A WORLD SHARED - A WORLD APART:
THE BEING AND DOING OF FAMILY
AFTER A CLOSE OTHER HAS DIED LATE IN LIFE
A HERMENEUTIC-PHENOMENOLOGICAL STUDY

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A world shared – a world apart: The being and doing of family after a close other has died late in life. A hermeneutic-phenomenological study

In later life, the death of a family member occurs most often after a challenging time of family caring. It denotes a dramatic event in families’ lives, and involves intense feelings for all. To date, bereavement has mainly been investigated as an intrapersonal process from the perspective of family carers or widow/ers. Little is known about families’ experience when an adult member has died. A review of pertinent literature located only six adult family bereavement studies, which exposed the importance of family cohesion, communication and emotion, and found that family characteristics denote the background from which families make sense of the death. Despite these insights, a dearth of research exists about families’ lived relational world after a death late in life. Such knowledge is needed to better grasp bereaved families’ life-world and to discern their capacities and adversities, which shape their support needs.

The purpose of this hermeneutic-phenomenological inquiry was to disclose meaning patterns and practices of families living with the loss of a close other. It included ten bereaved community-dwelling families, represented by widow/ers (mean age 80y), adult children, in-laws and grandchildren (n=30). Family was defined as a situated, relational involvement by those who feel close, and living with loss was seen as a process of changing relationships. A combination of in-depth family group (n=21) and solo interviews (n=16) were held six to 23 months after the death, and field-notes were written. The thematic and narrative analysis, embedded in a hermeneutic movement, involved reading, reflecting, and writing about gleaned data, fore-understandings, and emerging insights.

Findings revealed that families’ life with loss is a world shared, and a world apart. Families collectively looked back to weave the death into their family narrative, and in so doing, constructed a story of a good death, compared-contrasted it with other deaths and events, and situated it within their multigenerational family context. Families lived with their loss by sharing-not sharing interpretations and daily lives. They connected via remembering, talking, spending time, and enacting presence, but they disconnected for a variety of reasons. Families moved forward by continuing or reconstructing their family being and doing. While some families faced upheaval, others continued with little change.

These findings need to be seen as situated, temporal constructs of prolonged researcher-participant engagements. They yield insights into families’ world based on the accounts of ten traditional families. Even so, this study adds a much needed empirical family perspective on bereavement. Family relations arose as interplay of different, contradicting forces at play, which moved members together and apart in their daily lives with loss. As such, it supports family models that emphasize the multivocal, relational, contextual, and continuously shifting nature of family health. It revealed that families hold an inherent capacity to make meaning of the death and enact family thereafter, and understand their relationships as resource. Thus, families may not need professional therapeutic interventions to redress their “functioning” or to avert “adverse” outcomes, but health promoting and relationship-strengthening care and services. Nurses can be helpful to families by facilitating meaning-making, strengthening family relations in a way that values multiple voices at play, and by supporting family transition and caring in light of present concerns.
Declaration

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Dedication

I dedicate this thesis to the families who have so generously contributed their time and energy to this research, and offered a glimpse into their lives. This research will hopefully fulfil their intentions to be of help to others; those living close to death and experiencing bereavement, and those who are caring for them.

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I would like to express my sincere appreciation to my supervisors, Gunn Grande and Richard Ward, who have contributed immensely to this thesis. Their ongoing engagement with pieces and bits, ideas, lines of inquiry, notes, drafts, and more matured and polished versions of this thesis have helped it to come into its current form. I am indebted to their inquisitiveness, critical thought, time investments, encouragements, and belief in my ability to complete this work. It has been such a wonderful and rewarding collaborative experience, thank you!

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Lastly, I would like to recognize the Institute of Nursing at the Zurich University of Applied Sciences, which allowed me to use salaried time towards this thesis. I also sincerely thank the Ebnet Foundation for funding my tuition fees, and for doing it in such a flexible manner. Finally, I would like to acknowledge the support of the health and social care organizations that have provided me with access to research participants.

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The author

I am a nurse by training, and have obtained my basic nursing diploma in Switzerland in 1996. Subsequently, I earned my Bachelor’s degree (honours) in Nursing Science from York University (2004), and my Master’s degree from the University of Toronto (2006), both in Canada. Since 2010, I have been a postgraduate research student at the School of Nursing, Midwifery and Social Work at the University of Manchester in England. My background is in acute care, advanced nursing practice, and family health (with a focus on persons with advanced lung disease / lung transplant, and more recently on older persons / families living in the community). After my graduate studies, I have been working as a clinical nurse specialist leading quality improvement projects that focused on promoting nurses’ competencies in patient- and family centred care in acute settings, and subsequently as a nurse researcher.

