or your relative. It will involve discussing your experience in using services for caring for a person with a serious mental illness. This may be distressing and uncomfortable for some people, although please be reassured that the researcher has experience of talking to people who need to express their feelings. If you take part and are uncomfortable with a particular issues rising in the discussion, you do not have to give any comment. Also, if you take part and wish to stop the interview at any point, you could tell the lead researcher and you can leave the meeting. The researcher will not be upset if you change your mind. However, you will be offered time for talking about your feeling to a nurse working in the hospital. You could also wait for the lead researcher until she finishes facilitating the discussion, and she will give support to you based on guidance/leaflet from the hospital. If more help is needed the nurses or the lead researcher will advise you to go to GP then psychiatrist/psychologist as necessary.

What happens to the data collected?

The results of the group discussion will be then written down word for word and looked at to identify common ideas that might arise during the discussions. It is important to know that once data from discussion written, you could not withdraw from this study as we will not be able to identify people who gave the information.

How is confidentiality maintained?

Every participant in this study will be advised to keep the information gathered from a discussion only for the members.

All information collected about you during the research will be kept strictly confidential. For the purpose of data analysis, a very few people in addition to the principal investigator may access the information gathered i.e. two supervisors, co-moderator, and two people for transcription and checking the translation. Any information about you will be stored in a locked cabinet at the researcher’s office in Indonesia and at the University of Manchester or on an encrypted computer. We will not name anyone in reports we write up. You will be allocated a false name and any information that could identify you will be removed. Health care professionals responsible for you and your relative’s care might be informed that you have taken part for policy reasons of the hospital. The DVD taping materials will be stored 1 year after the PhD project finishes as we might need to go back to analyse. Other data will be stored for 5 years after the PhD project ends so we can return to the data for dissemination purposes. After this, all data will be destroyed.

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 after 48 hours. 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?

We can provide a small amount of money to cover your travel and meal expenses.

What is the duration of the research?

The study will last for about 15 months, although your involvement will only be taking part in one focus group discussion, each lasting for between 1.5 - 2 hours.
Where will the research be conducted?
The discussion will be conducted in the mental hospital where your relative is being cared or, if you wish another place, in can be run at a community venue.

Will the outcomes of the research be published?
So that others can learn from our study, we will write articles for nursing and other health and social journals and give presentations at health-related conferences. We will be careful to ensure that it is not possible to identify you individually in any reports, papers or presentations. If you take part, we will send you a summary of the results when we have completed the research.

Contact for further information
If you need more information you can contact the lead researcher at the School of Nursing, Midwifery and Social Work University of Manchester, University Place Oxford Road Manchester M13 9P phone: +44 (0)161 306 7614 or Faculty of Nursing University of Indonesia, Kampus UI Depok Indonesia, phone +6221788491120 or write email to herni.susanti@postgrad.manchester.ac.uk (to contact Herni Susanti only). Contact details for supervisors: Professor Karina Lovell, Room 6.322.a. Jean McFarlane Building University of Manchester M13 9PL, phone +44 (0) 161 306 67853, email Karina.Lovell@manchester.ac.uk and Dr Hilary Mairs, Room 6.317 Jean McFarlane Building University of Manchester M13 9PL, phone +44 (0) 161 306 7842, email Hilary.Mairs@manchester.ac.uk

What if something goes wrong?
We do not anticipate that taking part in the study will cause you problems. If, however, you are unhappy with any aspect of the way that you are treated, you should inform the lead researcher (Herni Susanti). Any complaint or question you make will be taken very seriously. If the lead researcher cannot satisfy your question or comment, you could contact my supervisors.

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 Practice and Governance Coordinator by either writing to 'The Research Practice and Governance Coordinator, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester M13 9PL', by emailing: Research-Governance@manchester.ac.uk, or by telephoning +44 161 275 7583 or 275 8093.

If you are interested in taking part in the research, you should complete the attached contact and personal data form and sign the consent form enclosed with this letter. The researcher will contact you to pick up the document as well as to arrange time, venue and date that is best for a discussion.

Thank you for taking the time to read this information
Participant Information Sheet (Professionals)

The needs of carers of people with serious mental illness from the perspectives of mental health professionals in Indonesia

You are being invited to take part in a research study as part of a PhD project to explore the needs of carers of people with mental health problems in Indonesia from the perspectives of health professionals.

Before you decide whether to take part 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?
Herni Susanti as the PhD student as well as the lead researcher under the supervision of Professor Karina Lovell and Dr Hilary Mairs in the School of Nursing, Midwifery, and Social Work, The University of Manchester, UK.

Title of the Research
Understanding the needs of carers of mental health hospital-based services from the perspectives of health professionals in Indonesia

What is the aim of the research?
The purpose of the study is to try to find out what carers need from mental health hospital-based services so that we can design an intervention to support carers in Indonesia.

Why have I been chosen?
You are being given this letter because you are a mental health professional being employed in a government mental health hospital in Jakarta Indonesia. We would like to talk to you to find out what you think carers needs from the hospital-based services and how the services might best supporting them.

What would I be asked to do if I took part?
If you agree to take part you will be invited to an individual interview and be asked to discuss about what you think carers need from mental health hospital services in Indonesia. The interview can be either face-to-face or via Skype or telephone decided based on your preference. The lead researcher will be the interviewer. Hopefully, the interview will last for no longer than 1.5 hours. The interview will be audio recorded with your permission. If you do not agree to be recorded, we would interview...
you but will be not recorded.

This study will not provide an intervention to change to your professionals’ practice. Additionally, this study will not have the potential adverse effects, risks or hazards for you as a health professional even though it will involve discussion about your experience in working with carers. However, if the conversation about your experience in involving carers is upsetting or uncomfortable, you can take a break and continue the interview when you are ready. Please be reassured that the interviewer has experience of talking to people who need to express their feelings as needed. Also, if you take part and wish to stop the interview, you could tell the researcher and you are allowed to withdraw from the interview at any point.

What happens to the data collected?

The results of the interview will be then written down word for word and looked at to identify common ideas that might arise during the interview. It is important to know that once data from the interview written, you could not withdraw from this study as we will not be able to identify people who gave the information.

How is confidentiality maintained?

All information collected about you during the research will be kept strictly confidential. Any information about you will be stored in a locked cabinet at the researcher’s office in Indonesia and at the University of Manchester or on an encrypted computer. We will not name anyone in reports we write up. You will be allocated a false name and any information that could identify you will be removed. Hospital managers might be informed that you have taken part for policy reasons of the hospital, yet only minimal information will be given such as initials and name of wards/clinic. Whether there is bad practice known from this investigation, relevant authorities of the hospital will be informed as necessary. The audio recording materials will be stored 1 year after the PhD project finishes as we might need to go back to analyse. Other data will be stored for 5 years after the PhD project ends so we can return to the data for dissemination purposes. After this, all data will be destroyed.

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 after 24 hours. 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?

We can provide a small amount of money to cover meal expenses.

What is the duration of the research?

The study will last for about 6 months, although your involvement will only be taking part in one interview, each lasting for between 45 - 90 hours.

Where will the research be conducted?

The discussion will be conducted at any place that is dependent on your preference i.e. inside or outside of the hospital. As mentioned earlier, if you cannot be interviewed face-to-face, interview via Skype or telephone can be conducted at any place that you want.

Will the outcomes of the research be published?
So that others can learn from our study, we will write articles for nursing and other health and social journals and give presentations at health-related conferences. We will be careful to ensure that it is not possible to identify you individually in any reports, papers or presentations. If you take part, we will send you a summary of the results when we have completed the research.

Contact for further information
If you need more information you can contact the lead researcher at the School of Nursing, Midwifery and Social Work University of Manchester, University Place Oxford Road Manchester M13 9P phone: +44 (0)161 306 7614 or Faculty of Nursing University of Indonesia, Kampus UI Depok Indonesia, phone +6221 788 49112 or write email to herni.susanti@postgrad.manchester.ac.uk(to contact Herni Susanti only). Contact details for supervisors: Professor Karina Lovell, Room 6.322 a. Jean McFarlane Building University of Manchester M13 9PL, phone +44 (0)161 306 67853, email Karina.Lovell@manchester.ac.uk and Dr Hilary Mairs, Room 6.317 Jean McFarlane Building University of Manchester M13 9PL, phone +44 (0)161 306 7842, email Hilary.Mairs@manchester.ac.uk

What if something goes wrong?
We do not anticipate that taking part in the study will cause you problems. If, however, you are unhappy with any aspect of the way that you are treated, you should inform the lead researcher. Any complaint or question you make will be taken very seriously. If the lead researcher cannot satisfy your question or comment, you could contact her supervisors.

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 Practice and Governance Co-ordinator by either writing to 'The Research Practice and Governance Co-ordinator, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester M13 9PL', by emailing: Research-Governance@manchester.ac.uk, or by telephoning +44 161 275 7583 or 275 8093.

If you are interested in taking part in the research, you should complete the attached contact and personal data form and sign the consent form enclosed with this letter. The researcher will contact you to pick up the document as well as to arrange time, venue and date that is best for a discussion.

Thank you for taking the time to read this information.
PARTICIPANT CONTACT CONSENT FORM

The needs of carers of people with serious mental illness from the perspectives of mental health professionals in Indonesia

Please complete the following information and return the form to the envelope provided.

Name:
Address:
Telephone: Is it OK to contact you using this information? (Please circle)
- Home YES NO
- Work YES NO
- Mobile YES NO

Email:

You will be contacted within 24 hours after you signed this form. If you would prefer to be contacted on certain times, please indicate here............................................................

Thank You very much for your assistance. If you wish to discuss anything with a member of our team, please contact us using the information below:

Herni Susanti
Faculty of Nursing University of Indonesia, Kampus UI Depok Indonesia, telp +6221788491120 or School of Nursing, Midwifery and Social Work, University of Manchester, University Place, Oxford Road, Manchester, M13 9PL, telp: +44 (0)161 306 7614 . Email: herni.susanti@postgrad.manchester.ac.uk
Discussion guide for FGD

This guide is particularly designed for participants of carers in the initial discussion. Guide for service user is approximately the same.

Good morning/good afternoon everybody. Before we start our discussion, let me introduce and explain myself so you are clear about our intention. My name is Herni Susanti. I am a PhD student conducting research through group discussions about what carers needs from mental health services in Indonesia. I will be the moderator for a discussion that we will conduct. I will try the best so everyone gets a turn to speak. Time for discussion will be based on members’ agreement. However, I think it would be effective if we could run each discussion for about two hours.

First, it will be helpful for us if we know each other. Let’s begin with introduction. X, could you please start by stating your name. We will go around the table (introductory phase starts)

Before we are really starting our discussion, I would like to request your attention for a few things. First, this meeting is DVD-taped for the purpose of writing up my report. If anyone disagrees with this recording procedure, please do not hesitate to say your objection, and of course, you are allowed to withdraw your participation. Second, you have right to not commenting any issues that you think unpleasant. You could also stop from the discussion and we will give you time to decide whether you would continue the discussion. Do not hesitate if you choose to discontinue, it will not affect anything to you and your relatives’ service from the hospital. You still be given time to talk about your feeling either to nurses working in the hospital or me after finishing this discussion. Third, as stated in the signed informed consent, the content of this discussion need to be secure from disclosing. It is highly appreciated that the issues from this discussion is only shared among the members. Lastly, please do not shy to speak up, but try to have just one person speak at a time. I will try the best to make sure everybody speaks. Please comment exactly what you think. Do not worry about me or other members’ thoughts about you. We are here to share opinions and let’s enjoy the process.
All right, for our discussion I would like to give you a brief statement regarding our topic. Mental health services for carers of people with serious mental illness are important. However, until now, it is unclear whether the existing services have met the needs of carers. Therefore, let’s discuss about what do the carers need related to their caregiving role.

(Following this, I will deliver transition questions to identify the nature of the needs of carers of people with serious mental illnesses in Indonesia. The questions include)

“What do you think about caring a person with serious mental illnesses?”

After that, I will deliver key questions during the session or ensure they are discussed by all members. The questions include:

“What are the needs of carers in relation to their caregiving role?”
(I will explore the needs of carers for their own wellbeing)

“What services are required to meet the needs of carers of people with serious mental illnesses in Indonesia?”

“How the support for carers have been delivered thus far?”

“Why are the existing services not being optimally used?”

“What affects the successful delivery of services for carers?”

“What barriers do exist to mental health system in operating services for carers?”
(I will explore the issues of lack of policy relating to carer contribution in mental health services and problems to access the existing guidance)

“What do you think about potential services for carers?”

We are arriving at the end of this discussion. I will be very thankful if you could share your feelings and opinions about this meeting. Can we start from Mr. X, then we will go around. I am so thankful that we have covered much information surrounding mental health services for carers of people with serious mental illness in Indonesia.

Thank you for your participation, see you again.
INTERVIEW SCHEDULE

The interview will begin by asking several background questions to the professional participants, as follows:

**Background questions**

- How many years have you been working in this hospital?
- What is your current position in this hospital?
- How many years have you been performing the current role?
- When did the last time you contact with carers of people with serious mental illnesses? What were you doing? How much time did you spent with the carers?
- In average, how much time did you spent with carers in a week/a month? What have you been doing with the carers?
- How do you meet the carers? Who do initiate the contact?

