A world shared – a world apart: The experience of families after the death of a significant other late in life

DOI:

[10.1111/jan.13107](https://doi.org/10.1111/jan.13107)

Document Version

Accepted author manuscript

[Link to publication record in Manchester Research Explorer](#)

Citation for published version (APA):

Naef, R., Ward, R., Mahrer-Imhof, R., & Grande, G. (2016). A world shared – a world apart: The experience of families after the death of a significant other late in life. *Journal of Advanced Nursing*, 73(1), 149-161. <https://doi.org/10.1111/jan.13107>

Published in:

Journal of Advanced Nursing

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**A world shared – a world apart: The experience of families
after the death of a significant other late in life**

Journal:	<i>Journal of Advanced Nursing</i>
Manuscript ID	JAN-2016-0258.R1
Manuscript Type:	Original Research: Empirical research - qualitative
Keywords:	Family care, Bereavement, Older People, Phenomenology, Carers, Hermeneutics
Category:	Nursing

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Revision Protocol – Manuscript ID JAN-2016-0258

A world shared – a world apart: The experience of families after the death of a significant other late in life.

Editing

Editorial comment	Comment
Format of headings: main headings UPPER CASE, major sub-headings lower case, subsidiary sub-headings italics.	Headings have been re-formatted to fit with the JAN guideline
Word count 5000 words	Reduced from 5331 to 5262
For Research papers, provide the inclusive years of data collection in both the abstract and the text.	Year of data collection included in abstract. No changes in the text since the date was already given under “sample / participants”

Reviewer 1

Reviewer comment	Comment
Because it was long winded at times, the summary after the abstract should be made clearer and possibly highlighted.	The summary statement was shortened and fully revised to make it more concise.
My major difficulty is in not knowing enough about the families. What were their incomes and what were their belief structures, do they attend church, what was there social standing etc. Most of the missing data could easily be added to table 1.	The only data collected on social standing was years of education and self-perceived financial situation. In addition to years of education, self-perceived ability to manage with monthly income has been inserted in table 1 No data was collected on belief structure.
Also were they chosen to be homogeneous or to be different or was it random.	Sampling was purposive guided by inclusion / exclusion criteria. The actual homogeneity of the sample occurred at random (but was probably due to the fact that most often, home care nurses created access to families). The heterogeneity / homogeneity of the sample were of concern in making decisions about the sample size (i.e. when the sample would have been heterogeneous, more cases might have been necessary. Thus, the sentence addressing decision-making about sample size has been slightly reworded (under “sample / participants”)
I am not sure if the family names are blinded, if not was permission sought to use the real names.	The last sentence under “ethical considerations” reads: “ To ensure anonymity, code names were used”. In the authors’ view, this states clearly that no real names were used. A footnote has been added in table 2 that states that the names given in the table are code names.
I notice some families were chosen by ministers and some by nurses was there a difference between them?	Only two families were recruited by ministers, one self-referred and 7 were recruited by nurses. The researchers noted no discernable difference between families based on recruitment process. Given the length restrictions of the paper, the sentence was simplified.

After the quotes there is a reference given but no explanation as to what it referred to or where the reference could be viewed, or for how long it would be available.	Reference indicates the document and line numbers of the interview transcripts. They can only be accessed via the researcher. Hence, references have been deleted (also out of considerations about word length), and only the participant names (either individual family member, family name or both) are now given since this can be checked with table 2.
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Reviewer 2

Reviewer comment	Comment
p.4 line 34 should say 'grieving' and not 'grief'	corrected
p.5 line 30 (≥ 18 years) not needed	deleted
p.5 line 42 unstructured not 'open'	changed
p.5 line 50 understood not understand	corrected
p.7 Findings – perhaps a mention of sub-themes should be made as these are evident within the themes.	Yes indeed, sub-headings are equal to the discerned family practices related to meaning-making of the death, living with the loss, and family life in the wake of loss. To clarify this point, a table was created that provides a succinct overview (table 3)
p. 8 and onwards... Quotes in text are given in Italics but not when free standing, why? It seems inconsistent.	In-text quotes have been reformatted according to the guideline given on the JAN website (no italics for quotations)
p.15 line 56 Tenuous statement, which I think needs to be elaborated on.	Statement was reworded and further clarified.
p.16 line 13 voices not 'voice'	corrected
p.16 line 22, the last sentence is not clear. This is about bracketing, but difficult to understand the point that is made.	Reworded to clarify the point.

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Abstract

Aims: To investigate the impact of the death of an older member on families.

Background: The death of a significant other in later life is a dramatic moment. Research has demonstrated that some older persons face negative consequences for their well-being. A majority, however, exhibits resilience in the wake of loss. Nonetheless, the relational process through which older persons come to terms with the loss in interaction with their families is little understood, but vital to support bereaved families.