I have first been involved in clinical research as a study nurse (see for instance [1]). During my graduate studies, I carried out a phenomenological research project investigating the experience of waiting as lived by persons on a waiting list for a lung transplant [2]. Since then, I have been the project manager of a randomized controlled trial testing an advanced nurse in-home consultation programme with older persons, for which I have recently co-received the Swiss Quality Award 2014 [3]. Further, I have been involved in a participatory action research project to develop and implement a nurse-led family counselling programme for families of older persons [4], and a qualitative investigation into home care admission from the perspective of older persons, family members, and staff (project lead: Prof. Dr. Andrea Koppitz). For my dissertation research, I have focused on families’ bereavement experience in a later life context (with Prof. Dr. Gunn Grande and Dr. Richard Ward) [5].

Published research


1. Introduction

Families in later life: Facing end-of-life, death, and bereavement

The parting of a close other through death is beyond the imaginable, a mystery of human life that eludes control, predictability and certainty, even though it is a universally shared fact of human existence (Attig, 1996; Wedemeyer, 1986a). Death is integral to family life, and the lived situation of family members involves inevitably that they experience the death of a close other at one time or another. In later life, the loss of a close other is particularly common. In Switzerland, where the study took place, almost two third of persons die when they are older than 80 years old (Swiss Statistics, 2013a, c). Such a death late in life reflects a trend in European countries that people are more likely to live into old age (European Commission, 2011). Although persons increasingly tend to enjoy wellbeing until late in life, they nonetheless die most often following a period of persistent illness for which they received family care (Hudson, 2013; Schulz et al., 2001). It is estimated that up to two third of persons die of a progressive illness, such as cancer or heart disease following an illness time lasting two to three years, and about 30-40% die following a prolonged period of disabling illness, mostly dementia, over a period of eight to ten years (von Wartburg and Näf, 2012). Less than 5% of persons die a sudden death.

Families play a crucial part in enabling their close other to remain at home as long as possible (Brink and Smith, 2008; Funk et al., 2010; Gomes and Higginson, 2006, 2008; Grande and Ewing, 2008; Singer et al., 2005), and about 17 to 40% of persons do indeed die at home (Federal Interagency Forum on Aging-Related Statistics, 2012; Fischer et al., 2004; Kate et al., 2010; Weber et al., 2012). Caring for a close other who is very ill and dying holds unique challenges in relation to the limitations, uncertainty and suffering inherent in the situation, the provision of practical care, the organization of professional support, and the fact that a shared life is ending (Andershed, 2006; Carlander et al., 2010; Grande et al., 2009; Hudson et al., 2012; Kreyer and Pleschberger, 2014). Spouses or intimate life partners, as well as adult children take on the majority of the responsibility and practical aspects of caring (Brotman et al., 2007; Conidis, 2010; Imhof et al., 2011a; Perrig-Chiello et al., 2010). Families often face the death after a challenging time of intense family caring, seeing suffering, and providing (end-of-life) care at home (Agree and Huges, 2012; Carr et al., 2006b; Martin-Matthews, 2011; Perrig-Chiello et al., 2010; Schulz et al., 2001; von Wartburg and Näf, 2012).
Families’ relationships and long standing habits and practices denote the background from which they live through intense family caring at the end-of-life and into bereavement (Chambers et al., 2009; Hayslip and Page, 2013). The death of a close other affects entire family groups (Gilbert, 1996; Hayslip and Page, 2013; Rosenblatt, 2013; Shapiro, 2001; Walsh and McGoldrick, 2013). A family death may upset family interactions and practices, and call for the re-negotiation of family relationships and organizations in everyday life (Berger and Weiss, 2009; Chambers et al., 2009; Jeffreys, 2011; Rycroft and Perlesz, 2001; Shapiro, 1994; Shapiro, 2001; Walsh and McGoldrick, 2004a, 2013). It has been demonstrated that after a death, families engage in a collective process of finding meaning in light of their family identity, rules, and beliefs (Black and Santanello, 2012; Black et al., 2014; Nadeau, 2001b).