Next, the interview will focus on questions related to the needs of Indonesian carers from mental health hospital-based services as follows:

**Questions about carer needs**

- What are needed by carers of people with serious mental illness from mental health hospital services in Indonesia?
- What types of services are required to meet the carers’ needs?
- What do you think about the role of health professionals in meeting the carers’ needs?
- How do you perform the roles?
- What are current services provided to meet the needs of carers?
- What is your opinion about the involvement of carers in these services?
- What resources have been available to support the carers (written and unwritten)?
- Why are the existing resources not being optimally used?
- What is your opinion related to uptake rate and what are the barriers to uptake?
- What do you think barriers in meeting the carers’ needs
- What do you think supports in meeting the carers’ needs?
- What actions should be done to minimise the barriers?
- What training and development opportunities you have had to support your service to the carers?
- In what way training and education received have influenced your role in providing services for the carers?
- How do you involve the carers in their ill relative’s care?
- What are the barriers and supports in involving the carers in their relative’s care?
- Could you describe what would be the optimal intervention for the carers in Indonesia?
- How do you think the optimal intervention can be delivered to the carers?
DEMOGRAPHIC DATA FOR CARER PARTICIPANTS

<table>
<thead>
<tr>
<th>NAME</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE</td>
<td>YEARS</td>
</tr>
<tr>
<td>GENDER</td>
<td>MALE/FEMALE</td>
</tr>
<tr>
<td>ADDRESS</td>
<td></td>
</tr>
<tr>
<td>PHONE NUMBERS</td>
<td></td>
</tr>
<tr>
<td>NAME OF SERVICE USERS</td>
<td></td>
</tr>
<tr>
<td>RELATIONSHIP WITH SERVICE USERS</td>
<td></td>
</tr>
</tbody>
</table>

DIAGNOSIS OF SERVICE USER (leave in blank if you are not sure):

DURATION OF SERVICE USER ILLNESS : YEARS ........ MONTH

MENTAL HEALTH SERVICES HAVE BEEN USED (you can choose more than one answer)

- Inpatient care in mental health hospital
- Outpatient care in mental health hospital
- Outpatient care in general hospital
- Outpatient care in general hospital
- Psychiatric clinics
- Public Health Services
- Traditional healers, mention
- Others, mention
<table>
<thead>
<tr>
<th>DEMOGRAPHIC DATA FOR SERVICE USER PARTICIPANTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>NAME :</td>
</tr>
<tr>
<td>AGE : YEARS</td>
</tr>
<tr>
<td>GENDER : MALE/FEMALE</td>
</tr>
<tr>
<td>ADDRESS :</td>
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<tr>
<td>PHONE NUMBERS :</td>
</tr>
<tr>
<td>NAME OF CARER :</td>
</tr>
<tr>
<td>RELATIONSHIP WITH THE CARER :</td>
</tr>
<tr>
<td>DURATION OF USING MENTAL HEALTH HOSPITAL SERVICES:</td>
</tr>
<tr>
<td>DIAGNOSIS (leave in blank if you are not sure) :</td>
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</table>
APPLICATION OF FRAMEWORK ANALYSIS IN THE FOCUS GROUP STUDY

PART I. FRAMEWORK ANALYSIS IN THE CARER FOCUS GROUPS

I. PHASE I: FAMILIARISATION

A. AIM:
   - To be familiar with the focus group data
   - To overview the substantive content of the data (e.g. behaviours and views of participants as well as interactions between group members such as disagreement/affirmation and the level of participation)
   - To identify recurrent topics and subjects of interest which may lead to the development of the themes

B. ACTIVITY:
   - Solely played the moderator role in all group discussions, allowing the researcher to be familiar with the data from the beginning of the data collection
   - Transcribed all transcripts, allowed the researcher to immerse in the data through listening and viewing the video recordings repeatedly
   - Translated all transcripts from English to Indonesian (n= 7), allowing the researcher to read the whole transcripts, and review the video recording as necessary
   - Studied field notes
   - Re-reading the transcripts and at the same time made notes on the document margins to record ideas
     o or topics so-called preliminary themes

C. RESULTS:
   - A long list of topics on what appears to be essential matters of interest in the data
   - An example of the result of re-reading transcript 2 is follows:
Recurrent topics and the researcher’s thoughts emerging from transcript 2

- **Journey in using mental health services:** started by seeking help from traditional healers due to the belief that mental health problems are caused by witchcrafts or demons; after years deciding to visit mental health professionals

- **Reactions in caregiving:**
  - Tiredness both physically and psychologically
  - Hardiness
  - Confusion
  - Feeling of being stigmatised
  - Wariness
  - Hopefulness
  - Gratefulness after received diagnosis
  - Acceptance as believing that the illness is God’s fate
  - Sympathy

- **What carers need from mental health hospital services:**
  - Information about medication (duration, dose, how to administer the drugs, government policy for free medication), symptoms of mental illness, progress of the individual relative’s illness, and how to use hospital services,
  - Financial support for transportation cost and free treatment
  - Recovery of ill relatives
  - Practical needs: easy access to hospital services

- **Current hospital services for carers:**
  - Education has been provided by offering repeated and superfluous topics
  - Lack of socialisation about the existing education provision
  - Barriers: distance, transportation cost.

- **Views of the carers’ involvement in the group discussion:** had opportunities to obtain inputs from others, share information, and feel ‘not alone’

- **Dynamics during the group discussion:**
  - Some carers expressed their feelings of being people who care for ill relatives for many years.
  - Some carers had opportunities to ask questions about general knowledge of mental illness to the whole group members
  - Carers shared experiences in using hospital services
  - There was disagreement with regards to the view of barrier in using hospital services. One carers maintained that distance was not an issue
II. PHASE II: CONSTRUCTING A CONCEPTUAL FRAMEWORK

A. AIM:
To construct an initial thematic framework for organising the data.

B. ACTIVITY:
Sorted out the recurring preliminary themes that emerged from the familiarisation phase, and grouped them under a number of higher and broader categories—assigned as main or key themes.

C. RESULTS:
A workable structure illustrating a hierarchy of four main themes and their subthemes.
### A Preliminary conceptual framework from carer focus groups

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
</table>
| 1. Experiences in caregiving | 1.1. Carers’ emotions associated with caregiving  
1.2. Carers’ attitudes associated with caregiving  
1.3. How carers are supported by other family members and wider community |
| 2. What carers need from mental health hospital services | 2.1. Information  
2.2. Emotional support  
2.3. Financial support  
2.4. Recovery  
   ✓ The meaning of recovery  
   ✓ Expectation associated with recovery  
2.5. Improvement of hospital physical facilities in caring for service users  
2.6. Increased professionalism of health workers in caring for service users |
| 3. Current hospital based support for carers | 3.1. Current support for meeting the carers’ needs  
✓ Information provision  
✓ Financial support  
3.2. Positive views of the current support  
✓ Attempts do exist  
✓ Increasing carers’ knowledge  
✓ Positive impacts on ill relative  
✓ Burden reduction  
✓ Positive professionals’ attitudes  
3.3. Weaknesses of the current support  
✓ Accessibility issues  
✓ Content-related issues  
✓ Discontinuing service  
✓ Unsupportive professionals’ attitudes |
| 4. How to improve support for carers | 4.1. Suggested information provision  
4.2. Suggested sharing among carers |

### III. PHASE III: INDEXING

#### A. AIMS:

To annotate and label the data to identify where themes or subthemes emerged in the initial conceptual framework

#### B. ACTIVITY:

- Read each phrase, sentence and paragraph of the whole 7 transcripts to index or detect which themes or subtheme is being mentioned/referred to within a particular section of the data as illustrated below
An illustration of indexing in the carer focus groups

Original phrase

Moderator: What do you need from mental health hospital services?

3A: For me, information of how to care for my child appropriately.
    How is it? Should I be more patience?
    Do I have to do something else to treat the child?
    I want the strategies to be explained to me, so he can recover

4A: Can he be better? If possible, let my son stay here (in this hospital)…
    I know the hospital has (day care) programmes so my son can have activities…
    he can participate… but he needs money to come regularly,
    we can’t afford the cost for transportation, yes the cost...

Indexed phrase

Moderator: What do you need from mental health hospital services? 1.1. Duration of current contact

3A: For me, information of how to care for my child appropriately.
    How is it? Should I be more patience?
    Do I have to do something else to treat the child?
    I want to be explained the strategies,
    so he can recover

4A: can he be better? If possible, let my son stay here (in this hospital)…
    I know the hospital has (day care) programmes so my son can have activities…
    he can participate… but we need money to come regularly,
    we can’t afford the cost for transportation, yes the cost...

- Refined the initial conceptual framework by restructuring the existing themes and subthemes,
  collapsed several subthemes and categories

C. RESULTS:

A refined conceptual framework of the carer focus groups exploring the needs of carers from mental health services in Indonesia

1.1. Duration of current contact

2. What carers need from mental health hospital services: information

2. What carers need from mental health hospital services: recovery

2. What carers need from mental health hospital services: financial support
refined conceptual framework of carer focus groups  
(after the implementation of the indexing phase)

<table>
<thead>
<tr>
<th>Main themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Experiences in caregiving</td>
</tr>
<tr>
<td>5.3. Emotional reactions associated with caregiving</td>
</tr>
<tr>
<td>5.4. Coping strategies in undertaking caregiving roles</td>
</tr>
<tr>
<td>2. Carer needs and expectations from mental health hospital–based services</td>
</tr>
<tr>
<td>2.1. Information</td>
</tr>
<tr>
<td>2.2. Emotional support</td>
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<tr>
<td>2.3. Financial support</td>
</tr>
<tr>
<td>2.4. Recovery for service users</td>
</tr>
<tr>
<td>2.5. Professionalism in contact with service users and carers</td>
</tr>
<tr>
<td>3. Current support for carers</td>
</tr>
<tr>
<td>3.1. Available support for carers</td>
</tr>
<tr>
<td>3.2. Positive views of current support for carers</td>
</tr>
<tr>
<td>3.3. Weaknesses of current support for carers</td>
</tr>
<tr>
<td>4. Recommendations for service improvement</td>
</tr>
<tr>
<td>4.2. Group-based emotional support</td>
</tr>
<tr>
<td>4.3. Improvement for information provision</td>
</tr>
</tbody>
</table>
IV. PHASE IV: CHARTING

A. AIM:

To summarise the essence of what the group said about a particular theme, and display them in a set of matrices

B. ACTIVITY:

- Devised four charts in which the headings were drawn from the key themes of the conceptual framework stemmed from the previous stage,
- Summarised the key points of each piece of the data that was sourced from the indexed phrases, and then transferred them to relevant cells in the charts. Here, the researcher employed the ‘whole group analysis’ approach, where the data produced by every group were treated as a whole without demarcating the contribution of each participant (Ritchie et al. 2003). The application of the approach meant each row on a thematic chart is designated for a separate group discussion. In addition, a note of which the dynamics that occurred within a group process (e.g. interactions between members or non-verbal communication) was recorded in each of the data charted.

C. RESULTS:

- Four charts, each of them referred to the emerging key themes. One of the chart is presented as follows:
A complete thematic chart of a main theme on the focus groups with carers:
Carer needs and expectations from mental health hospital–based services

<table>
<thead>
<tr>
<th>Number of focus group</th>
<th>Information</th>
<th>Emotional support</th>
<th>Financial support</th>
<th>Recovery</th>
<th>Professionalism in contact with service users and carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (Soeharto Heerdjan hospital)</td>
<td>Carers need information about strategies to care for service users. Carers also want to know the 'way out' because the service users often laugh and talk to self. Carers want to know the progress of the illness.</td>
<td>Carers want someone to listen to them e.g. professionals so they can be more patient in playing their caring role. Sometimes when visiting doctors carers talk to other carers because they need sharing stories with peers. Carers need a sharing moment as they experienced in the current focus group. The group has made the carers happy and calmed down.</td>
<td>There are cost issues to get medical treatment for service users. Carers need transportation cost so the service users can visit doctors every two weeks. For this visit, carers do not only need money for transportation but also for the service users’ snacking. At home, the service users also need to be supported financially for smoking or buying food. Carers also need money for another responsibility such as schooling of other children. Carers want the medication treatment for service users to always be free of charge. Carers also want financial support from the government to run small business.</td>
<td>Carers want their relative to recover so he/she can work like selling some products in a market or carrying people’s shopping bags to cars. Carers want the government to give places for service users’ activities at home so they are not bored, and not only spending time for sleeping and smoking. Carers also want the service users to recover so they can have friends.</td>
<td>One carer criticised hospital staff who was upset because she visited the outpatient quite late. She expected the staff to understand the long distance she had for reaching the hospital site.</td>
</tr>
<tr>
<td>2 (Soeharto Heerdjan hospital)</td>
<td>Carers want information because sometimes service users seem to be healthy or told by the doctor that they have recovered but why the users still needs visit outpatient? Carers don’t understand to an extent what the recovery means.</td>
<td>Sometimes some carers are sad and need someone to talk to.</td>
<td>The financial need of family with people with mental illnesses is double compared to those with the normal ones. These people need money for cigarette and coffee. Moreover, carers need transportation cost to go to the hospital. Sometimes carers have to change the schedule of visiting doctors because they do not have money.</td>
<td>Carers want their relative to recover. One carer said “Thank God we have a religion teaching us that every disease is curable. Maybe this is God’s will”</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Note: Sharing information among participants was apparent. Some carers asked and answered questions about some of the needed information

Note: all carers benefited from the focus groups for sharing thoughts, reducing burden and feeling ‘not alone’

Note: all participants were very enthusiastic in discussing about financial issues. They complement each other

Note: there was no disagreement among the participants when describing the expectation related to recovery of service users

Note: only one participant divulged her experience of interaction with ‘unfriendly’ health workers
<table>
<thead>
<tr>
<th>3 (Soeharto Heerdjan hospital)</th>
<th>Carers need guidance on how to manage service users at home. Carers want to learn from doctors how to manage service users so they can recover more quickly. Carers need guidance on crisis management. There are some possible causes of mental illness, such as, spirits, spell, witchcraft or stressful life events. Every significant change of service users treated in the hospital should be informed via sms immediately.</th>
<th>Carers need people to talk to, express their feelings and exchange ideas and feedbacks. After joining the focus groups, carers felt some happiness as they were able to confide in each other.</th>
<th>Hospitals should continue providing free medication for people with mental illness who were living with poor families.</th>
</tr>
</thead>
<tbody>
<tr>
<td>No note provider.</td>
<td>Note: there was disagreement about the cause of mental illness.</td>
<td>Note: all carers agreed about the benefit of focus groups for sharing thoughts, feelings and experiences in caregiving</td>
<td>Note: there was information sharing regarding the policy of free medication.</td>
</tr>
<tr>
<td>No note provider.</td>
<td>No note provider.</td>
<td>No note provider.</td>
<td>No note provider.</td>
</tr>
</tbody>
</table>
| 4 (Duren Sawit Hospital) | There should be information from nurses about the service user progression. The information should include the treatment given and what the service users need from the service. The hospital should not ring carers only when there is a problem or when need something from them. The information given should be updated. Although the service user is not progressing, carers want to know their condition regularly especially during the first week of inpatient care where seeing service users is strictly prohibited. Another question is about the cause of mental illness whether or not it is inherited by parents.  

*Note: information sharing occurred during the group discussion i.e. some carers delivered questions and responded by other carers* | One carer said: when we are confused, for example when the relative relapses, where we can talk to? Luckily some carers could ring one of the nurses privately; but how about the other carers? What carers want is that there are professionals who are ready whenever they want to talk. The hospital should ask the carers’ condition actively, and give them attention. Carers need to express feeling when their relatives are being hospitalised.  