Design: Heideggerian hermeneutic phenomenology.

Methods: A purposive sample of ten older persons with their families, represented by children, grandchildren and in-laws (n=30) were interviewed several times in 2013, alone (n=16) and in family groups (n=21), six to 23 months after their significant other's death (mean age 81y). Data collection and thematic analysis was informed by van Manen's and Benner's analytical strategies.

Findings: Three family themes were discerned. First, through meaning-making, bereaved families weaved the death into their family narrative. Second, through sharing-not sharing their feelings and daily moments, family members lived with the loss both together and alone. Third, some families faced upheaval in their family life, which required them to re-create their everyday life, whereas other families continued with little change.

Conclusions: Findings demonstrate that families hold an inherent capacity to make meaning of the death and enact family thereafter. Family relations arose as interplay of different, contradicting forces. Nurses should facilitate families' meaning-making of the death, attend to their converging and diverging sense of loss, and strengthen family caring.

SUMMARY STATEMENT

Why is this research or review needed?

- To date, grief has predominantly been studied as an intrapersonal process from the perspective of bereaved older spouses and carers.
- Families' situation following a loss late in life remains poorly understood.
- To provide meaningful and relevant bereavement care across settings, nurses require an in-depth understanding of families' relational loss experience.

What are the key findings?

- Findings revealed that death happens to "a family", but affects members and generations in unique ways.
- Families collectively integrate shared meanings into their family narrative, enact community through connecting in daily life, and move together as they transition into their new family situation without the deceased.
- Concurrently, families' life with loss unfolds in diverging ways for individual members, and involves disconnection during moments in which family members did not want to, or could not share.

How should the findings be used to influence policy/practice/research/education?

- Family nursing interventions should enable families' meaning-making and aim to strengthen their relational and caring capacities in bereavement while also attending to individual, diverging experiences and needs.
- Relationship-focused, health-promoting approaches to care should be used when working with bereaved persons and families in later life.
- Research should further explore family needs and health outcomes in bereavement.

Keywords: Family care, family relations, older person, bereavement, phenomenology, hermeneutics

INTRODUCTION

Most persons die late in life after a persistent illness for which they received family care (Schulz *et al.* 2001, Hudson 2013). Although the loss of siblings and friends is most frequent among the very old, the death of a significant other affects older persons in intimate ways (Lalive d'Epinay *et al.* 2009). It not only ends a long-standing relationship, but uproots personal identities, social roles, and established daily activities (Carr *et al.* 2006, Moss & Moss 2014). Conjugally bereaved older persons face difficult emotions and a pervasive sense of loneliness despite busy lives (Naef *et al.* 2013), which may have negative consequences for their well-being (Thomas *et al.* 2014). Notwithstanding these manifold challenges, most are able to cope with their bereavement situation over time, and only a smaller proportion experience debilitating forms of grief (Bonanno *et al.* 2002, Ott & Lueger 2002, Spahni *et al.* 2015). It is well established that social networks are an important source of support (Brazil *et al.* 2003, Naef *et al.* 2013, Powers *et al.* 2014). For older bereaved persons, adult children play a pivotal role in providing emotional and instrumental support (Ha 2008, Ha & Ingersoll-Dayton 2008). Hence, a consensus has evolved that most come to terms with their grief in interaction with their families and friends (National Institute for Clinical Excellence 2004, Rumbold & Aoun 2014). However, the relational process by which a group of interconnected people experiences a change in relationships through death remains poorly understood (Hayslip & Page 2013, Thirsk & Moules 2013).

Background

Most insights about later life bereavement are based on research with individuals. Hence, grief has predominately been recognized as an intrapersonal process and only to a lesser extent as an interpersonal experience (Hayslip & Page 2013, Neimeyer *et al.* 2014). However, a small body of research with adult bereaved families has demonstrated that family system characteristics impact on individuals' experience of grief. Individuals within families with low to some cohesiveness and moderate to high conflict were found to experience more intense grief and to be at greatest risk for depression compared to individuals of families who felt close and had no conflicts (Kissane *et al.* 1996a, Kissane *et al.* 1996b, Kissane *et al.*

1997, Traylor *et al.* 2003). It has also been found that bereaved families engage in an interactive, collective process of finding meaning in light of their family identity, rules, and beliefs (Nadeau 1998, Black & Santanello 2012, Black *et al.* 2014).

Theoretical writings most often posit family as a relational context to individuals' lives, whereby families are seen as a source of support (Gilbert 1996, Shapiro 2001). Moreover, family system perspectives recognize family as more and different from individuals merely interacting with each other (Nadeau 2001, Hayslip & Page 2013). As such, the death of a family member is a system-wide event that disrupts families in their particular situation and context (Berger & Weiss 2009, Hayslip & Page 2013). Bereaved families' unique configurations, needs, capacities, and meaning-making strategies are of interest (Berger and Weiss, 2009; Davis *et al.*, 2012; Gilbert, 2007; Nadeau, 2008). While a focus on what constitutes age-normative family functions continues to abound, it is increasingly appreciated that manifold ways of living as a family and grieving meaningfully co-exist (Hedtke & Winslade 2004, Nadeau 2008, Neimeyer 2012, Thirsk & Moules 2012).