Nonetheless, families’ experience of loss after the death of an older member, in contrast to the experience of individuals, has scarcely been investigated (Hayslip and Page, 2013; Hudson and Payne, 2011; Moules et al., 2007; Rycroft and Perlesz, 2001; Walsh and McGoldrick, 2013). While a consensus has evolved that most surviving family members are able to come to terms with their grief with the support of their families and friends in their local community contexts (Aoun et al., 2012; National Institute for Clinical Excellence, 2004; Rumbold and Aoun, 2014), little is known about families’ lived relational world; that is, how families find and provide support, and the interactive nature through which their living with loss unfolds. Hence, the relational experience and support needs of family groups, rather than individual, surviving family carers, are little understood. Moreover, even though deaths occur most often in later life, there is a paucity of research on grief and bereavement that focuses especially on a later life context (de Vries, 2012; Hansson and Stroebe, 2007). The current lack of knowledge about family bereavement clearly points to the need to increase understanding of the unique situation that bereaved families encounter as a group of interconnected people who experience a change in relationships through death late in life (Hayslip and Page, 2013; Moules et al., 2007; Stroebe et al., 2001; Thirsk and Moules, 2013). Such knowledge is needed to identify families’ capacities and adversities that give rise to their support needs.

Nurses are well positioned among health professionals to support families who are facing a loss through death (Lyttle 2005; Moules et al., 2007; Nagraj and Barclay, 2011; Thirsk and Moules, 2013; White and Ferszt, 2009). However, a lack of training in how to work with families, and deeply engrained normative understandings of
grief may inhibit meaningful care for families (Agnew et al., 2010; Birtwistle et al., 2002; Hudson and Payne, 2011; Moules, 1998; Nagraj and Barclay, 2011; National Institute for Health and Care Excellence, 2011). Nurses also face structural limitations, mainly due to resource constraints (Hudson and Payne, 2011; Hudson et al., 2012; Malone, 2003; Varcoe and Rodney, 2002). Therefore, families may lack access to nursing support following end-of-life and the death of their close other, and even when they do have access, they may not receive the care they need (Higginson et al., 2007; Hudson, 2013; Payne and Grande, 2013; Stajduhar et al., 2010a; Stephen et al., 2013). However, in order to be able to provide meaningful and relevant family-centred care, and to offer interventions to bereaved families, nurses need an in-depth understanding of families’ experience of loss and unfolding everyday lives without their close other. As a consequence, families’ experience of living with loss in later life after an older person’s spouse or intimate partner has died is the central phenomenon of concern for this interpretive inquiry.

In the following, first, a more detailed background to family relations as they unfold in later life through caring and end-of-life is given to illuminate the context from which families enter bereavement. In so doing, the unique challenges that families face in the time leading up to their close other’s death and beyond are emphasized, and the heteronormative assumptions that underlie the majority of family caregiving and end-of-life research are noted. Then, the specific background situation to this interpretive study is brought to light. Local health policy constraints that exist in bereavement care are pointed out, and the researcher is situated in her lived world of clinical care, research, and family nursing. Next, current perspectives about grieving families are reviewed to pave the way for a conceptualization of family as a situated, relational involvement by those who feel close, and of living with loss as a process of changing relationships. A brief overview of the current state of research about bereaved families and family bereavement support follows thereafter to delineate a need for further systemic inquiry about families’ lives with loss. In so doing, it is claimed that such knowledge is needed to inform nurses’ work with families after a close other has died late in life. As the reviewed research about bereavement care indicates that bereaved families value nursing support, the role of family nursing in bereavement care is highlighted. Subsequently, the current state of family bereavement care is outlined, emphasizing the structural problems in health care more in depth, and bringing to the fore a call to action. To conclude this chapter, an overview of the content of this PhD thesis is presented.
1. 1. **Illuminating the context: Families in later life**

In today’s society, families are not a uniform configuration of particular persons, but a rather diverse and manifold grouping of people who feel committed and care for each other (Connidis, 2010; Voorpostel, 2012). Who is family for any given person evolves and shifts over time, with persons coming and leaving the family through birth, death, new connections, and separations (Connidis, 2010; Parse, 2009). The meaning of family is therefore ever-changing depending on the perspective and situation of those involved (Cody, 1995b; Hartrick, 1995). Current understandings of family in health and social care have started to move beyond literal configurations of persons arising from a shared origin, marriage, or from procreation, including a distinct composition of people holding a certain gender, function, or responsibility. Even so, heteronormative assumptions continue to pervade family research and practice (Calasanti and Kiecolt, 2012; Connidis, 2010). Non-traditional family groupings have been less researched, which limits the knowledge base about family caring in later and at the end of life to more traditional family ties (Silverstein and Giarrusso, 2010). It is posited here that family caring is a relational process that transcends normative assumptions, and is expressed through shared actions, involvements, and commitments (Hartrick Doane and Varcoe, 2005b).