*Note: all carers agreed about the benefit of focus groups for reducing stress because they can talk with peers* | Transportation cost has become an obstacle. Furthermore, when carers come to the hospital, they need additional money at least to buy drink. Sometimes the carers have to spend more money for tipping the security guards or administration staff as they hope the staff would provide better services to their relatives. Consequently, money for the carers’ own foods or grocery becomes minimal. Moreover the carers need money for their (relatives’) cigarettes.  

Carers wish the government could provide a specific policy for people with mental illnesses, such as issuing an insurance card that valid for life. Also, the services given should be similar with those for moneyed people.  

Some parent carer shope their children to recover. The carers expect that as the children recover, there is a job which is suitable to their ability, they can be a more confident person. | Some parent carers expect the professionals can carry out their tasks according to the standard, like the ISO standard in companies or bank services. One carer said: When we come here and the professionals greet us unfavourably, of course we can become ill while our relatives are already sick. Carers also want a forum of communication with doctors so when they have problems they can answer, they are thought of how to deal with ill relatives and they know where they can call to ring when having a problem. |

| 5 (Duren Sawit Hospital) | Carers need written information about medication for service users. Carers want to know how and when to give prescribed drugs to service users. Carers also want to know the effects of medication as it seems there is no change on the service users’ health state. Carers want to know what pills can be bought outside of hospital, especially during a crisis. Carers need information on the real cause(s) of mental illness.  

*Note:  
- All carers were enthusiastic when expressing their need of receiving information about medication during crisis.  
- There was disagreement about the cause of mental illness* | Carers need a gathering like the focus groups once a month; so they might not feel lonely in caring for relatives with mental illnesses. Carers are grateful because it turns out from the discussion that their relatives’ condition is better than they thought previously.  

*Note  
- Some carers were emotional (crying) when expressing their efforts to reduce caregiving distress, but they realised that the efforts were only useful temporarily  
- All carers agreed about the benefit of focus groups* | Although the medication given is free, carers need money for transportation cost as well as to buy drugs that are not covered by the insurance. Carers are concerned about the future of service users because the families cannot give financial support for life. Carers need money for buying food, coffee and cigarettes for service users.  

Carers expect the ill relative can be a human being even he/she continues taking medication and sometimes raging. | Carers expect the ill relative can be a human being even he/she continues taking medication and sometimes raging.  

*Note: all carers agreed about the benefit of focus groups* | NA |
| 6  | (Soeharto Heerdjan Hospital) | Carers are blind and need a lot of information about mental illness. Carers need information of how to handle or treat service users at home such as how to establish supportive communication and how to deal with hallucination. Carers also want to know the progress or the level of the recovery. Carers need information about the side effects of medication and how to handle the effect on service users. Carers need specific knowledge about the drugs prescribed and how to give the medication when relapse occurs, because service users often reject pills even though we have tried to administer them in many ways. | Carers come to the existing education provision to find those ‘in the same boat’. It is important to develop a group of families for sharing experiences in caregiving. The sharing moment in the current focus group has reduced the carers’ burden, because they know the conditions of other patients then they feel more relieved. | N/A | Carers want their relatives to be able to work or run a business. | Doctors need to establish good or friendly communication with service users, but not necessarily to the carers because they considered themselves as healthy.  
**Note:** A carer was quite emotional when expressing her expectation related to communication professional, rising her intonation when she said: do not need good communication with us, at least to our relatives |
V. **PHASE V : MAPPING AND INTERPRETATION**

1. **MAPPING**

A. **AIMS**:

- To devise categories and identify the linkage between them
- To produce descriptive accounts of all themes and subthemes generated from the study

B. **ACTIVITY**:

Developed a separate table to display the elements/dimensions and identified categories from a particular theme across the 7 cases/focus groups

- Column A was assigned for the summarised data of all cases/focus groups transferred from the constructed matrices.
- Column B was assigned for elements/dimensions identified from a particular case (so-called the phase of detection in the mapping process)
- Column C was assigned for categories, derived from a more conceptual interpretation of the identified elements/dimension (so-called the phase of categorisation in the mapping process)

- Inspected all elements/dimensions, determined for their categories and labelled into a more abstract categorisation
  - Implemented the highlighting approach in columns A and B, continued in column C to indicate which elements/dimensions were relevant to the established category as illustrated in the following table
### DESCRIPTIVE ANALYSIS OF CARER FOCUS GROUPS

**Under a key theme:**

Carer needs and expectations from mental health hospital–based services

<table>
<thead>
<tr>
<th>Data charted in the theme</th>
<th>Elements/Dimensions detected</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need information of how to care for people with mental illnesses</td>
<td>General Information of mental disorder: caregiving strategies</td>
<td></td>
</tr>
<tr>
<td>Want to know about service users’ illness progress</td>
<td>Information of service user’s mental health state</td>
<td></td>
</tr>
<tr>
<td>Want to be listened by professionals</td>
<td>Need emotional support from professionals</td>
<td></td>
</tr>
<tr>
<td>Expecting patience in caregiving</td>
<td>Emotional reaction associated with caregiving</td>
<td></td>
</tr>
<tr>
<td>Need to share stories among carers</td>
<td>Need emotional support: talking with others</td>
<td></td>
</tr>
<tr>
<td><strong>Benefit of the focus group:</strong> sharing moment</td>
<td>Sharing opportunities in the focus group</td>
<td></td>
</tr>
<tr>
<td><strong>Benefit of the focus group:</strong> calming down</td>
<td>Stress reduction during the focus group involvement</td>
<td></td>
</tr>
<tr>
<td>Need financial support for service user’s medication</td>
<td>Cost for service user’s treatment</td>
<td></td>
</tr>
<tr>
<td>Need transportation cost to visit hospital</td>
<td>Transportation cost to hospital services</td>
<td></td>
</tr>
<tr>
<td>Need money to support other family members</td>
<td>Cost for supporting service user’s activities</td>
<td></td>
</tr>
<tr>
<td>Need financial support to increase family income</td>
<td>Additional family income</td>
<td></td>
</tr>
<tr>
<td><strong>Want service user to recover</strong></td>
<td>Recovery of service user</td>
<td></td>
</tr>
<tr>
<td>Want service user to work</td>
<td>The meaning of recovery: have a job</td>
<td></td>
</tr>
<tr>
<td><strong>Activity after hospitalisation</strong></td>
<td>The meaning of recovery: engage in after-care activities</td>
<td></td>
</tr>
<tr>
<td>Want service user to make friends</td>
<td>The meaning of recovery: social contact with others</td>
<td></td>
</tr>
<tr>
<td>Upset hospital staff</td>
<td>Unexpected professional attitude</td>
<td></td>
</tr>
<tr>
<td>Expecting professionals to understand the long distance travelled to reach hospital</td>
<td>Professionalism of health workers: understanding barrier in using hospital service: distance</td>
<td></td>
</tr>
</tbody>
</table>

**Focus group1**

- Carers need information about strategies to care for service users. Carers also want to know the way out because the service users often laugh and talk to self.
- Carers want to know the progress of the illness.
- Carers also want to share their stories with other carers because they need a sharing moment as they experienced in the current focus group. The group has made the carers happy and calmed them down.
- There are cost issues to get medical treatment for service users. Carers need transportation cost so the service users can visit doctors every two weeks. For this visit, carers do not only need money for transportation but also for the service users’ snacking. At home, the service users also need to be supported financially for smoking or buying food. Carers also need money for another responsibility such as schooling of other children.
- Carers want the medication treatment for service users is always free of charge. Carers also want financial support from the government to run small business.
- Carers want their relative recovers so he/she can work like selling some products in a market or carrying people’s shopping bags to cars. Carers also want the government gives places for the service users’ activities at home so they are not bored, and not only spending time for sleeping and smoking.
- One carer criticised hospital staff who was upset because she visited the outpatient quite late. She expected the staff to understand the long distance she had to travel in reaching the hospital site.

---

### Elements/Dimensions detected

<table>
<thead>
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</tr>
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<tbody>
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<td>Data charted in the theme: Carer needs and expectations from mental health hospital–based services</td>
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<tr>
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<tr>
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</tr>
</tbody>
</table>

---

### Categories

<table>
<thead>
<tr>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Information of mental disorder: caregiving strategies</td>
</tr>
<tr>
<td>Information of service user’s mental health state</td>
</tr>
<tr>
<td>Need emotional support from professionals</td>
</tr>
<tr>
<td>Emotional reaction associated with caregiving</td>
</tr>
<tr>
<td>Need emotional support: talking with others</td>
</tr>
<tr>
<td>Sharing opportunities in the focus group</td>
</tr>
<tr>
<td>Stress reduction during the focus group involvement</td>
</tr>
<tr>
<td>Cost for service user’s treatment</td>
</tr>
<tr>
<td>Transportation cost to hospital services</td>
</tr>
<tr>
<td>Cost for supporting service user’s activities</td>
</tr>
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<td>Additional family income</td>
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<tr>
<td>The meaning of recovery: social contact with others</td>
</tr>
<tr>
<td>Unexpected professional attitude</td>
</tr>
<tr>
<td>Professionalism of health workers: understanding barrier in using hospital service: distance</td>
</tr>
</tbody>
</table>
**Focus group 2**

Carers want information because sometimes service users seem to be healthy or told by the doctor that they have recovered but why the users still need visit outpatient? Carers don’t understand of what and how extent the recovery means.

We’ve never got information whether there is a medical record for schizophrenia and bipolar like in lung disease or cancer which have stage 1 and stage 2. We want to know the stage of our child illness and the drug dose required. We don’t understand the drugs given including the name. We are also concern whether our ill children be drug addicted as we don’t know when the doctor will stop the medication.

In addition, we want to know how to care mentally ill people such as how to bring our ill children to the hospital during relapses, whether they need sports and whether we have to be honest about the illness to the person who wants to be married. It would be helpful if we get information of how to get free health insurance, and this is more appropriately given by the government.

Sometimes some carers are sad and need someone to talk to. The financial need of family with people with mental illnesses is double compared to those with the normal ones. These people need money for cigarette and coffee. Moreover, carers need transportation cost to go to the hospital. Sometimes carers have to change the schedule of visiting doctors because they do not have money.

The government should build hospitals nearby our houses so we only come to this hospital for inpatient service. Visiting this hospital is expensive because we don’t have any income at all. We also wish that the government guarantees our ill relatives can receive free medication in any hospital in this town, for example by issuing a health card which can be used in all hospitals.

Carers want their relative to recover. One carer said ‘Thank God we have a religion teaching us that every disease is curable. Maybe this is God's will’

**Need information about the meaning recovery of people with mental illnesses**

**Need information about the progress of mental illness**

**Do not understand about the medication given**

**Do not know the effect of medical treatment**

**Want to know how to care people with mental illnesses**

**Need information about health insurance**

**Sadness associated with caregiving**

**Want service user to recover**

**Belief that God will cure people with mental illnesses**

**General information of mental disorder; concept of recovery**

**General information of mental disorder; progression**

**Information about medication and other possible treatments**

**General information of mental disorder; caregiving strategies**

**Information about hospital regulation**

**Emotional reaction associated with caregiving**

**Need emotional support: talking with others**

**Need emotional support: sharing in peer group**

**Need emotional support: talking with family members or other carers**

**Benefit of the focus group: Happiness**

**Benefit of the focus group: express feeling**

**Stress reduction during the focus group involvement**

---

**Focus group 3**

Carers need guidance of how to manage service users at home. Carers want to learn from doctors how to manage service users so they can recover more quickly. Carers need guidance of crisis management. There are some possible causes of mental illness such as, spirits, spell, witchcraft or stressful life events. Every significant change of service users treated in the hospital should be informed via sms immediately.

Carers need people to talk to, so they can express their feelings, exchange ideas and feedbacks. After joining the focus groups, carers felt some happiness as they were able to confide in each other.

Carers need guidance of how to manage service users at home. Carers want to learn from doctors how to manage service users so they can recover more quickly. Carers need guidance of crisis management. There are some possible causes of mental illness such as, spirits, spell, witchcraft or stressful life events. Every significant change of service users treated in the hospital should be informed via sms immediately.

Carers need people to talk to, so they can express their feelings, exchange ideas and feedbacks. After joining the focus groups, carers felt some happiness as they were able to confide in each other.

**Need to know how to manage people with mental illnesses at home**

**Want service user to recover**

**View about cause of mental illness**

**Want information about the progress of the illness**

**Want immediate information provision**

**Want to talk with other family members and other carers**

**Want to talk to express feeling**

**Want to share ideas**

**Benefit of the focus group: Happiness**

**Benefit of the focus group: express feeling**

**General information of mental disorder: caring strategies**

**Recovery of service user**

**General information of mental disorder: causes**

**Information of service user’s mental health state**

**Suggestion for information provision**

**Need emotional support: talking with others**

**Need emotional support: sharing in peer group**

**Stress reduction during the focus group involvement**

---
Focus group 4

There should be information from nurses about the service user progression. The information should include the treatment given and what the service users need from the service. The hospital should not ring carers only when there is a problem or when something is told to them. The information given should be updated. Although the service user is not progressing, carers want to know their condition regularly, especially during the first week of inpatient care where seeing service users is strictly prohibited. Another question is about the cause of mental illness whether or not it is inherited by parents.

One carer said: when we are confused, for example when the relative relapses, where can we talk to? Luckily some carers could ring one of the nurses privately; but how about the other carers? What carers want is that there are professionals who are ready whenever they want to talk. The hospital workers should ask the carers' condition actively, and give them attention. Carers need to express feelings when their relatives are being hospitalised.

Transportation cost has become an obstacle. Furthermore, when carers come to the hospital, they need additional money at least to buy food. Sometimes the carers have to spend more money for tipping the security with the hope the staff would provide better services to their relatives. Consequently, money for the carers' own foods or grocery becomes minimal. Moreover, the carers need money for their (relatives') cigarettes.

Carers wish the government could provide a specific policy for people with mental illnesses, such as issuing an insurance card that valid for life. Some parent carers hope their children recover. The carers expect that as the children recover, there is a job which is suitable to their ability, they can be a more confident person.

Some parent carers expect the professionals can carry out their tasks according to the standard, like the ISO standard in companies or bank services. One carer said: When we come here and the professionals greet us unfriendly, of course we can become ill while our relatives are already sick.