THE STUDY

Aim

The aim of this study was to investigate families' bereavement experience after an older person's significant other has died.

Design

Hermeneutic phenomenology informed the study design (Heidegger 1926/2001, Gadamer 1975/1989). Based on the premise that understandings and actions are intersubjective, and arise from a particular world shared with others (Heidegger 1926/2001), families' practical involvement with their world and the meanings they gain were the focus of this inquiry (Plager 1994, Chesla 1995). Within hermeneutics, the linguistic nature of understanding gives rise to the possibility to gather families' accounts through dialogue (Gadamer 1975/1989, van Manen 1990). To seek understanding, hermeneutic researchers depart from their own being-in-the-world, in this case from that of a nurse researcher, spouse, mother and daughter, who has witnessed dying in her clinical practice and in her

oldest family generation. An interpretation is sought through an abiding engagement with the text and a hermeneutic spiralling process (Benner 1994, Spichiger & Prakke 2003, Smith 2007). Interpretive efforts attempt to gain insights through explicating fore-understandings as they evolved in relation to the phenomenon under study and the emerging textual interpretation (Gadamer 1975/1989, Geanellos 1998a).

Sample / Participants

Older persons (≥ 75 years) whose significant other had died within the two previous years of various causes, together with their families, were purposively selected and recruited from an urban area in (country) between November 2012 and October 2013, **predominantly by home care nurses who had provided care to the deceased**. At least one additional family member or someone close was recruited through the bereaved spouse. Exclusion criteria were institutionalization, cognitive incapacity to take part in the study, or serious mental illness. Decisions about sample size were guided by **considerations around the** homogeneity of the sample, the completeness of each family case, and the redundancy of the gathered data (Benner 1994).

Data collection

Twenty-one family and 16 individual **unstructured**, face-to-face interviews were carried out by the first author six to 23 months after the death. Family interviews aimed to learn about family interpretations and practices with loss and set up a context to speak as naturally as possible (Benner 1994, Bell *et al.* 2000, Taylor & de Vocht 2011). Individual interviews sought to discern how individuals **understood** family processes and to better comprehend individual meanings and actions. Several interviews were held with each family over a time period ranging between ten to 23 weeks. The first interview began with an invitation to families to talk about the death and to portray their close other. A family genogram was drawn to understand family configurations (Rempel *et al.* 2007). The researcher invited participants to discuss what had happened since the death, and how they experience life without their significant other. Follow-up interviews served to further explore and complement families' and individuals' stories and descriptions. Field-notes were written

and included observations of the interview, reflections on the researcher's role and on participants' descriptions. Demographic information was collected with a short questionnaire. Interviews were held in (language). Data were transcribed verbatim, and anonymized transcripts entered into Atlas.ti version 7 for data management purposes.

Ethical considerations

The study was approved by the (name) Ethics Committee and the University (name) Research Ethics Committee. Each family member was contacted to obtain oral consent before the first interview, upon which each signed a written informed consent. Family members had the opportunity to renew or withdraw consent at any point of contact (Rosenblatt 1995). Families made decisions about the number, type and order of the interviews. Although they experienced painful moments during the interviews, no situation of emotional distress occurred that required further care. To ensure anonymity, code names were used.

Data analysis

To discern family meanings and actions, thematic analysis was conducted, which unfolded through a recurring process of reading and writing, developing interpretive questions and refining emerging lines of inquiry through moving between parts and the whole of the text (van Manen 1990, Benner 1994). Analysis commenced with single interviews, then moved back and forth between family cases and the whole data set, asking questions such as: "What is the main twist of the story told by each member and family?", "What is a description about, and why is it told in the way it is?" Initial thematic lines of inquiry were formulated from across cases by asking "How do thematic ideas arise across families?", "How is it the same or different for each family?", "Is there a family whose experiences, actions or concerns stand out as paradigmatic, i.e. illustrate thematic threads particularly well?", and substantiated by re-engaging with thematically organized text or particular cases until no new insights could be derived.

Rigour

The four validity criteria by Whittemore *et al.* (2001) were applied to this study. Credibility and authenticity were sought through a prolonged and repeated engagement with participants through multiple interviews that generated rich textual data, which has likely achieved completeness and redundancy in relation to the research question (Smith *et al.* 2009). To ensure criticality and integrity, the researcher explicated fore-understandings and engaged in ongoing critical reflection to render visible the imprints on the study (Geanellos 1998a, Geanellos 1998b). Regular interpretive team meetings were held, and analytical decisions were kept in a research log. Representative sections of transcripts were translated into English to facilitate joint interpretation (Santos *et al.* 2015).