1. 1. 1. **Challenges at the end of life and in bereavement**

In later life, the death of a close other occurs most often after a period of family caring (Koop and Strang, 2003; Schulz et al., 2001; Schulz et al., 1997). Spouses or intimate partners provide most of the care, as do adult children, of which a majority are women (Connidis, 2010; Pruchno and Gitlin, 2012). In a recent study co-authored by the researcher, community-dwelling persons 80 years or older reported that their primary person of support was a spouse (27% of total, 83% of married only sample), or an adult child (55%) who were on average 61 years old and mostly women (62%) (Imhof et al., 2011a; Imhof et al., 2012). In the context of disabling, multiple chronic conditions in later life, family caring is time-intense, with many hours each week that is spent on caring (Perrig-Chiello et al., 2010). Family caring at the end-of-life holds unique challenges for those involved, and entails difficult, upsetting emotions, vulnerability and exposure to suffering, practically demanding and physically strenuous situations, and feelings of uncertainty and helplessness (Andershed, 2006; Borland et al., 2014; Funk et al., 2010; Grande et al., 2009; Stajduhar et al., 2010b). Sharing end-of-life as a family or couple also holds positive
meanings, and leaves carers feeling strengthened and affirmed in their situation (Andershed, 2006; Carlander et al., 2010; Funk et al., 2010; Hudson, 2004). Calendar and colleagues (2011) found that living close to death as a family whose terminally ill member is at home involves a balancing between being a family and being an individual who faces the impending death. Individual members’ experiences involved feeling alienated, on hold, handling the responsibility of care, and being constantly reminded of the death by seeing the failing body. The family experience, in contrast, was marked by a need to reach out across the silence around the death, affirming their views of the kind of family they were, and moving forward in developing a plan for the death.

Although families use professional services that support them in their care at home, they feel primarily responsible and carry the brunt of care (Carlander et al., 2010; Grande et al., 2009). Studies found that families often feel alone with their responsibility and practical task in caring for their loved one and have unmet needs, while they also find security, hope, reassurance and concrete help from professional home-based services and their social network (Bee et al., 2008; Funk et al., 2010; Payne et al., 2010; Stajduhar et al., 2013). A lack of helpful communication and information about the illness course, the practicalities of caring for a dying member, and about the services available has consistently been reported in studies, adding to families’ challenges in caregiving (Akiyama et al., 2010; Harrop et al., 2014; Jo et al., 2007; Weber et al., 2012). Even though family caregivers may not receive adequate and needs-based care, many have access to home nursing and specialized palliative services during end-of-life (Grande et al., 2009; Hudson and Payne, 2011). However, they usually lack this possibility following the death of a close other, even though a need for follow-up services has been found and recognized as an area of needed improvement (Department of Health, 2005; Funk et al., 2010; Milberg et al., 2008; National Institute for Clinical Excellence, 2004; National Institute for Health and Care Excellence, 2011).

Families take their unique, intense experiences and memories of caregiving and end-of-life care with them as they face life without their close other. Research to date remains somewhat inconclusive about the effect of caregiving on bereavement, but overall suggests that it can have both, positive and negative effects on individual health and well-being (Breen, 2012; Ghesquiere et al., 2011; Hansson and Stroebe, 2007; Kelly et al., 1999; Koop and Strang, 1997; Schulz et al., 2001; Schulz et al., 2008; Schulz et al., 1997; Stajduhar et al., 2010b; Stroebe et al., 2007). It is hypothesized that caregiving may be helpful and prepare families for bereavement.
because individuals within families may expect and plan for a life without the close other, feel relieved about an end to their close other’s suffering, and might already have organized themselves as a family who supports each other before the death (Dumont et al., 2008; Schulz et al., 2003). Positive experiences for bereaved caregivers include a sense of accomplishment, strengthened family relationships, and having been close to the reality of dying (Brazil et al., 2002; Dumont et al., 2008; Kim et al., 2011; Koop and Strang, 2003). In contrast, exhaustion and ill health from caregiving, missing the close other, memories of difficult decisions, images of suffering, and challenging circumstances during caregiving and the death, financial concerns, and conflicted relationships within families have been reported to compound the challenges in grieving for individual family carers (Boerner et al., 2004; Brazil et al., 2003; Dumont et al., 2008; Koop and Strang, 2003; Sanderson et al., 2013; Stajduhar et al., 2010c).