Carers also want a forum of communication with doctors so when they have problems they can answer. They are thought of how to deal with ill relatives and they know where they can call to get professional help when having a problem.
### Focus group 5

<table>
<thead>
<tr>
<th>Carers need written information about medication for service users. Carers want to know how and when to give prescribed drugs to service users. Carers also want to know the effects of medication as it seems there is no change on the service users' health state. Carers want to know what pills can be bought outside of hospital, especially during a crisis. Carers need information on the real cause(s) of mental illness.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Although the medication given is free, carers need money for transportation costs as well as to buy drugs that are not covered by the insurance. Carers are concerned about the future of service users because the families cannot give financial support for life. Carers need money for buying food, coffee and cigarettes for service users.</td>
</tr>
<tr>
<td>Carers expect the ill relative can be a human being even he/she continues taking medication and sometimes raging. Carers need a gathering like the focus groups once a month; so they might not feel lonely in caring for relatives with mental illnesses. Carers are grateful because it turns out from the discussion that their relatives' condition is better than they thought previously.</td>
</tr>
</tbody>
</table>

### Focus group 6

<table>
<thead>
<tr>
<th>Carers are blind and need a lot of information about mental illness. Carers need information of how to handle or treat service users at home such as how to establish supportive communication and deal with hallucination. Carers also want to know the progress or the level of the recovery. Carers need information about the side effects of medication and how to handle the effect on service users. Carers need specific knowledge about the drugs prescribed and how to give the medication when relapse, because service users often reject pills even though we have tried many ways.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers come to the existing education provision to find those 'on the same boat'! It is important to develop a group of families for sharing experiences in caregiving. The sharing moment in the current focus group has reduced the carers' burden, because they know the conditions of other patients then they feel more relieved.</td>
</tr>
<tr>
<td>Carers want their relatives are able to work or run a business. Doctors need to establish good or friendly communicate with service users, but not necessarily to the carers because they considered themselves as healthy</td>
</tr>
</tbody>
</table>

---

<table>
<thead>
<tr>
<th>Need information about medication</th>
<th>Need information about the cause of mental illness</th>
<th>Need money for transportation cost to hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Want to know how and when to give medication</td>
<td>Need information of how to handle service user at Home</td>
<td>Need money to medication uncovered by insurance</td>
</tr>
<tr>
<td>Want to know the effects of medication</td>
<td>Need to know how to build supportive communication</td>
<td>Need financial support</td>
</tr>
<tr>
<td>Need information of how to administer medication during crisis</td>
<td>Need information about the effects of medication</td>
<td>Need money for service user’s daily expenses</td>
</tr>
<tr>
<td>Need emotional support</td>
<td>Benefit of the focus group: not lonely</td>
<td>The meaning of recovery: continue medication and sometimes relapses</td>
</tr>
<tr>
<td>Benefit of the focus group: grateful</td>
<td>Need emotional support: sharing in peer groups</td>
<td>Need emotional support: sharing in peer groups</td>
</tr>
</tbody>
</table>

---

<table>
<thead>
<tr>
<th>Information about medication and other possible treatments</th>
<th>General information of mental disorder: causes</th>
<th>Transportation cost to hospital services</th>
</tr>
</thead>
<tbody>
<tr>
<td>General information of mental disorder: caregiving strategies</td>
<td>Need of financial support</td>
<td>Need of financial support</td>
</tr>
<tr>
<td>General information of mental disorder: how to build supportive communication</td>
<td>Cost for supporting service user’ activities</td>
<td>The meaning of recovery: having a job</td>
</tr>
<tr>
<td>Information about medication and other possible treatments</td>
<td>Information about service user’s mental health state</td>
<td>Stress reduction during the focus group involvement</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Need emotional support</th>
<th>Need emotional support: sharing in peer groups</th>
<th>Stress reduction during the focus group involvement</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Benefit of the focus group: reducing burden of care</td>
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</tr>
<tr>
<td>Expecting service users to have a job</td>
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</tr>
<tr>
<td>Expecting professionals to build friendly communication to service user</td>
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<td>Need emotional support: sharing in peer groups</td>
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</tbody>
</table>
**Focus group 7**

Carers need information about medication including the effect on menstruation, non-prescribed drugs that can be bought during crisis and duration in taking the medication. Carers suggested a hotline service so they can consult to doctor about the prescribed drugs.

Carers need information about the progress of the illness.

Carers need information about rehabilitation centre to live in; including the costs, location and facilities available. Carers need information of how the service users can express their talent in art.

In general, getting together in the current focus group could reduce carers’ stress because they could talk, laugh and express concerns with families having the same problems, feelings and experiences in caregiving. Carers expected similar gatherings to be held in the future.

Carers need financial support to cover expenses such as transportation costs to bring service users to hospital, clothing and food for the service users, and sometimes additional treatment required like injections and medication which is not covered in the free medication policy.

After hospitalisation, service users need a place outside home, supported by a lot of different activities so they are not dependent upon their families.

<table>
<thead>
<tr>
<th>Need information about the effect of medication</th>
<th>Need information about the duration of medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need information about the progress of the illness</td>
<td>Need information about rehabilitation services in the community</td>
</tr>
</tbody>
</table>

**Benefit of the focus group**: reducing stress

**Benefit of the focus group**: sharing opportunities

**Benefit of the focus group**: express feelings

**Financial support**
- Transportation cost to bring service users to hospital
- Cost for service user's daily expenses
- Cost for other treatments

**Need of aftercare services in the community**

**Information about medication and other possible treatments**

**Information of service user's mental health state**

**Aftercare services**

**Stress reduction through the focus group involvement**

**Sharing opportunities in the focus group**

**Need emotional support: sharing in peer group**

**Need of financial support**
- Transportation cost to hospital services
- Cost for supporting service user's activities
- Cost for service user's treatment

**The meaning of recovery: engage in after-care activities**
The mapping procedures were continued to investigate all materials in column C and made a decision about what categories to be used for describing each subtheme. Relevant categories were maintained and the irrelevant categories were eliminated. Finally this activity generated a set of descriptive classifications of data in one subtheme.

An example of this process is provided below in the categories related to carers’ need of emotional support recorded in column C under the key theme of carer needs and expectations from mental health hospital–based services.

Firstly, grouped and characterised by the similar or recurrent categories relating to the need of emotional support:

1. Need emotional support
2. Need emotional support: talking with others
3. Need emotional support: talking with others
4. Need emotional support: talking with others
5. Need emotional support: talking with others
6. Need emotional support: talking with others (family members and carers)
7. Need emotional support: talking with others (family members and carers)
8. Need emotional support: sharing in peer group
9. Need emotional support: sharing in peer group
10. Need emotional support: sharing in peer group
11. Need emotional support: sharing in peer group
12. Need emotional support from professionals
13. Need emotional support: talking with professionals
14. Need emotional support: talking with professionals
15. Sharing opportunities in the focus group
16. Sharing opportunities in the focus group
17. Stress reduction during focus group involvement
18. Stress reduction during focus group involvement
19. Stress reduction during focus group involvement
20. Stress reduction during focus group involvement
21. Stress reduction during focus group involvement
22. Emotional reaction associated with caregiving
23. Emotional reaction associated with caregiving

- Secondly, summarised all the categories listed in the previous step:

Five categories that were relevant to the need of emotional support were identified and each of them was recorded in different features. One category which was irrelevant was also indentified but recorded without any colour/characteristic (see the last category below):

 ✓ Need emotional support: talking with others (family members and carers)
 ✓ Need emotional support: sharing in peer group
 ✓ Need emotional support: talking with professionals
 ✓ Sharing opportunities in the focus group
 ✓ Stress reduction during focus group involvement
 ✓ Emotional reaction associated with caregiving

Thirdly, determined the categories to be used and established a descriptive categorisation

- Maintained the five recurrent and relevant categories
- Groupied some of the similar categories into one category
- Discharged one category which was irrelevant to the description of the need of emotional support for carers:
The need of emotional support for carers:

- Need emotional support: talking with family members, other carers and professionals
- Need emotional support: sharing in peer group
- Value of the focus group involvement: Sharing opportunities and stress reduction

- Finally, employing an approach of categorisation for another subtheme under the same key theme (i.e. the need of carers for information, financial support, recovery of service user, and professionalism of health workers).

C. RESULTS:

- The application of the categorisation approach on all subthemes and key themes resulted in a general description of the whole findings:
I. Experiences in caregiving

1. Emotional reactions association with caregiving
   - Negative emotional responses (feeling of shame, stigmatisation, sadness, distressed, frustration, tiredness, worried, confusion, resentment and anger)
   - Positive emotional responses (gratefulness and compassion for service users)

2. Coping strategies in undertaking caregiving roles
   - Strategies which might be supportive to service users (detecting early signs of mental illness, managing the illness symptoms and maintaining good relationship with service users)
   - Strategies which could be disadvantageous for service users (restricting service users form social contacts)

II. Carer needs and expectations from mental health hospital-based services

1. Information
   - General information of mental disorders (e.g. causes, symptoms, progression, and how to care for people with the illnesses-including supportive communication with the service users)
   - Information relating to service users’ mental health state
   - Information about medication and other possible treatments
   - Information about hospital regulations

2. Emotional support
   - Talking with other family members, carers, and health professionals
   - Need emotional support: sharing in peer group
   - Involvement in the focus groups for sharing opportunities and stress reduction

3. Financial support
   - Cost for supporting service users’ daily activities
   - Cost for service users’ treatment
   - Transportation cost to hospital services
   - Financial support for other family members

4. Recovery for service users
   - having a job
   - Social contacts with others
   - involved in after-care activities
   - individualised recovery
   - continue taking medication and sometimes exhibiting symptoms

5. Professionalism in contact with service users and carers
   - Open communication with service users
   - Understanding
   - Encouraging
   - Focused on relatives’ wellbeing
   - Equal service
   - Sufficient time for interaction
III. Current support for carers

1. Available support for carers
   - Information provision about mental illness (e.g. cause, symptoms and strategies for caring for people with the illness)
   - The carer group education was conducted every month at one hospital, and every six months at another hospital
   - Written information (e.g. flyers or booklets about mental health problems)

2. Positive views of current support for carers
   - Improvement of knowledge about mental illness among few carers

3. Weaknesses of current support for carers
   - Difficulties to access information from the mental health hospitals
     - Distance between the hospital and the carers’ residence, problems associated with transport costs, and lack of time
     - Lack of socialisation
   - The extent of information given by the health professionals
     - Insufficient information
     - Very brief Information
   - The content of the given information
     - Similar unneeded information

IV. Recommendations for service improvement

1. Group-based emotional support
   - Strategies of group-based emotional support
     - opportunities to express feeling
     - In conjunction with information provision
     - use collaborative approach
     - involve information sharing about caring strategies
   - Time for group-based emotion support
     - One hour in every month
   - Setting
     - Hospital
   - People involved
     - The optimum number about 10 carers
     - When carers would lead the meeting, a mental health professional should also be present to observe
   - Anticipated barriers
     - Time constraints and transportation costs (financial constraints)
2. Improvement for information provision

✓ **Strategy**
  - face-to-face interaction
  - Individualised approach during consultation
  - Group-based education: delivering various and non-repetitive topics, using lay language, effective announcement, extra time for sharing thoughts and experiences

✓ **Time of delivery**
  - At the beginning contact with health professionals
  - Group-based education: following the existing group education (i.e. once in a month from 10-12 am)

✓ **Setting**
  - Hospital

✓ **People involved**
  - 10-40 carers in one group

✓ **Anticipated barriers**
  - Attrition issues

2. INTERPRETATION

A. **AIMS**: to interpret data as a whole

B. **ACTIVITY**:

  - Detected for associations between the key substantive findings systematically (i.e. the generated themes surrounding the needs of Indonesian carers from the view of carer participants). This was accomplished by detecting explicit information of the connections from the participants as well as implicit associations derived from the data
  - Constructed central chart to portray the identified associations between the themes

C. **RESULTS**:

  - A chart which describes the association between themes
  - Explanation of the substantive findings of the carer focus groups exploring the needs of carers from mental health hospital services in Indonesia
Relationships among the themes emerged from carer focus groups exploring Carer needs from mental health hospital services

1. Experiences of caregiving
   - Emotional reactions associated with caregiving
   - Coping strategies in undertaking caregiving roles

2. Carer needs and expectations from mental health hospital–based services
   - Information
   - Emotional support
   - Financial support
   - Recovery of service user
   - Professionalism in contact with service users and carers

3. Current support for carers
   - Positive views of the current support
   - Weaknesses of the current support

4. Suggested improvement in services for carers
   - Improvement for information provision
   - Group-based emotional support

Attempts to Meet the Carer’s needs
From the perspectives of carers, the experience of caring for a person with a serious mental illness has resulted in a number of negative emotional responses, though a few positive responses were also revealed. Likewise, some coping strategies were identified to describe the carers’ endeavours in playing their caring role (Theme 1). The discussions of the caregiving experiences led to the identification of carer needs and expectations from mental health hospital services (Theme 2). It was found that the current services have tried to meet some of the needs, but these are suffering from limitations (Theme 3). Therefore, improvement of support for carers was suggested, especially for fulfilling the needs of information and emotional support provision (theme 4).
In general, the application of framework analysis in the service focus groups was similar to the analysis in the carer focus groups (PART I). For this reason, some procedures (i.e. aims and activities) presented in this part will not be given in details, but the reader can refer to the description in the PART I.