FINDINGS

Participant characteristics are displayed in table one, and individual family cases in table two. Ten widow/ers (80±4 years) and their families, represented by adult children (n=14; 51±5y), grand-children (n=3; 20±4y), and in-laws (n=3; 77±4y) took part in 37 interviews lasting on average 82 (15-129) minutes, most often in their homes (n=30). All participants were of xx (country) origin.

Interviews revealed three family themes (table 3). First, bereaved families weaved the death into their family narrative. Second, through sharing-not sharing their feelings and daily moments, family members lived with the loss both together and alone. Third, some families faced upheaval in their family life, which required them to re-create their everyday life. In contrast, others continued with little disruption and change.

Theme one: Weaving the death into the family narrative

Families strived to make meaning of the death through the processes of *weaving the death into their family narrative*. This process involved constructing a positive family story of “a good death”, highlighting the uniqueness of the death compared to other existential family moments, and reflecting on the changes in their multigenerational family configurations.

Storytelling: “It was a good death”

Families’ interactively constructed a story of a “good death”. They understood their close other’s death as “good” because it had happened late in life and peaceful, as Keira, a

daughter, noted: "She simply fell asleep. (...) From that point; if it had to happen it could not have been better" (Fisher family). For most, the death occurred after a period of time that not only enabled them to feel prepared but also to fulfil their close other's preferences for the place of death. However, in some families, members lived with differing perceptions and lingering doubts about, for instance, the expectedness or the peacefulness of the death, as Ona, a widow, explained: "It was too bad that I did not get to the hospital in time. (...) I would have liked to know how he died, if he had suffocated?" (Gibson family). Gerard, a son, felt bad about not having been able to fulfil his mother's wish to die at home. Yet he created a positive meaning in that he found that "she probably could like let go in [name of respite care]" (Clarke family). Hence, participants derived positive meanings of the death no matter the exact circumstances. Families' interactive *storytelling* about the death created conciliation about the ways they had worked together during the end-of-life, and had handled the dying as a family, and enabled them to conclude an intense period in their lives in a positive manner.

Comparing-contrasting: "It's such a vulnerable family moment"

Family participants understood the death of their significant other as more immediate and consuming than previous deaths in or close to the family, as Marlene, a daughter, stressed: "When someone in the family dies, it's totally different" (Ferro family). It left families feeling vulnerable, as Sophie, a daughter said: "I've seen a few people pass away, but it astonishes me how raw you can feel, over how long a time when it's someone so close to you" (Mendes family). The death denoted a drastic moment and disrupted their lives similar to other extraordinary family moments, such as becoming a parent or seeing the children leave home, as the Patterson sisters explained:

Uma: You say this when you get children, right? Everything's somewhat relative. And when someone dies, you see things in a different light too. The big happenings, right?

Brigitta: That's something you can really say. If you would draw a scale of your life to see where there were turning points. That's one, of course, that's been one.

Comparing-contrasting was one family practice through which participants created a meaning of the death as an existential moment that was alike, yet different from previous

family situations. As such, families drew on their past experiences of incisive family moments to grasp the vulnerability that the death instilled in their family life.

Generational situating: “It’s different for everybody”

The death brought to light for each generation distinct insights about their own life. For spouses, the prospect of dying moved closer, as Henry, a spouse explained: “You don’t see it as hard anymore when you know your time comes. It doesn’t get at you anymore; you don’t chase it away and you know it’s not far away anymore” (Brown family). The second family generation gained new insights about their priorities in life. At the same time, they felt enabled to make choices about their own later and end-of-life. Adult children felt like they had received a last parental lesson about how to die in peace, as Susan, a daughter explained (Ford family):

And the whole dying phase (...) was a very formative experience. To experience (...) this finitude, you know, and all the stupid things we worry about. That’s something that I’ve taken away from it. I mean I have a different way of life now.

The third generation encountered death for the first time. Grandchildren faced an utterly unfamiliar experience during a sensitive time in their lives, during which they had to make important decisions about their future, and struggled with adolescence or young adulthood, as Charlotte, a 17-year old granddaughter said: “I’m more irritable. (...) Someone says something and I’m either completely pissed off or immediately very sad. It may be part of adolescence, but it’s become like amplified with grandpa’s death” (Graham family). Through the family practice of *generational situating*, families discerned the differences the death implied across generations.

Theme two: Sharing-not sharing the loss

Family sharing-not sharing surfaced as an oscillating, paradoxical relational pattern that was continually negotiated. It included knowing-not knowing how others in the family were doing, making decisions about revealing-concealing to other family members, and finding comfort or being burdened by others in the family.