1.1.2. The unique challenge of losing a spouse / intimate partner in later life

Members of the oldest generation are often the family members to be particularly and profoundly affected when a close other needs care, and eventually dies. With increasing age, older persons have to get by without many of those with whom they have shared much of life’s joys and sorrows (Lalive d’Epinay et al., 2009). Although the loss of siblings and friends is most frequent among those aged 80 years or older, the death of a spouse or life partner affects older persons in intimate ways and holds unique consequences for daily life (Lalive d’Epinay et al., 2009; Williams et al., 2006). In Switzerland, the loss of a spouse occurs on average when women are 71 and men 74 years old, with women becoming widowed more often and at a younger age than men do (Federal Interagency Forum on Aging-Related Statistics, 2012; Swiss Statistics, 2009; Williams et al., 2006).

Some controversy exists about the nature of partner loss for older persons. While some suggest that old age prepares persons for bereavement because of their experience in dealing with stressful life events, and their expectancy of and preparedness for the loss, others propose that partner loss is particularly difficult given the nature of the relationship, and the fact that age-related changes, chronic illness, and adverse health arising from caregiving may lead to an accumulation of losses (Boerner et al., 2004; Carr, 2008; Gilbar and Ben-Zur, 2002; Hansson and Stroebe, 2007; Moss et al., 2001; Stroebe et al., 2007). Indeed, the loss of a life partner not only ends an intimate and long-standing relationship, but uproots
personal identities, social roles, and established activities in daily and family life (Carr et al., 2006a; Carr and Pudrovska, 2012; Moss et al., 2001). Moreover, in later life, other, non-bereavement related losses pose many emotional and practical challenges for older persons, like facing failing health and symptoms, struggling with one’s limitations during everyday activities, living with an increased need for support, maintaining social connections and a sense of belonging, reviewing one’s life, and having hopes for the future (Crist, 2005; Easley and Schaller, 2003; Hinck, 2004; Montbriand, 2004; Nicholson et al., 2013; Wondolowski and Davis, 1991). Although it has been reported that newly widowed older persons have a higher mortality risk (Elwert and Christakis, 2008; Martikainen and Valkonen, 1996; Stroebe et al., 2007), experience higher rates of institutionalization (Nihiiliä and Martikainen, 2008), and more depression, despair and distress than their non-bereaved peers (Bennett, 1997a, b, 1998; Kanacki et al., 1996; Onrust and Cuijpers, 2006; Shah and Meeks, 2012), only a minority of widowed persons are diagnosed with clinically significant depression (Bonanno et al., 2005; Carr, 2008; Lobb et al., 2010). As a consequence, there is a rising consensus that while partner loss is a unique and profound loss, most older persons are resilient and well able to cope with their new life situation (Arthur et al., 2011; Bonanno et al., 2008; Bonanno et al., 2004; Hansson and Stroebe, 2007). Research has also demonstrated that older, bereaved persons’ social network is an important source of support (Brazil et al., 2003; Ha et al., 2006; Kanacki et al., 1996; Kaunonen et al., 1999). Studies have found that interactions with and support from adult children are strengthened within the first six months following the death of a spouse, with widow/ers experiencing an increased dependence on adult children for various types of support, such as emotional, financial / legal, and instrumental support (Ha, 2008; Ha et al., 2006; Ha and Ingersoll-Dayton, 2008; Lalive d’Epinay et al., 2009). It is likely that families, in particular children, continue to look after their surviving member or rally around him or her during the initial months that follow the death. In contrast, research found that same-sex partners receive less support, and may even be excluded from the deceased’s family (Bent and Magilvy, 2006; Whipple, 2006). While it has been suggested that the grief experience of same-sex partners unfolds in similar ways than for married persons, their grief may remain unrecognized and become disenfranchised, which compounds the challenges and suffering associated with grief (Bonanno et al., 2005; Connidis, 2010; Green and Grant, 2008).