I. PHASE I: FAMILIARISATION

A. AIM : Similar to Part I

B. ACTIVITY: Similar to Part I, except the number of transcripts translated (n=2)

C. RESULTS :

A long list of topics on what appears to be essential matters

An example of the result of re-reading transcript 2 of the service user focus group is presented as follows
<table>
<thead>
<tr>
<th>Recurrent topics and the researcher’s thoughts emerging from transcript 2 of service user focus groups</th>
</tr>
</thead>
</table>
| ✓ **What carer needs from mental health hospital services**  
  - **Emotional support**  
    - Reducing carers’ distress/burden  
  - **Financial support**  
    - Financial support for service users  
    - Cost for service users’ daily activities  
    - Transportation cost to mental health service  
  - **Information**  
    - Progress of illness  
    - Medication and other treatment given  
    - How to care for service users  
    - Regulation to use hospital services  
  - **Supportive professional-carer relationship**  
  - **Recovery of service users**  |
| ✓ **Service users’ need and expectation**  
  - **Expectation to families**  
    - Frequent visits during hospitalisation  
  - **Expectation to hospital services**  
    - Private space for communication with carer  
    - Communication facilities (e.g. phone)  |
| ✓ **The views of service users about caring for a person with mental illness**  
  - **Carers’ emotions associated with caregiving**  
    - Exhaustion  
    - Compassion  
    - Caring  
    - Distress  
  - **Carers’ responses**  
    - Limiting interaction with service users  
    - Caring for service users  
    - Helping service users to get medical treatment  
    - Being critical for service users  |
| ✓ **View about current hospital services**  
  - **Positive views**  
    - Free medication policy  
    - Open communication from professionals  
  - **Weaknesses**  
    - Limited hospital contact with carers  
    - Discontinue services in community  
    - Distance issues  |
| ✓ **Dynamics during the group discussion:**  
  - Some service user participants talked incoherently, therefore  
    The moderator often focused the discussions.  
  - Sharing information/knowledge was apparent, especially when a service user  
    Asked questions to other group members about the illness she had. |
II. PHASE II : CONSTRUCTING A CONCEPTUAL FRAMEWORK

A. AIM : Similar to Part I

B. ACTIVITY: Similar to Part I

C. RESULTS:

A workable structure illustrating a hierarchy of four main themes and their subthemes

A Preliminary conceptual framework from service users focus groups

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
</table>
| 1. The views of service users about caring for a person with a mental illness | 1.1. Carers’ responses  
  ✓ Helping service users to receive medical treatment  
  ✓ Looking after service users  
  ✓ Limiting interaction with service users  
  1.2. Carers’ emotions associated with caregiving |
| 2. What carer needs from mental health hospital services               | 2.1. Information  
  2.2. Emotional support  
  2.3. Financial support  
  ✓ Financial support for service user  
  2.4. Recovery of service user  
  2.5. Supportive professional-carer relationship |
| 3. Views about current hospital services                                | 3.1. Positive views  
  3.2. Weaknesses |
| 4. Recommendations for service improvement                             | 4.1. Improvement for information provision |
| 5. Service users’ need and expectation                                  | 5.1. Expectation to families  
  5.2. Expectation to hospital services |
III. PHASE III: INDEXING

A. AIMS : Similar to Part I

B. ACTIVITY :

- Read each phrase, sentence and paragraph of the whole 2 transcripts to index or detect which themes or subtheme is being mentioned/referred to within a particular section of the data. The indexing procedure was similar to the indexing in the carer focus groups (Part I)
- Refined the initial conceptual framework by restructuring the existing themes and subthemes, collapsed several subthemes and categories

C. RESULTS :

A refined conceptual framework of the service user focus groups exploring the needs of carer needs from mental health hospital services in Indonesia

<table>
<thead>
<tr>
<th>Main themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. The views of service users about caring for a person with a mental illness</td>
</tr>
<tr>
<td>1.1. Emotional reactions associated with caregiving</td>
</tr>
<tr>
<td>1.2. Coping strategies in undertaking caregiving roles</td>
</tr>
<tr>
<td>II. Carer needs and expectations from mental health hospital–based services</td>
</tr>
<tr>
<td>2.1. Information</td>
</tr>
<tr>
<td>2.2. Emotional support</td>
</tr>
<tr>
<td>2.3. Financial support</td>
</tr>
<tr>
<td>2.4. Recovery of service users</td>
</tr>
<tr>
<td>2.5. Professionalism in contact with service users and carers</td>
</tr>
<tr>
<td>III. Current support for carers</td>
</tr>
<tr>
<td>3.1. Positive views of current support for carers</td>
</tr>
<tr>
<td>3.2. Weaknesses of current support for carers</td>
</tr>
<tr>
<td>IV. Recommendations for service improvement</td>
</tr>
<tr>
<td>4.1. Improvement for information provision</td>
</tr>
<tr>
<td>V. Service users’ needs and expectations from carers and hospital services</td>
</tr>
</tbody>
</table>
IV. PHASE IV: CHARTING

A. AIM:

To summarise the essence of what the group said about a particular theme, and display them in a set of matrices.

B. ACTIVITY:

- Devised five charts in which the headings were drawn from the key themes of the conceptual framework stemming from the previous stage (each chart signifies one key theme comprising of a number of columns which represent the subthemes, and 2 rows which represent group of the study).

- Summarised the key points of each piece of the data that was sourced from the indexed phrases, and then transferring them to relevant cells in the charts.

C. RESULTS:

Five charts, each of them referring to the emerging key themes. One of the chart is presented as follows:
A complete thematic chart of a main theme on the service user focus groups: Carer needs and expectations from mental health hospital–based services

<table>
<thead>
<tr>
<th>Number of focus group</th>
<th>Information</th>
<th>Emotional support</th>
<th>Financial support</th>
<th>Recovery</th>
<th>Professionalism in contact with service users and carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (Soeharto Heerdjan hospital)</td>
<td>Carers need information about the progress of the service user’s illness, the treatment given, and the service user’s mental health state. Carers also need to know the hospital regulations such as when they are allowed to see service users during inpatient visits.</td>
<td>Carers need mutual attachment from doctors and nurses. There should be good communication and a horizontal relationship between carers and professionals so they are connected and everything can become easy. Professional hospitality is needed because it is conducive for healing. The sharing moment in the current focus groups should be held in this hospital for families.</td>
<td>The major need is money. What carers need is money to meet everyday life, especially when service users are being hospitalised. When the carers come to visit the service users, they give money for buying snacks. It is also a big issue because carers also have other family members to be taken care of such as school children who need money for their books, pens, clothing, and food. Service users need money for communication with carers who are living far away from the hospital.</td>
<td>All health care workers need to support each other for the service users’ recovery. What is needed is healing. Our carers want recovery so we do not need to go back to hospital anymore.</td>
<td>N/A</td>
</tr>
</tbody>
</table>

*Note: the discussion gave opportunities to the members to question and share knowledge about mental illness*

*Note: all service user participants voiced the need of financial support*
| 2 (Duren Sawit Hospital) | Carers need detailed information about their relatives’ illness which is written in the medical record including the complaints, treatment given, progress of the illness or mental health state, and drugs given. Carers should be given information of how to treat their ill relative at home and to be close with the service user through frequent visits.

*Note: A service user cried when expressing the need of carers to be close with the ill relative through frequent visits.* |
| Hospital workers need to deliver proper approach to carers so they can be harmonious with the professionals and calm down. Sometimes carers get emotions which triggers service users to relapse.

*One service user looked upset when describing her sibling who was so emotional that influenced her relapse.* |
| Carers should be assisted economically so they can take care of service users and able to carry out their own activities. Carers need money for buying food for service users. |
| Our carers want us to live in a perfect life or live in peace, meaning that there are no dispute between us and other family members. Carers also want their relative is progressing, have passion to work and these are connected with our recovery. |
| Professionals need to be friendly to carers as well as and the service users. |
V. PHASE V: MAPPING AND INTERPRETATION

1. MAPPING
   A. AIMS: Similar to Part I
   B. ACTIVITY: Similar to Part I

The application of the highlighting approach is illustrated in the following table
### DESCRIPTIVE ANALYSIS OF SERVICE USERS FOCUS GROUPS

Under a key theme:  
**Carer needs and expectations from mental health hospital–based services**

<table>
<thead>
<tr>
<th>Data charted in the theme: Carer needs and expectations from mental health hospital–based services</th>
<th>Elements/Dimensions detected</th>
<th>Categories</th>
</tr>
</thead>
</table>
| **Focus group 1** | Need information about the progress of the service user’s illness  
**Need information about the treatment given**  
**Need to know hospital regulation**  
**Need mutual carer-professional relationship**  
**Professionals need to build good communication with carers**  
**Professional need to show hospitality to encourage recovery**  
**Carers need to share with peers**  
**Financial support is very important**  
**Carers need money for service users’ treatment**  
**Carers need money for service users’ food**  
**Carers need money for supporting other family members**  
**Service users need money for communications with relatives**  
**Professionals should support recovery of service users**  
**Carers want service users to recover**  
**Recovery means no need hospitalisation anymore** | **Information of service user’s mental health state**  
**Information about medication and other possible treatments**  
**Information about hospital regulation**  
**Professionalism of health workers: mutual relationship with carers**  
**Professionalism of health workers: open communication with carers**  
**Professionalism of health workers: hospitality**  
**Need emotional support: sharing with peers**  
**The need of financial support**  
**Cost for supporting service user’s activities**  
**Cost for service user’s treatment**  
**Cost for other family members**  
**The need of service users: communication with relatives**  
**The need of recovery of service user**  
**The meaning of recovery: no need hospitalisation** |

**Carers need information about the progress of the service user’s illness**, the treatment given, and the service user’s mental health state. Carers also need to know the hospital regulation such as when they are allowed to see service users during inpatient visits.

Carers need mutual attachment from doctors and nurses. There should be good communication and horizontal relationship between carers and professionals so they are connected and everything can become easy. Professional hospitality is needed because it is conducive for healing. The sharing moment in the current focus groups should be held in this hospital for families.

The major need is money. What carers need is money to meet everyday life, especially when service users are being hospitalised. When the carers come to visit the service users, they give money for buying snacks. It is also a big issue because carers also have other family members to be taken care of such as school children who need money for their books, pens, clothing, and food. Service users need money for communication with carers who are living far away from the hospital.

All health care workers need to support each other for service users’ recovery. What is needed is healing. Our carers want recovery so we do not need to go back to hospital anymore.
### Focus group 2

Carers need detailed information about their relatives' illness which is written in the medical record including the complaints, treatment given, progress of the illness or mental health state, and drugs given. Carers should be given information of how to treat their ill relative at home and to be close with the service user.

Hospital workers need to deliver proper approach to carers so they can be harmonious with the professionals and calm down. Sometimes carers get emotions which triggers service users to relapse.

Carers should be assisted economically so they can take care of service users and able to carry out their own activities. Carers need money for buying food for service users.

Our carers want us to live in a perfect life or live in a peace meaning that no dispute between us and other family members. Carers also want their relative is progressing, have passion to work based on their ability and these are connected with our recovery.

Professionals need to be friendly to carers as well as and the service users.

| Need information about the illness progress | Need information about the treatment given |
| Need information of how to treat service users at home | Need information of how to be close with service users through frequent visits |
| Carers need professional help to calm down | Need harmonious carer-professional relationship |
| Emotional carers can trigger relapse | |
| Financial support for taking care of service users | Financial support for carers own needs |
| Carers want service users have peaceful life | Money for service users’ food |
| Carers want service users life harmonious with other family members | |
| Carers want service users want to work | Carers want service users to recover |
| Professionals should be friendly to carers | |
| Professionals should be friendly to service users | |

Service user’s mental health state information about medication and other possible treatments
General information of mental disorder: caregiving strategies

Need emotional support
Professionalism of health workers: harmonious relationship with carers

Cost for service user’s treatment
Cost for carer own needs
Cost for supporting service user’s activities

The need of recovery of service user
The meaning of recovery: service user lives harmonious with others
The meaning of recovery: service user progresses state
The meaning of recovery: harmonious state

Professionalism of health workers: open communication with carers
Professionalism of health workers: open communication with service users
The mapping procedures were continued to investigate all materials in column C and made a decision about what categories to be used for describing each subtheme. Relevant categories were maintained and the irrelevant categories were eliminated. Finally this activity generated a set of descriptive classifications of data in one subtheme.

An example of this process is provided below in the categories related to the need of financial support recorded in column C under the key theme of carer needs and expectations from mental health hospital–based services.

**Firstly**, grouped and characterised similar or recurrent categories relating to the need of emotional support:

1. Cost for supporting service user's activities
2. Cost for supporting service user’s activities
3. Cost for service user's treatment
4. Cost for service user’s treatment
5. The need of financial support
6. Cost for other family members
7. Cost for carer own needs

**Secondly**, summarised all the categories listed in the previous step:

- Five categories that were relevant to the need of emotional support were identified and each of them was recorded in different features.

1. Cost for supporting service user's activities
2. Cost for service user's treatment
3. The need of financial support
4. Cost for other family members
5. Cost for carer own needs

**Thirdly**, determined the categories to be used and established as a descriptive categorisation:

- Maintained the five recurrent relevant categories, rearranged them into a hierarchy of subthemes and its categories.
The need of financial support:

1. Cost for service user's treatment
2. Cost for supporting service user's activities
3. Cost for carer own needs
4. Cost for other family members

Finally, employed an approach of categorisation for another subtheme under the same key theme (i.e. the need of carers for information, financial support, recovery of service user, and professionalism in contact with carers and service users).