Being together

Families engaged in various sharing practices. For instance, during festive occasions, families *remembered* the deceased to honour his or her legacy in their lives through sharing memories, talking about who the deceased was as a person, or making a reference to a typical characteristic. In everyday life, *talking and taking note* allowed family members to create awareness about each other's well-being and feelings around the loss. For instance, adult children made inferences about their parents' well-being based on the conversations they had, and by observing their behaviours and actions. Sebastian, a son explained: "When I visit her [mother] I basically know right away what kind of week she had because you can eat from the floor" (Ford family). Members found comfort from each other, as one granddaughter noted: "I had people around me. (...) That's why I was not pulled down so much, I was rather comforted: Something is now missing, but the basic bricks are still the same as before. And that has helped me the most" (Graham family). Finding comfort occurred through *talking*, as Edith, a widow explained: "It calms you when someone says something that you've not thought about. This happened a lot with my three [daughters] (...). I remember thinking: 'Look, you didn't get this idea on your own, it does you good'. It calms you" (Mendes family). Family members *enacted presence* during painful and sad moments, as Sophie said: "Standing by each other is unbelievably helpful. When you're feeling alone, then you can go to the other" (Mendes family). To alleviate spouses' aloneness, families *spent time* with each other. For instance, they took turns to spend Sundays with their widowed member and made an effort to be with their close other as often as they could, particularly during holidays, birthdays, or anniversaries. Families enacted sharing on manifold occasions and manners. However, reaching out was not always possible, and situations of aloneness co-occurred.

Being alone

Not-sharing arose when family members concealed their emotional upset or consciously refrained from sharing. Spouses in particular encountered daily moments during which no human presence could soothe the pain they felt, as Edith illustrated (Mendes family):

When I get back to the house and nobody is around. Even when a child is with me, but he's not there (cries). It happens all the time, right. I call out: „I am back!“. Doesn't give me an answer, right? But I call out anyway, just as I used to do it: „I'm back“.

Not-sharing also occurred when family members decided not to reveal their sadness, as Chlo, a granddaughter said (Fisher family):

When Mom's sad she doesn't want to tell me because I'm not sad at that moment. When I'm sad I don't want to tell her. (...) If it's happy things, I will speak to Mom about them. Or if I'm more really upset and then I feel even more sad, then I will speak to Mom because I know that she'd be upset that I'm alone and upset.

In their daily lives, family members made decisions from moment to moment about revealing or concealing based on their mutual concern and affection.

Theme three: Continuing to reconstructing family life

Two family transition trajectories became manifest in families' description of their lives after the loss. While some families faced considerable challenges within their family, particularly around family interactions and practical caring involvements, others did not.

Continuing: "Not much has changed for us"

Some families (ID 2, 3, 5, 6) experienced little change in their family lives. For some members within these families, particularly spouses (ID 3, 5, 6), death came as a release after a long, worrisome illness period and / or a constraining marriage, as Ida explained: "It simply hasn't been a shock. (...) Rather, it was a release. (...) I've been once well beyond everything, with my strength, right" (Graham family). While some members within these families deeply missed their close other's presence in their lives, the death did not unravel the established ways of being and doing family. Due to the confining presence that the deceased's disabling physical or mental illness had brought about while still alive, these families had previously re-created their interactions and activities before the death, as Ida continued to explain: "I've been alone long before my husband died because he's been so infinitely far away (...). I've been alone, but not lonely". The death enabled families to address issues that they had not been able to talk about previously, such as the family tensions inherent in caregiving, haunting illness memories, or difficult life situations in the deceased's past. Spouses were well able to manage on their own despite some health

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3 limitations, which reassured their families, as Ida's daughter Susan noted: "She organized
4 herself a good bit already before. And ... (reflects) very self-sufficient. Yes, and basically (...)
5 she embodied that (...). Well, we don't have to worry, we know she's managing" (Graham
6 family). Families' being and doing underwent little change with the death, and was marked by
7 stability and continuation.
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10 11 12 **Re-constructing: "We have to figure it out"**

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15 Other families faced upheaval that required them to reconfigure their family lives.
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17 They had lost with their close other someone who had welded them together through an
18 anchoring or connecting presence. Families were left with a painful void (ID 7, 9, 10) or
19 upheaval around family interactions (ID 1, 4, 8). For instance, the deceased's absence
20 instilled a dis-balance and required families to re-learn what individuals' concerns and
21 actions stood for, negotiate expectations, and craft new ways of doing family, as the example
22 of the Ford family illustrates. Sebastian, the son, explained:
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29 I have to take over [from the deceased] to a certain extent. (...) You need to learn
30 again to find out those things that really bother her, well, like helping her to balance
31 out. (...) When she is all worked up and you get a list of fifteen things, you don't
32 recognize the five central things anymore, and you wipe the whole thing away. Well,
33 we had to find ourselves (...). It's now that this void comes up in everything, with the
34 balancing, being here for-. (...) That's what's missing, and we try to fill it up a bit.
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36 In addition, these families worried about their widowed member's health or emotional well-
37 being. Hence, they intensified, rekindled or created new involvements to enact caring that
38 fitted their new situation. As a consequence, some family members became closer with each
39 other, for instance through the process of looking after their widowed parent, or by spending
40 more time together. Sara said about her relationship with her sister (Ford family):
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46 The closeness came about because my mother had (....) reacted very strongly and
47 (...) we were somehow able to look at the difficult stuff and put it into perspective. (...)
48 We talk about that Kirstin does a lot and I don't, and what that's like when she does a
49 lot and it's never enough. And then we get to this good place where we don't have to
50 change anything.
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52 In the wake of loss, these families had to re-create their family being and doing. While they
53 faced some conflict and a painful void, and had to mutually negotiate relationships, they also
54 took away new insights about their family, and felt assured and confident for their shared
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future, as Louis, a widower explained: “You did see our connection, that [it] was real, right” (Ferro family).

DISCUSSION

This study revealed that families’ bereavement experience involves a world that is shared, and a world that lies apart. Families live with their loss together as they integrate shared meanings into their family narrative, enact community through connecting in daily life, and move together to continue or re-create their family life without the deceased. Yet, life with loss unfolded in diverging ways for individuals of the same family, and involved disconnection during moments in which members did not want to, or could not share. Death happens to “a family”, but affects members and generations in unique ways.

Families’ research participation created a facilitated space for them to construct meanings of the death through the family practices of storytelling, comparing-contrasting, and generational situating. This study demonstrates that families co-construct their narrative in a way that helps them to find peace with their experience of death (Attig 2001, Kiser *et al.* 2010, Koenig Kellas & Trees 2013). Previous research has found that meaning-making of a death or a difficult life event occurs during ordinary family conversations (Nadeau 1998, Koenig Kellas & Trees 2006, Trees & Koenig Kellas 2009). Such everyday “family speak” allowed families to interlace “individual threads of meaning” (Nadeau, 1998, p. 148), and, similar to this study, unfolded through telling stories and making analogies. Creating a family story of the death is a public act that reveals the “family in operation” (Langellier & Peterson 2006) and enables them to come away with a meaningful, shared story which they are able to live by (Rober & Rosenblatt 2013), even when circumstances were painful (Koop & Strang 2003, Dumont *et al.* 2008). This study suggests that families construct death in positive ways to grasp it as an incisive family moment that holds generation-specific ramifications, bringing about existential reflections (Black & Santanello 2012).

Family sharing-not sharing surfaced as an ambiguous but complementary relational process in bereavement. It suggests that family community and aloneness coexist through the interplay of differing forces that move people together and apart (Hartrick 1995, Baxter

2004, Parse 2009). The current debate about grieving families may thus overemphasize the importance of open family communication and closeness. This study questions the widespread assumption that family members need to talk about their emotions in order to adapt to their new situation, alleviate their pain, and forego a sense of alienation (Walsh & McGoldrick 2013). Kissane and colleagues (1996a, 1996b) found that those families who tend to feel close, share their distress, and have no or little conflict experience few adverse individual outcomes and adapt well to their new family situation, in contrast to families who do not speak with each other, feel estranged, have some conflict, or do not share emotions. However, in line with an evolving body of research, this study suggests that not-sharing, expressed as not-talking and concealing emotions may be as vital to families' well-being as is sharing through talking and revealing (Stroebe *et al.* 2005, Baxter 2006). Such a seemingly contradictory way of living relationships already occurs during end-of-life care. In one study, connecting-disconnecting was the main pattern of intimacy and sexuality in couples' relationships when facing a life-limiting illness (Taylor 2014). In another study, "being me and being us in a family" constituted families' "striving for the optimal way of living close to death" at home (Carlander *et al.* 2011). The negotiation of talking-not talking and revealing-concealing has also been found in couples' relationship after the death of a child (Hooghe *et al.* 2011, Hooghe *et al.* 2012, Bergstraesser *et al.* 2014). Couples faced their young child's loss by negotiating the closeness they could bear to the pain of loss, and the distance they needed to live with the child's absence. It has been postulated that protectionism is a reason for not-sharing (Nadeau 1998, Moss & Moss 2014). Confronting and avoiding the loss may thus both be needed to regulate grief (Hooghe *et al.* 2011, Hooghe *et al.* 2012). However, those aspects in people's grief experience that entail intense suffering remain utterly unsharable, and are an expression of existential aloneness (Stroebe *et al.* 2005, Wilkinson 2005).