C. RESULTS:

The application of the categorisation approach on all subthemes and key themes resulted in a general description of the whole findings:
I. The views of service users about caring for a person with a mental illness

1. Emotional reactions associated with caregiving
   ✓ Exhaustion
   ✓ Distress
   ✓ Disappointment
   ✓ Compassion
   ✓ Caring

2. Coping strategies in undertaking caregiving roles
   ✓ Limiting interaction with service users
   ✓ Caring for service users
   ✓ Helping service users to get medical treatment

II. Carer needs and expectations from mental health hospital–based services

1. Information
   ✓ General knowledge of mental disorder: caregiving strategies-including how to be close with service user through frequent visits
   ✓ Service users’ mental health state
   ✓ Medication and other possible treatment
   ✓ Hospital regulation

2. Emotional support
   ✓ Reducing carers’ distress/burden

3. Financial support
   ✓ Cost for service user’s treatment
   ✓ Cost for supporting service user’s activities
   ✓ Cost for carer own needs
   ✓ Cost for other family members

4. Recovery of service users
   ✓ Progressing state
   ✓ Willingness to work
   ✓ No need for hospitalisation
   ✓ Harmonious relationship with others

5. Professionalism in contact with service users and carers
   ✓ Open communication with carers
   ✓ Equal relationship (horizontal relationship) between professional and carer
III. Views about current support carers

1. Positive views
   ✓ Free medication policy
   ✓ Open communication by professional

2. Weaknesses
   ✓ Limited hospital contacts with carers
   ✓ Lack of socialisation of the offered services
   ✓ Distance issues
   ✓ Discontinue services in community

IV. Recommendation for service improvement

V. Service users’ need and expectation from carers and hospital services

1. Expectation from carers
   ✓ Adequate attention during hospitalisation

2. Expectation from hospital services
   ✓ Privacy for communication with carer
   ✓ Facilities for communication with relatives
   ✓ Improvement in the fulfilment of basic needs (e.g. clothing, food)
2. INTERPRETATION

A. AIMS: to interpret data as a whole

B. ACTIVITY:

- Detected for associations between the key substantive findings systematically (i.e. the generated themes surrounding the needs of Indonesian carers from the view of service user participants). This was accomplished by detecting explicit information of the connections from the participants as well as implicit associations derived from the data
- Constructed central chart to portray the identified associations between the themes

C. RESULTS:

- A chart which describes the association between themes
- Explanation of the substantive findings of service user focus groups exploring the needs of carers from mental health hospital services in Indonesia
Relationships among the themes emerged from service user focus groups exploring
Carer needs from mental health hospital services

Theme 1: The views of service users about caring for a person with a mental illness
- Emotional reactions associated with caregiving
- Coping strategies in undertaking caregiving roles

Theme 2: Carer needs and expectations from mental health hospital–based services
- Information
- Emotional support
- Financial support
- Recovery for service users
- Professional in contact with service users and carers

Theme 3: Views about current support carers
- Weakness

Theme 5: Service users’ need and expectation from carers and hospital services
- Need and expectation from carers
- Need and expectation from hospital services

Theme 4: Recommendation for service improvement
From the perspectives of service users, the experience of caring for a person with a serious mental illness resulted in more negative rather than positive emotional responses. Also, the service users found that sometimes their carers show coping strategies which were disadvantageous for the ill individuals (Theme 1). The discussion of the service users’ views about caring for mentally ill people led to the identification of what carers need from mental health hospital services (Theme2). To which extent the current services had met the carer needs was in question because they are delivered with many limitations (theme3). Therefore, improvement of the services is required (Theme 4). In addition, the focus groups with service users could identify what they expected from their carers and hospital services (Theme 5), and these should also be responded by the services in the country.
APPLICATION OF FRAMEWORK ANALYSIS IN
THE PROFESSIONAL INTERVIEWS

I. PHASE: FAMILIARISATION

A. AIM:

- To be familiar with or immerse in the data for an in-depth cognisance
- To overview the substantive content of the data (e.g. attitudes, behaviours, motivations or views of participants)
- To identify recurrent topics and subjects of interest which may lead to the development of the themes

B. ACTIVITY:

- Solely interviewed all participants, allowing the researcher to be familiar with the data from the beginning of the data collection process
- Transcribed the majority of interviews, allowing the researcher to immerse in the data through listening the recordings repeatedly
- Translated all transcripts from English to Indonesian (n= 24), allowing the researcher to read the whole transcripts, and re-listen the recordings as necessary
- Studied field notes
- Re-reading the transcripts and at the same time made notes on the document margins to record ideas or topics so-called preliminary themes

C. RESULTS:

- A long list of topics what appears to be essential matters of interest in the data

An example of the result of re-reading transcript 4 is presented as follows
Recurrent topics and the researcher’s thoughts emerging from transcript 4

✓ The purpose of interaction:
- To inform carers about service user’s condition
- To provide information but little opportunities carers can discuss/express their concerns
- To carry out assessment of service user- focus on professional needs
- To provide information –do carers always need information? –carers seemed to be subordinate

✓ How the interactions were held?
- 1 hour : Length of time for interaction
- Unaccompanied by service user- the aim of seeing carers without the service user-for calming down and promoting privacy of the carers
- Efforts have been made to contact carers Information provision is not necessarily delivered with the support of teaching aids because it should be individual

✓ Professional view of carer involvement (why carers need to be involved)
- Carers as one of the contributors of the mental illness
- Carers as the main support for users
- Carers continuing professional care-the main task of carer is for caregiving
- Carers are the target of education because they are viewed as not having knowledge.

✓ What carer need
- Information about the illness progress
- Information about the therapy given to user
- Commitment from professional to work with carers
- Psychological need: professionals show a willingness to help as per need
- Psychological need: professionals possess empathy/willingness to help

✓ Barriers of interaction
- Barriers from carers: defensive carers- carers denied their mistakes which resulted in the mental illness
- Barriers from carers: carers provide false information- focus on the assessment/professional need
- Barriers from carers: lack of knowledge of mental illness
- Barriers from carers: time constraints
- Barriers from carers : Financial issue: carers have to pay to use consultation services delivered by some professionals
- Barriers from carers: Lack of knowledge regarding services for people with mental illness-influenced by stigma of mental illness
- Barriers from carers: minimal visit to service user
--barriers of interaction-
  - Less educated carers - feature of carers in the country
  - Barriers from professional: workload
  - Barriers from the hospital: Teaching aids are not prepared by the hospital
  - Barriers from hospital/management: A specific division organises carers’ gathering but little involvement of practitioners who interact with carers day-to-day
  - Barriers from hospital/management: No preparation given for professional in working with carers
  - Barriers from hospital: no sufficient opportunities to the staffs to update their knowledge and skills through trainings

- support for interaction between carer-professional
  - Support from professional: willingness to give service after hours

- suggested intervention
  - Training is needed for professional skill improvement - not only theoretical
  - Training needed: counselling
  - In house training is needed – yet topic about carer seems not to be prioritised at the moment
  - Suggested intervention: should be standardised
  - Suggested intervention: maintaining the existing program
  - Suggested intervention: group based-intervention
  - Suggested intervention: providing general information - this may not meet individual carers need
  - Suggested intervention: aims to provide information - are there any other purposes such as an opportunity to reduce carers’ burden?
  - Suggested intervention: the time: once in a month

- others
  - The professional concluded that the cornerstone of services is for service user - this might have influenced how the participant responded the question / provided information about carer during this interview which focused more on service users instead of the carers.
II. PHASE II: CONSTRUCTING A CONCEPTUAL FRAMEWORK

C. AIM:
- To construct an initial thematic framework for organising the data

D. ACTIVITY:
- Sorted out the recurring preliminary themes that emerged from the familiarisation phase, and grouped them under a number of higher and broader categories - assigned as main or key themes.

E. RESULTS:
- A workable structure illustrating a hierarchy of four main themes and their subthemes
A Preliminary conceptual framework of the study exploring carer needs from the perspectives of health professionals in Indonesia

<table>
<thead>
<tr>
<th>Key theme</th>
<th>Subthemes</th>
</tr>
</thead>
</table>
| 1. Current contact with carers | 1.1. Duration  
1.2. Focus of contact  
- Administrative activities  
- Express feeling of carers  
- Information provision  
1.3. Initiated by  
- Professionals  
- Carers  
1.4. Payment scheme  
- Paid by governmental insurance  
- Paid by carers  
1.5. Views of current contact  
- Efforts have been done to support carers  
- The existing support have partly fulfilled carers needs  
- Improvement needed for the available support for carers  
- No significant impact for carers and service users from the given support |
| 2. Rationale for carer involvement | 2.1. Carers are responsible for service users’ adherence to treatment  
2.2. Carers are the main support of service users  
2.3. Carers as the cause of mental illness and its relapses  
2.4. Carers continue professional care at home  
2.5. Research project-based interaction  
2.6. To obtain information related service users  
2.7. The professionals are under supervision |
| 3. What carers need from professionals | 3.1. Information  
- Administration for using hospital services for service users  
- Illness progress of service users  
- General mental health issues  
3.2. Psychological support  
- Catharsis  
- Peer group support  
3.3. Technical support to use hospital services for ill relatives |
| 4. Potential support for carers | 4.1. Barriers to developing services  
- Barriers related to carers  
- Barriers from professionals  
- Barriers from hospital  
4.2. Focus on service users  
4.3. Need or no need to provide additional support  
- Need additional support  
- No need for additional support |
III. PHASE III: INDEXING

A. AIMS:

- To annotate and label the data to identify where themes or subthemes emerged in the initial conceptual framework

B. ACTIVITY:

- Read each phrase, sentence and paragraph of the whole 24 transcripts to index or detect which themes or subthemes are being mentioned/referred to within a particular section of the data as illustrated below:

An illustration of indexing in the study exploring carer needs from the perspectives' of health professionals in Indonesia

**Original phrase**

P1: For at least half an hour. Maximum ... It's up to the carer (laughs)... to complete their need to talk and be heard... because consultation with doctor is only brief. Especially for doctors who are careless. Merely asking how is it? Then saying that this is the prescription... the time to wait for the call is much longer that the time for consultation. But in nursing consultations, I am often given a chance, 'Come on Mom, do you want to say anything else. Do you want to vent about something?' Moreover, there are even tears, and it usually takes more time.

**Indexed phrase**

P1: For at least half an hour. Maximum... It's up to the carer (laughs)... to complete their need to talk and be heard... because consultation with doctors is only brief. Especially for doctors who are careless. Merely asking how is it? Then they say this is the prescription... the time to wait for the call is much longer that the time for consultation. But in nursing consultations, I often give a chance, 'Come on Mom, do you want to say anything else. Do you want to vent about something?' Moreover, there are even tears, and it usually takes more time.

3.2. What carers’ need from professionals: psychological support

4.1. Barriers for current contact from professionals: time limitation

1.2. Focus of current contact: service user medication

1.2. Focus of current contact: express feeling of carers
Refined the initial conceptual framework by restructuring the existing themes and subthemes, composed one additional theme and collapsing several subthemes and categories

C. RESULTS:

A refined conceptual framework of the study exploring carer needs from the perspectives of health professionals in Indonesia

<table>
<thead>
<tr>
<th>Key Themes</th>
<th>Subthemes</th>
</tr>
</thead>
</table>
| 1. Professional views of why services should involve carers | 1.1. Carers as the cause of mental illness and its relapses  
1.2. Main support of service users  
1.3. Carers should help professional care  
1.4. Supervisory activities |
| 2. Professional views of what carers need for ill relatives | 2.1. Aftercare services  
2.2. Recovery |
| 3. Professional views of what carers need for own wellbeing  | 3.1. Information  
3.2. Psychological support |
| 4. Focus of current contact  | 4.1. Information provision  
4.2. Emotional support  
4.3. Data exploration related to service users |
| 5. Perspectives of support provision | 5.1. Views of current contact with carers  
✓ Hospital endeavours for supporting carers  
✓ Current support have partly fulfilled carers needs  
✓ Limited impact on service users’ mental health and carers  
✓ Improvement needed  
5.2. Views of potential support for carers  
✓ No need/need to provide additional support  
✓ Focus on service users  
✓ Barriers in developing support |
IV. PHASE IV: CHARTING

A. AIM:

- To summarise the essence of what a participant said about a particular theme, and display them in a set of matrices

D. ACTIVITY:

- Adopted a thematic approach to devise five charts in which the headings were drawn from the key themes of the conceptual framework stemmed from the previous stage (each chart signifies one key theme comprising of a number of columns which represent the subthemes, and 24 rows which represent each participant in the study)
- Summarised the key points of each piece of the data that was sourced from the indexed phrases, and then transferred them to relevant cells in the charts

C. RESULTS:

Five charts, each of them referred to the emerging key themes-one of the charts i.e. Professional views of what carers need for own wellbeing is presented as follows:
<table>
<thead>
<tr>
<th></th>
<th>A: Information</th>
<th>B: Psychological Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Carers need some information from professionals including the condition of their ill relatives, the therapy/treatment given as well as the effects to the service users.</td>
<td>Carers come to psychologists because they want to vent</td>
</tr>
<tr>
<td>2</td>
<td>Carers need to know how to care service users at home or in acute conditions, even there was carers locked their ill relative in a room for 10 years as they did not know how to manage the effects of medication. Also, they need information about health insurance.</td>
<td>Carer experience burnout because they meet service users every day therefore they need to share the burden with others.</td>
</tr>
<tr>
<td>3</td>
<td>Mostly carers ask how to cope with specific behaviours of their relatives such as irritability and smoking.</td>
<td>Carers need time to talk to professionals because sometimes they are stuck and don't know where to go.</td>
</tr>
<tr>
<td>4</td>
<td>Carers need detailed verbal information on how to handle their ill relatives on a daily basis, such as strategies to give reinforcement or with respect to the service users.</td>
<td>Carers want to talk more to express their feelings to professionals.</td>
</tr>
<tr>
<td>5</td>
<td>Carers ask what to do when service users refuse taking the medication.</td>
<td>It's not easy for carers to contact with service users everyday, therefore they need psychological support to survive.</td>
</tr>
<tr>
<td>7</td>
<td>Carers ask nurses about issues surrounding mental illness such as the diagnosis/the kind and the symptoms of the illness, how it can appear, how to care their relatives at home, and how to make the ill can take medication regularly. Carers also need information about procedures in using hospitals services for service users.</td>
<td>Many carers want to talk but there is no vessel, even not all family members care about the ill relatives therefore professionals offer a place for them to vent or to cry in expressing their burden.</td>
</tr>
<tr>
<td>8</td>
<td>Carer need to know more about mental health problems such as the mental illness suffered by their relatives, the real cause of mental illness (which is not by witchcrafts), the treatment as well as how to care the ill relative at home.</td>
<td>Carers are tired but they cannot talk to anyone except nurses as these professionals understand mentally ill people.</td>
</tr>
<tr>
<td>Transcription_Interview_11 (Nurse)</td>
<td>Carers need information of how to Care for ill relatives suffering from hallucination. Carers also need to know about the services offered by the hospital.</td>
<td>N/A</td>
</tr>
<tr>
<td>Transcription_Interview_12 (Nurse)</td>
<td>Carers need knowledge on how to care for service users at home especially when they act bizarrely therefore they are not brought to hospital quickly. They also need to know about the free governmental insurance so that they can bring service users to hospital even though they have no money, and do not need to seclude the ill relatives at home.</td>
<td>N/A</td>
</tr>
<tr>
<td>Transcription_Interview_14 (Nurse)</td>
<td>Carers need information of the cause of mental illness as well as an explanation to the bizarre thoughts, aggression, and worsening condition demonstrated by their ill relatives.</td>
<td>N/A</td>
</tr>
<tr>
<td>Transcription_Interview_15 (Nurse)</td>
<td>Every carer needs information on how to care for their ill relatives at home so they do not go into relapse anymore. There are also carers who want to know about the progress of their ill relatives.</td>
<td>Carers feel hard because they have to take care of mentally ill persons, therefore they need support. They are sometimes ashamed to talk and ask.</td>
</tr>
<tr>
<td>Transcription_Interview_16 (Psychologist)</td>
<td>The most frequent questions of carers is related to medication therapy, whether their ill relatives can be 100% released from the drugs. However, they also ask how to care for the service users at home</td>
<td>Carers needs to be listened, they want to vent, talk or consultation with professionals to express their problems in longer time; yet sometimes the time is limited.</td>
</tr>
<tr>
<td>Transcription_Interview_19 (GP)</td>
<td>Carers do not understand and need information about the difference between addiction and the need of medication. Carers should receive correct information about taking medication which does not result in addiction. Carers also need information of caregiving mentally ill relatives, including how to make them able to sleep, handle them when they are aggressive or emotional.</td>
<td>Psychological support that focuses on reducing carers’ burden is important because carers can reach boredom in caring for their ill relatives. If carers cannot handle the boredom, they may become ill too.</td>
</tr>
<tr>
<td>Transcription_interview_2 (Psychiatrist)</td>
<td>Carers need education or information about the process in the brain of people with mental illness that can be helped through medication. They also need to know that the medication can be minimised one time. Carers need to be explained the importance of support for service users in dealing with stress so they do not relapse anymore. Lastly, carers need to be informed about the signs and symptoms of relapse.</td>
<td>N/A</td>
</tr>
<tr>
<td>17</td>
<td>Transcription_Interview_21 (nurse)</td>
<td>Carers need information what to do when their ill relatives relapse before they are brought to hospital. Carers also want to know whether the hallucination shown is related to being possessed.</td>
</tr>
<tr>
<td>18</td>
<td>Transcription_Interview_23 (psychiatrist)</td>
<td>Most carers ask about the duration in taking medication.</td>
</tr>
<tr>
<td>19</td>
<td>Transcription_Interview_24 (psychiatrist)</td>
<td>Carers ask of what and why the illness suffered by their ill relatives. They also usually ask surrounding drug dependency and the cause of relapse.</td>
</tr>
<tr>
<td>20</td>
<td>Transcription_Interview_3 (Nurse)</td>
<td>Carers need information of the illness suffered by their ill relatives as well as their condition during hospitalisation.</td>
</tr>
<tr>
<td>21</td>
<td>Transcription_Interview_5 (Nurse)</td>
<td>The main questions from carers are related to the cause of relapse and explanation whether their ill relative are truly mentally ill as they are still able do many activities. Carer also often ask about medication including the type, function, effects and duration of the medication treatment.</td>
</tr>
<tr>
<td>22</td>
<td>Transcription_Interview_6 (Psychiatrist)</td>
<td>Carers need basic information even though their relative has been ill for a long time, such as what the illness is and when it can recover.</td>
</tr>
<tr>
<td>23</td>
<td>Transcription_Interview_9 (Nurse)</td>
<td>The first need of carers is information about mental illness suffered by their relative, also information about the kinds of available hospital services as well as the administration procedures.</td>
</tr>
<tr>
<td>24</td>
<td>Transcription_Interview_18 (Nurse)</td>
<td>Carers commonly ask about the duration of mental illness suffered by their relative as well as the duration in taking the medication regime. They also ask what to do when the user is at home.</td>
</tr>
</tbody>
</table>
V. PHASE V: MAPPING AND INTERPRETATION