Later life families seem to either experience continuity or disruption after the death of an older member. Participants' new family situation brought to the fore concerns related to widow/ers' health, ability to manage alone and care needs. The death of a family member

may increase tensions, and bring about the need to negotiate ambiguous and contradictory feelings and expectations around caring commitments between generations (Luescher & Pillemer 1998, Ingersoll-Dayton *et al.* 2003, Ha & Ingersoll-Dayton 2008). At the same time, an augmented sense of closeness, or inner-family strength arose for participants from their ability to share life in different and new ways (Greeff & Human 1994). Prior research reported that bereaved families felt strengthened in their family “we” (Black & Santanello 2012). Following the death of a parent, couples may experience greater closeness since they share a new awareness that they had gone through something painful together that enabled them to experience mutual support and understanding (Rosenblatt & Barner 2006). However, not all families experience changes in their family caring. The extent of continuity experienced by some of the families suggests that later life families may experience a relational loss unrelated and prior to the death, for instance due to emotional distance or chronic illness, which forced them to forge new relationships and caring practices (Schulz *et al.* 2008, Stajduhar *et al.* 2010). Hence, death may come as a relief when the work of caregiving or marriages were particularly challenging (Schulz *et al.* 1997, Pruchno *et al.* 2009). Relationships between surviving family members may exhibit remarkable stability, as instrumental and emotional support from children undergoes little change when one parent becomes widowed (Utz *et al.* 2004, Ha *et al.* 2006). This was also true for some family participants, yet not for others in this study. The coexistence of both change and continuity in this study somewhat questions the widespread assumption that peoples’ taken-for-granted life-world (Attig 2004), or the equilibrium of their system is inherently disrupted by a death (Walsh & McGoldrick 2004, Walsh & McGoldrick 2013), as some families in this study experienced little changes in their ways of being and doing family following the death.

Limitations

The sample was limited to ten multigenerational families who had experienced an age-normative death and who found a common ground to speak about their loss to an outside person. Most family members were spouses and adult daughters, thus, the voices of some family members are only marginally or not represented. Families with non-traditional

ties, estranged relationships, constrained family resources, or inability to talk about the death could not be recruited into the study. Findings will therefore not capture the full variance of families' bereavement experience. Every effort was undertaken to be reflective of the manners in which the researchers' own positions and pre-understandings have influenced the study. Inevitably however, not all influences could be made conscious. Despite efforts to do so, not every way that the researchers' own perspective shaped the interpretation could be made explicit (Gadamer 1975/1989, de Witt & Ploeg 2006).

CONCLUSIONS

This study revealed that families hold an inherent capacity to make meaning of an age-normative death and to enact family thereafter. Findings support narrative approaches to bereavement care (Moules & Streitberger 1997, Hedtke & Winslade 2004) and family models that emphasize the multivocal and paradoxical nature of family health (Baxter & Montgomery 1996, Doane & Varcoe 2005, Parse 2009). Nurses working with bereaved families should first, assess whether families have a need for follow-up care; second, provide primary bereavement care that entails an opportunity for families to ask questions, talk about the end-of-life and dying itself, and receive information; and third, create access to specialist bereavement care as needed (National Institute for Clinical Excellence 2004, Agnew *et al.* 2010). In so doing, they can invite storytelling to facilitate meaning-making. "Remembering conversations" create an opportunity to shape and re-shape meanings with others (Hedtke 2014). It is important that nurses appreciate the diversity in families' loss experiences and are aware that families differ considerably in the change they experience after a family death. They should recognize that there are moments that cannot be shared, and feelings that persons choose not to divulge. Taking a stance of non-partiality, and without a pre-set agenda for solutions, they can create a space for families to talk about their needs, hopes, and concerns for the future. Nurses may explore with individuals and families how not-sharing might be helpful, and how sharing may be comforting (Moules *et al.* 2007, Hooghe 2012, Kissane & Dumont 2014). When nurses attend to families' abilities to share, and thematise their adversities or choices to not share, they can strengthen family relationships

through increasing family members' mutual understanding and respect. Hence, relationship-focused, health-promoting family interventions that aim to strengthen family relations and to build skills in communicating, working with differences, and creating viable solutions to concrete problems may be most suited to support bereaved families (Martire 2005, Chesla 2010, Thirsk & Moules 2013, Rumbold & Aoun 2014).

As one of only a few family bereavement studies whose methodology capture the interactive nature of families' experience, this study's interpretive potential lies in its capacity to enlighten clinicians in their understanding of families' bereavement situations in later life. Further research into diverse families and family health and response patterns is necessary. Longitudinal designs and the inclusion of more than one member allow for a better understanding of how family bereavement unfolds over time. Further inquiry is needed into how families' needs are best assessed, and which families in which circumstances experience an additional burden and suffer more because they lack professional attention. When evaluating family bereavement interventions, it is important to capture the oscillating, paradoxical family processes and avoid privileging one indicator over others, such as closeness, affection, or emotional disclosure. Research should also attend to the intervention processes to render visible the mechanism through which family well-being is achieved.