a. MAPPING

B. AIMS:
- To devise categories and identify the linkage between them
- To produce descriptive accounts of all themes and subthemes generated from the study

B. ACTIVITY:
- Developed a separate table to display the elements/dimensions and identified categories from a particular theme across the 24 cases/participants
  - Column A was assigned for the summarised data of all cases/participants transferred from the constructed matrices.
  - Column B was assigned for elements/dimensions identified from a particular case (so-called the phase of detection in the mapping process).
  - Column C was assigned for categories, derived from a more conceptual interpretation of the identified elements/dimension (so-called the phase of categorisation in the mapping process)
- Inspected all elements/dimensions, determined for their categories and labelled into a more abstract categorisation.
  - Implemented the highlighting approach in columns A and B, continued in column C to indicate which elements/dimensions were relevant to the established category as illustrated in the following tabl
### DESCRIPTIVE ANALYSIS OF PROFESSIONAL INTERVIEWS

**Professional views of what carers need for own wellbeing**

<table>
<thead>
<tr>
<th>Data charted in the theme : Professional views of what carers need for own wellbeing</th>
<th>Elements/Dimensions detected</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 : Transcription <em>Interview</em> 20 (OT)</td>
<td>Asking ill relatives' behaviours at home</td>
<td>General information of mental health problems</td>
</tr>
<tr>
<td></td>
<td>Asking what to do to ill relatives' behaviours at home</td>
<td>Information of managing service user at home</td>
</tr>
<tr>
<td></td>
<td>Need time to talk</td>
<td>Psychological support</td>
</tr>
<tr>
<td></td>
<td>Don't know where to go</td>
<td>Catharsis</td>
</tr>
<tr>
<td></td>
<td>Carers need time to talk because sometimes they are stuck and don't know where to go</td>
<td>Carer emotion associated with caregiving: confusion</td>
</tr>
</tbody>
</table>

| 2 : Transcription _Interview_ 8 (Nurse) | Need to know how to care ill relatives at home | Information of managing service user at home |
|  | Need to know how to care ill relatives in acute conditions | Information of medication and other treatments |
|  | Did not know how to manage effects of medication | Information of services and access to financial support |
|  | Lacking ill relative because no knowledge about medication effect | Carer emotion associated with caregiving: tiredness |
|  | Need information about health insurance | Psychological support: peer group support |
|  | Experience burnout because meet ill relatives every day | |
|  | Need to share burden with others | |

Carers need to know how to care service users at home or in acute conditions, even there was carers locked their ill relative in a room for 10 years as they did not know how to manage the effects of medication. Also, they need information about health insurance.

Carer experience burnout because they meet service users every day therefore they need to share the burden with others.
<table>
<thead>
<tr>
<th>3 : Transcription Interview _22 (Social worker)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers need detail verbal information <strong>how to handle service users' in daily basis, such as strategies in giving reinforcement or respect to service users.</strong> Carers want to talk more to vent to professionals</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Need verbal information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need information how to handle ill relatives in daily basis</td>
</tr>
<tr>
<td>Need information strategies in giving reinforcement and respects to ill relatives</td>
</tr>
<tr>
<td>Need to talk with professionals</td>
</tr>
<tr>
<td>Need to vent to professionals</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Method of potential information given</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information of managing service user at home</td>
</tr>
<tr>
<td>Psychological support catharsis</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4 : Transcription Interview _4 (Psychologist)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers need some information from professionals including the condition of their ill relatives, the therapy/treatment given as well as the effects to the service users. Carers come to psychologists because they want to vent</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Need information condition of ill relatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need information therapy given and the effects on ill relatives</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Want to vent</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Information of individualised illness progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information of medication and other treatments</td>
</tr>
<tr>
<td>Psychological support catharsis</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5 : Transcription Interview _17 (Psychiatrist)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers ask what to do when service users refuse taking the medication. It's not easy for carers to contact with service users every day, therefore they need psychological support to survive.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Asking what to do when ill relatives refusing medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not easy to contact with ill relatives every day</td>
</tr>
<tr>
<td>Need psychological support to survive</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Information of managing service user at home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer emotion associated with caregiving: hardness</td>
</tr>
<tr>
<td>Psychological support</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6 : Transcription Interview _7 (Psychiatrist)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers do not receive sufficient information about mental illness and may become overreact or be too anxious about their mentally ill relatives; therefore they need professionals to advise them of how to care the service users.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>No sufficient information about mental illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Too overreact about their ill relatives</td>
</tr>
<tr>
<td>Too anxious about their ill relatives</td>
</tr>
<tr>
<td>Need advice of how to care ill relatives</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>General information of mental health problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer response associated with caregiving: Overreaction</td>
</tr>
<tr>
<td>Carer emotion associated with caregiving: compassion</td>
</tr>
<tr>
<td>Information of managing service user at home</td>
</tr>
</tbody>
</table>
| Carers ask nurses about issues surrounding mental illness such as the diagnosis/the kind and the symptoms of the illness, how it can appear, how to care their relatives at home, and how to make the ill can take medication regularly. Carers also need information about procedures in using hospitals services for service users.  
Many carers want to talk but there is no vessel, even not all family members care about the ill relatives therefore professionals offer a place for them to vent or to cry in expressing their burden. |
|---|
| Asking diagnosis or kind of illness of ill relatives  
Asking symptoms of mental illness  
Asking how mental illness can appear  
Asking how to care ill relatives at home  
Asking how ill relatives can take medication regularly  
Need information procedures in using hospital services  
Want to talk but no vessel  
Not all family members care about ill relatives  
Venting or crying to professional to express burden |
| General information of mental health problems  
Information of managing service user at home  
Information of services and access to financial support  
Inability to talk  
Unsupportive response from other relatives  
Psychological support catharsis |
| Carer need to know more about mental health problems such as the mental illness suffered by their relatives, the real cause of mental illness (which is not by witchcrafts), the treatment as well as how to care the ill relative at home.  
Carers are tired but they cannot talk to anyone except nurses as these professionals understand about mentally ill people |
| Need to know about mental illness suffered by the ill relatives  
Need to know the cause of mental illness  
Need to know the treatment given to ill relatives  
Need to know how to care ill relative at home  
Tired  
Cannot talk to others but nurses  
Nurses understand about mentally ill people |
| General information of mental health problems  
Information of medication and other treatments  
Information of managing service user at home  
Carer emotion associated with caregiving: tiredness  
Psychological support catharsis |
<table>
<thead>
<tr>
<th>9  : Transcription_Interview_11 (Nurse)</th>
<th>Carers need information of how to care ill relatives with hallucination. Carers also need to know about the services offered by the hospital.</th>
<th>Need information of how to care people with hallucination. Need to know about hospital services.</th>
<th>Information of managing service user at home. Information of services and access to financial support.</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 : Transcription_Interview_12 (Nurse)</td>
<td>Carers need knowledge of how to care service users at home especially when they are bizarre therefore they are not brought to hospital soon. They also need to know about the free governmental insurance so they can bring service users to hospital even though they have no money, and do not need to seclude the ill relatives at home.</td>
<td>Need knowledge of how to care ill relatives. Need to know about the free governmental insurance to bring ill relatives to hospital. Carer seclude ill relatives at home Carers do not have money</td>
<td>Information of managing service user at home. Information of services and access to financial support. Carers attitudes toward ill relatives: seclusion Barriers from carers: financial constraint.</td>
</tr>
<tr>
<td>11 : Transcription_Interview_13 (Social Worker)</td>
<td>Carers need explanation of the laziness demonstrated by mentally ill people. For carers, sometimes telling stories about service users is embarrassing but when they can talk, it is releasing.</td>
<td>Need explanation ill relatives’ laziness. Telling stories about ill relatives is embarrassing. Talking about ill relatives is releasing.</td>
<td>General information of mental health problems. Carer emotion associated with caregiving: shame Carer feeling after talking: satisfaction.</td>
</tr>
<tr>
<td>12 : Transcription_Interview_14 (Nurse)</td>
<td>Carers need information of the cause of mental illness as well as explanation of why bizarre thoughts, aggression, and worsening condition demonstrated by their ill relatives.</td>
<td>Need information cause of mental illness. Need explanation of bizarre thoughts and aggression of ill relatives. Need information worsening condition demonstrated by ill relatives.</td>
<td>General information of mental health problems. Information of individualised illness progress.</td>
</tr>
<tr>
<td>13 : Transcription_Interview_15 (Nurse)</td>
<td>14 : Transcription_Interview_16 (Psychologist)</td>
<td></td>
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<tr>
<td>----------------------------------------</td>
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<td></td>
</tr>
<tr>
<td>Every carer needs information of how to care their ill relatives at home so they cannot relapse anymore. There are also carers who want to know about the progress of their ill relatives. Carers feel hard because they have to take care of mentally ill person, therefore they need support. They are sometimes ashamed to talk.</td>
<td>The most often questions of carers are related to medication therapy, whether their ill relatives can 100% release from the drugs. However, they also ask how to care the service users at home. Carers need to be listened, they want to vent, and talk or consultation with professionals to express their problems. In longer time; yet sometimes the time is limited.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need information how to care ill relative at home. Want carers not relapse anymore. Want to know progress of ill relatives. Need support because taking care mentally ill person is hard. Need to talk.</td>
<td>Asking medication therapy. Asking ill relatives can 100% release from drugs. Asking how to care ill relatives at home. Need to be listened. Want to vent to professionals. Want to talk or consultation with professionals to express problems. Time for consultation with professionals limited.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 : Transcription_Interview_19 (GP)</td>
<td>Need information about the difference between addiction and the need of medication. Carers should receive correct information about taking medication which does not result in addiction. Carers also need information of caregiving mentally ill relatives, including how to make they are able to sleep, handle them when they are aggressive or emotional. Psychological support that focuses on reducing carers' burden is important because carers can reach boredom in caring for their ill relatives. If carers cannot handle the boredom, they may become ill too. Need information of addiction in psychiatric medication Need information about caregiving mentally ill relatives Need information of how to handle mentally ill relatives when they are unable to sleep, aggressive or emotional Need psychological support to reduce burden Need psychological support to handle boredom Carers can be ill if they can handle caregiving boredom</td>
<td>Information need Information of medication and other treatments Information of managing service user at home The need of psychological support</td>
<td></td>
</tr>
<tr>
<td>16 : Transcription_interview_2 (Psychiatrist)</td>
<td>Carers need education or information about the process in the brain of people with mental illness that can be helped through medication. They also need to know that the medication can be minimised one time. Carers need to be explained the importance of support for service users in dealing with stress so they do not relapse anymore. Lastly, carers need to be informed about the signs and symptoms of relapse. Need information brain process related to the psychiatric medication given Need information about when medication can be minimised Need information of how to help service users in dealing with stress Need information of signs and symptoms of relapse</td>
<td>Information of medication and other treatments Information of managing service user at home General information of mental health problems</td>
<td></td>
</tr>
<tr>
<td>17 : Transcription_Interview_21 (nurse)</td>
<td>Carers need information what to do when their ill relatives relapse before they are brought to hospital. Carers also want to know whether the hallucination shown is related to being possessed. Need information what to do when ill relatives relapse Want to know cause of hallucination</td>
<td>Information of managing service user at home General information of mental health problems</td>
<td></td>
</tr>
<tr>
<td>18 : Transcription_Interview_23 (psychiatrist)</td>
<td>Most carers ask about the duration in taking medication Asking duration in taking medication</td>
<td>Information of medication and other treatments</td>
<td></td>
</tr>
<tr>
<td>19 : Transcription_Interview_24 (psychiatrist)</td>
<td>Carers ask of what and why the illness suffered by their ill relatives. They also usually ask surrounding drug dependency and the cause of relapse Asking illness suffered by relatives Asking why mental illness suffered by relatives Asking drug dependency Asking cause of relapse</td>
<td>General information of mental health problems Information of medication and other treatments</td>
<td></td>
</tr>
<tr>
<td>20 : Transcription_Interview_3 (Nurse)</td>
<td>21 : Transcription_Interview_5 (Nurse)</td>
<td>22 : Transcription_Interview_6 (Psychiatrist)</td>
<td>23 : Transcription_Interview_9 (Nurse)</td>
</tr>
<tr>
<td>--------------------------------------</td>
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<td>--------------------------------------</td>
</tr>
<tr>
<td>Carers need information of the illness suffered by their ill relatives as well as their condition during hospitalization.</td>
<td>Need information illness suffered by relatives. Asking condition of ill relatives during hospitalisation.</td>
<td>Carers need basic information even though their relative has been ill for a long time. Carers take care of their ill relatives but they actually need places to vent.</td>
<td>The first need of carers is information about mental illness suffered by their relative, also information about the kinds of available hospital services as well as the administration procedures. Carers need support or motivator who says it's alright having a mentally ill relative. They also need to share among carers to express their thoughts of having a mentally ill relative.</td>
</tr>
<tr>
<td>Carers need information of the illness suffered by their ill relatives as well as their condition during hospitalization.</td>
<td>General information of mental health problems. Information of individualised illness progress.</td>
<td>General information of mental health problems. Information of medication and other treatments.</td>
<td>General information of mental health problems. Information of services and access to financial support.</td>
</tr>
<tr>
<td>Need in information illness suffered by relatives. Asking condition of ill relatives during hospitalisation. Information of individualised illness progress.</td>
<td>Asking cause of relapse. Asking relatives truly mentally ill. Asking type, function, effects and duration of the medication treatment.</td>
<td>Need basic information even though their relative has been ill for a long time. Need information what the illness of relatives. Need information when the mental illness can recover.</td>
<td>Need information mental illness suffered by relatives. Need information available hospital services. Need information administration procedures.</td>
</tr>
<tr>
<td>Psychological support: catharsis.</td>
<td>Psychological support: peer group support.</td>
<td>Psychological support: peer group support.</td>
<td>Psychological support: peer group support.</td>
</tr>
</tbody>
</table>
Carers commonly ask about the duration of mental illness suffered by their relative as well as the duration in taking the medication regime. They also ask what to do when the user is at home.