Funding Statement: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Conflict of Interest Statement: No conflict of interest.

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Table 1: Participant characteristics

Families	n=10
No of participating members mean (range)	3 (2-4)
Family composition n(%)	
Spouse, adult child(ren)	6 (60)
Spouse, adult child, grandchild(ren)	2 (20)
Spouse, adult child, sister / brother-in-law	2 (20)
Age of the deceased mean (range)	81 (76-86)
Place of death n(%)	
Home	5 (50)
...Hospital	3 (3)
...Respite care	2 (20)
Cause of death n(%)	
Cancer	4 (40)
...Chronic lung disease	2 (20)
...Heart failure	2 (20)
...Acute infection	1 (10)
Alzheimer's disease	1 (10)
Professional home care before the death n(%)	8 (80)
Family members	n=30
Relationship to deceased n(%)	
Spouse	10 (33.3)
Adult child	14 (46.7)
Grandchild	3 (10.0)
Brother or sister-in-law	3 (10.0)
Age mean (range)	60.4 (17-88)
Female n (%)	23 (76.7)
Marital status n(%)	
married / partnership	17 (56.7)
widowed (spouses only)	10 (33.3)
separated / divorced / single	3 (10.0)
Number of children n(%)	
≥3 children	10 (33.3)
1-2 children	17 (56.7)
no children (grandchildren only)	3 (10.0)
Education in years n(%) (n=29)	
≤ 9 years	11 (37.9)
10-12 years	8 (27.6)
≥ 13-16 years	10 (34.5)
Ability to manage with monthly income (%) (n=29)	
Easy to manage	14 (48)
Rather easy to manage	10 (35)
Sometimes difficult to manage	5 (17)
Difficult to manage	0 (00)

Table 2: Family participants

Family*	Family members*	Relationship to deceased	Caregiving situation	Age at, cause & place of death*	Interviews	Duration
Clarke (01)	George (88y), Gerard (57y), Barbara (54y)	Widower, son, daughter	End of life family and home nursing care for 2 months	Bertha (87y) died of cancer in respite care	3 family	4:11h
Brown (02)	Henry (84y), Victoria (59y)	Widower, daughter	Family and home nursing care for 4.5 years	Molly (84y) died of Alzheimer's disease in respite care	2 family 2 individual	6:14h
Ferro (10)	Louis (81y), Marlene (48y), Harry (80y), Helen (73y)	Widower, daughter, brother & sister-in-law	-	Ella (76) died of sudden cardiac arrest at home	3 family 1 individual	4:40h
Fisher (05)	Marcus (83), Keira (54y), Chloé (18y)	Widower, daughter, grand-daughter	Family and home nursing care for about 2 years	Elizabeth (82y) died of COPD at home	2 family 1 individual	5:11h
Ford (08)	Alice (78y), Sebastian (49y), Kirstin (50y), Susan (52y)	Widow, son, 2 daughters	End of life family and palliative home care for 3 weeks	Alfie (80y) died of prostate cancer at home	1 family 4 individual	7:58h
Gibson (03)	Ona (81y), Emma (61y)	Widow, daughter	Family and oncology home care for 2 years	Arthur (81y) died of lung cancer in hospital	1 family 3 individual	3:49h
Graham (06)	Ida (78y), Susan (48y), Nina (24y), Charlotte (17y)	Widow, daughter, 2 grand-daughters	-	Joseph (78y) died of heart failure at home	3 family 1 individual	6:13h
Mendes (09)	Edith (75y), Sophie (46y)	Widow, daughter	End of life family and palliative home care for 2 months	Carlos (81y) died of prostate cancer at home	2 family	2:39h
Patterson (07)	Isabelle (81y), Brigitta (49y), Uma (42y)	Widow, 2 daughters	Wound home care	Paul (81y) died of an acute infection in hospital	2 family 1 individual	4:16h
Richard (04)	Rosa (75y), Maria (77y), Stella (50y)	Widow, sister-in-law, daughter	Family and home nursing care for 2 years	James (80y) died of COPD in hospital	2 family 3 individual	5:37h

* Code names were used throughout the study.

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Table 3: Thematic overview

Main themes	Family practices (sub-themes)
Weaving the death into the family narrative	Storytelling Comparing-contrasting Generational situating
Sharing-not sharing the loss	Being together Being alone
Continuing to reconstructing family life	Continuing Re-constructing

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Impact Statement

This study takes a relational approach to understand families' interactive experience when they are faced with the death of an older member. Since grief has predominantly been studied as an intrapersonal process from the perspective of bereaved spouses or carers, families' situation and interactions following a loss late in life is poorly understood. This qualitative study informs family-centred, relationship-focus end-of-life and bereavement care across a variety of settings and is of particular interest to nurses, but holds relevance to a broad range of health professionals who are working with older persons, carers, and families in later life.

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