Carers want to vent, they need to talk thus they need good listeners and a channel for sharing because there are times when they deny the illness and feel don't have someone to talk to.

<table>
<thead>
<tr>
<th>Asking duration of mental illness of ill relative</th>
<th>Asking duration for medication</th>
<th>Asking what to do when ill relatives at home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denying the mental illness</td>
<td>Need to talk</td>
<td>Need good listener</td>
</tr>
<tr>
<td>Don't have someone to talk to</td>
<td></td>
<td>Need channel for sharing</td>
</tr>
</tbody>
</table>

General information of mental health problems
Information of medication and other treatments
Information of managing service user at home
Psychological support: catharsis

Psychological support: peer group support
Carer response to mental illness: denial
Carer response associated with caregiving: loneliness
The mapping procedures were continued to investigate all materials in column C and a decision was made about what categories to be used for describing each subtheme. Relevant categories were maintained and the irrelevant categories were eliminated. Finally this activity generated a set of descriptive classifications of data in to one subtheme.

An example of this process is provided below onto the categories related to carers’ need of information recorded in column C under the key theme of what carers need for their own wellbeing.

- **Firstly**, grouped and characterised similar or recurrent categories by the same colour:

1. General information regarding mental health problems
2. General information regarding mental health problems
3. General information regarding mental health problems
4. General information regarding mental health problems
5. General information regarding mental health problems
6. General information regarding mental health problems
7. General information regarding mental health problems
8. General information regarding mental health problems
9. General information regarding mental health problems
10. General information regarding mental health problems
11. General information regarding mental health problems
12. General information regarding mental health problems
13. General information regarding mental health problems
14. Information about managing service user at home
15. Information about managing service user at home
16. Information about managing service user at home
17. Information about managing service user at home
18. Information about managing service user at home
19. Information about managing service user at home
20. Information about managing service user at home
21. Information about managing service user at home
22. Information about managing service user at home
23. Information about managing service user at home
24. Information about managing service user at home
25. Information about managing service user at home
26. Information about medication and other treatments
27. Information about medication and other treatments
28. Information about medication and other treatments
29. Information about medication and other treatments
30. Information about medication and other treatments
31. Information about medication and other treatments
32. Information about medication and other treatments
33. Information about medication and other treatments
34. Information about individualised illness progress
35. Information about individualised illness progress
36. Information about individualised illness progress
37. Information about individualised illness progress
38. Information about services and access to financial support
39. Information about services and access to financial support
40. Information about services and access to financial support
41. Information about services and access to financial support
42. Method of potential information given
Secondly, summarised all the categories listed in the previous step:

- Five categories that were relevant to the information needed by carers were identified and recorded in colours; and one category which was irrelevant was also indentified but recorded without colouring:
  
  - General information regarding mental health problems
  - Information about managing service user at home
  - Information about medication and other treatments
  - Information about individualised illness progress
  - Information about services and access to financial support
  - Method of potential information given

Thirdly, determined the categories to be used and establishing a descriptive categorisation

- Maintaining the five recurrent relevant categories and discharging one category which was irrelevant to the description of information needed by carers:

  **Information needed by carers**

  1. General information regarding mental health problems
  2. Information about managing service user at home
  3. Information about medication and other treatments
  4. Information about individualised illness progress
  5. Information about services and access to financial support

Finally, employed an approach of categorisation for another subtheme under the same key theme (i.e. the need of carers for psychological support), and this resulted in two categories:

- the needs of catharsis and peer group support

RESULTS:

The application of the categorisation approach on all subthemes and key themes resulting in a general description of the whole findings:
I. Professional views of why services should involve carers

1. Carers cause mental illness and relapse
   - Unsupportive family environment has caused mental illness
   - Carers’ bad emotions towards mentally ill relatives as well as poor knowledge of mental health have caused relapses

2. Carers as main support for service users
   - Carers and ill relatives as a system therefore carers should care for their ill relatives
   - Carers help service users to control illness symptoms
   - Carers support service users to carry out activity daily life
   - Carers provide financial support

3. Carers could help professional care
   - Professionals only provide limited care to service users
   - Carers can help professional care in hospital
   - Carers can continue professional care at home

4. Supervisory activity
   - Contact with carers for nursing supervisory activities

II. Focus of current contact

1. Information provision
   - Information provision about service users’ illness progress
   - Information provision of managing service users at home
   - Provision of general information about mental health problems
   - Information provision of services available and access to financial support

2. Emotional support provision
   - Emotional support provision through peer support
   - Emotional support provision through allowing for catharsis
   - Emotional support provision through spiritual approach
   - Emotional support provision through psychotherapy

3. Gathering information of service users
   - Exploring data of service users through carers
   - Filling assessment and report forms of service users

III. Perspectives of support provision

A. Perspectives of current support provision

1. Hospital endeavours for supporting carers
   - Current programmes for information provision
     - Family gathering
       ✓ Benefit: receiving information associated with caregiving and support from others
     - Nursing consultation
       ✓ Benefits: fulfilling information needs uncovered by one profession (i.e. psychiatrists)
     - 24 hour hotline service
       ✓ Current condition: minimal usage
       ✓ Unable to service in 24 hours
   - Endeavours for increasing the number of carers attending education Programmes
2. Have partly fulfilled carers needs:
   - Complete fulfilment (according to several participants)
   - Incomplete fulfilment (according to several participants)

3. Limited impact of current support to carers and service users
   - Limited change in service users’ mental health state
   - Limited change in carers’ understanding of mental illness and attitudes towards their ill relatives

4. Improvement needed in current support for carers
   - Improvement in verbal and written information provision
   - Improvement in emotional support provision

B. Perspectives of potential support for carers

1. Support for carers focus on service users’ wellbeing
   - Support for carers is designed for caring for their ill relatives: minimising relapse rate and helping service users to be independent in dealing with life problems

2. Additional support needed: A smaller group of sharing among carers (5-12 people)
   - Benefits for carers: more opportunity for sharing and discussion about caregiving experiences
   - Benefit for professionals: time efficiency
   - Time and duration of delivery: when carers come to outpatient, discharging service users from inpatient, or after participating in current family gathering for about 30 minutes
   - Professional involvement: professional (nurse) or experienced carers as the group facilitator

3. Barriers in developing support
   - Barriers from carers
     - Economic problem
     - Uncooperative carers: unwillingness to continue caregiving role, reducing attention towards ill relatives, incompliance to professionals’ request, difficult to be contacted by professionals
     - Time constraint
     - Stigmatised thoughts of mental illness
     - Distance constraint
     - Low education background
   - Barriers from hospital
     - Standardisation issues: Unclear standardisations surrounding the procedures in providing information and written resources for carers
     - Issues of socialisation: lack of socialisation of available services
     - Human resource issues: limited human resources and small incentives for support providers
     - Methodological issues: one way provision in carer group education with unsuitable topics given
   - Barriers from professionals
     - Lack of interest, knowledge and skills to work with carers
     - Time limitation due to excessive workload
b. **INTERPRETATION**

A. **AIMS**: to interpret data as a whole

B. **ACTIVITY**:

- Detected for associations between the key substantive findings systematically (i.e. the five generated themes surrounding the needs of Indonesian carers from the view of professionals). This was accomplished by detecting explicit information of the connections from the participants as well as implicit associations derived from the data
- Constructed a central chart to portray the identified associations between the themes
- Generated an explanation of the overall findings

C. **RESULTS**:

- A chart which describes the associations between themes
- Explanation the substantive findings of the study exploring carers needs from mental health hospital service in Indonesia
Relationships among the themes emerged from a study exploring carer needs from mental health hospital services from the perspective of health professionals in Indonesia

1. Carers’ aspiration for mentally ill relatives
   - Aftercare service engagement
   - Recovery

2. What carers need for own wellbeing
   - Information
   - Psychological support

3. Why carers should be involved in service
   - Carers as the cause of mental illness and relapse
   - Carers as main support of service users
   - Carers could help professional care
   - Professionals' supervisory activities

4. Focus of current contact
   - Information provision
   - Emotional support provision
   - Obtaining data of service users

5A. Perspectives of current support provision
   - Hospital endeavours for supporting carers
   - Have partly fulfilled carers needs
   - Limited impact on carers and service users
   - Improvement needed

5B. Perspectives of potential support
   - Need additional support: smaller sharing group among carers
   - Focus on service users
   - Barriers from carers, hospital and professionals

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Representing the scope where the professional participants provided data regarding carers needs for their Own wellness exclusively (i.e. not related (i.e. not related to service users)
The interview with health professionals in Indonesia uncovered some rationales for carer involvement in the care provision to service users (theme 3). From the perspectives of the professionals, carers in the country have several aspirations for their mentally ill relatives (theme 1). These aspirations have become the concerns of the carers, thus the effect on the emergence of several needs for their own wellbeing (theme 2). The professionals have attempted to address both the aspirations and the carer needs when contacting the carers in mental health hospitals (theme 4). In addition, the study has revealed the professionals’ views about current support provision for carers (theme 5). According to the professionals, the existing support only met some of the carer needs and gave limited impact on the mental health state of carers and service users (subtheme 5a). As a result, a number of recommendations were revealed in order to improve the services for Indonesian carers including developing additional support, focusing the services for service users’ wellbeing, and anticipating potential barriers in the course of the implementation (subtheme 5b).
## Summary of findings of qualitative studies in the PhD

<table>
<thead>
<tr>
<th>No</th>
<th>Study</th>
<th>What carer needs</th>
<th>Current support for carers</th>
<th>Views of current support provision</th>
<th>Recommendation for improvement</th>
</tr>
</thead>
</table>
| 1  | Carer and service user focus groups | - Information  
- Emotional support  
- Financial support  
- Recovery for service users  
- Professionalism in contact with service users and carers | - Information provision  
- Emotional support | - Positive views  
  - Knowledge improvement  
- Weaknesses  
  - Access difficulties due to lack of time, distance and transport cost  
  - Unknown information provision  
  - Insufficient information | - Improvement for information provision  
- **Strategy:**  
  Face to face than written education; individualised approach; group-based education which delivers various and non-repetitive topics, using lay language, effective announcement, extra sharing among carers  
- **Time delivery:**  
  Initial contact with professionals, after current education, once in a month  
- **Setting:** hospital  
- **People involved:** 10-40 carers in one group  
- **Anticipated barriers:** attrition  
- Group-based emotional support  
- **Strategy:**  
  In conjunction with group-based education; aims to exchange information about caregiving strategies, progress service users, express feelings; organised by hospital  
- **Time delivery:**  
  Once in a month  
- **Setting:** hospital  
- **People involved:** 10 carers in a group, facilitator from professionals at the start  
- **Anticipated barriers:**  
  Time and financial constraints |
<table>
<thead>
<tr>
<th>No</th>
<th>Study</th>
<th>What carer needs</th>
<th>Current support for carers</th>
<th>Views of current support provision</th>
<th>Recommendation for improvement</th>
</tr>
</thead>
</table>
| 2  | Professional interview | - What carers need for ill relatives  
  - Follow-up activities after hospitalisation  
  - Recovery  
  - What carers need for own wellbeing  
  - Information  
  - Psychological support | - Providing or supporting service user medication  
  - Information provision  
  - Emotional support  
  - Data exploration related to service users | - Hospital endeavours for supporting carers  
  - Current support have partly fulfilled carer needs  
  - Limited impact on service users ‘mental health and carers’ knowledge  
  - Improvement needed | - Information provision should change carer behaviours and attitudes in caring for service user  
  - More sharing among carers  
  - Time delivery for sharing among carers : after current information provision, during in-patient discharge  
  - Barriers in developing support  
  - Encountered by carers: transport cost, stigmatised thought from general public, ‘uncooperative carers’  
  - From hospital: lack of standardisation, socialisation, and human resources (relating to limited time, excessive workload, insufficient optimal personnel for educators),  
  - From professionals: insufficient knowledge and and skills of working with carers, lack of empathy and motivation to interact with carers |