In summary, family members face profound and unique challenges at the end-of-life of their close other, and into bereavement. The reviewed research points to the
diversity that exists in family caring and in spousal bereavement in later life, attends
to changes in relationships that occur in illness and through death, and their
implications for individuals’ health and quality of life. What is missing is an attention
to the complex, multi-layered, and interactive manner in which family experiences
unfold in the wake of loss, when most health and nursing services withdraw.

1. 2. Situating the study in the local health care context

In the local Swiss context, similar to other countries, nurses and family physicians
are often the ones to be most involved with families who provide care to an ill or
dying member, particularly so in primary care and in the community (Lyttle 2005;
Nagraj and Barclay, 2011). Community-based, end-of-life care is delivered through
general practices, home nursing care and sometimes by specialized palliative
services. Primary and home-based care services are established and accessible
parts of the Swiss health care system. As 75% of those receiving home nursing care
are 65 years or older, it is likely that older persons use home nursing particularly
during their last years of life (Swiss Statistics, 2013b). In 2010, the Swiss
government launched a national strategy to establish palliative care as an integral
part of primary care to close gaps in access, and to increase the availability of
specialized care (Binder and von Wartburg, 2010; von Wartburg and Näf, 2012). At
present, outpatient nursing services that provide specialized home palliative or end-
of-life care exist, but they tend to be only available in urban areas and for cancer
populations, and often lack the recognition and integration into the established
system of institutional care, such as acute or long term care, or community-based
services provided by general home care nurses and physicians (Imhof et al., 2013;

1. 2. 1. Caring for bereaved families: The current context

Within the Swiss national palliative care strategy, close others are defined explicitly
as co-recipients of care (Binder and von Wartburg, 2010; Eychemüller et al., 2001;
von Wartburg and Näf, 2012), reflecting an international trend that increasingly
acknowledges the essential part that family carers have at the end of life (Help the
Hospices, 2009; World Health Organisation, 2002). Over the last years, practice
initiatives to establish family-centred care, and efforts to recognize family carers as
the legitimate recipients of nursing support in their own right have increased (Imhof
et al., 2008; Kläusler-Troxler et al., 2014; Mahrer-Imhof et al., 2014). However, in
Switzerland, no official guidelines for bereavement support exist, in contrast to the UK, where the need to be available and support family members not only during palliative and end-of-life care, but also following the death is well established (Bereavement Services Associations, 2011; Department of Health, 2010; Hall et al., 2011; National Institute for Clinical Excellence, 2004; National Institute for Health and Care Excellence, 2011; Relf et al., 2010). A lack of funding and the possibility to remunerate services provided to bereaved family members following the death of the “patient” hinders the provision of nursing care to bereaved families in Switzerland, particular so in the community context. While efforts exist within nursing to offer services to those bereaved, families have usually little, direct access to nursing (bereavement) care (Mahrer-Imhof et al., 2014; Schärer-Santschi, 2012).

1. 2. 2. A nursing experience: Locating the researcher

This inquiry arises from the researcher’s clinical practice and research with families in acute care and later life. It evolved from her interest into existential life situations and family health, and reflects her intention to address families’ needs by attending to their particular contexts, unique situations, and specific priorities and hopes through family-centred caring practices and advanced family nursing interventions (Bournes and Naef, 2006; Mahrer-Imhof et al., 2014; Naef, 2006).

My own past clinical experience in acute care revealed a lack of attention to families following the death of the patient. As nurses, we worked with family members and attended to how they lived with the illness situation or acute crisis, sometimes over years, but it abruptly ended with the death. Families were left on their own with their questions, their pain, and lingering experiences of witnessing suffering. In my subsequent research practice, together with colleagues, I started to focus on the situation of the rising number of oldest-old persons living in the community to better understand their unique life contexts and family situations, and to develop and trial an advanced nursing in-home counselling service to promote not only individual self-care and well-being, but to strengthen families with their relational and practical challenges (Imhof et al., 2014; Imhof et al., 2011b; Imhof et al., 2012; Naef et al., 2008; Naef et al., 2010). During this clinical trial, family relations and caregiving-receiving practices were the most frequent topics (in terms of frequency and intensity) for which persons sought counselling and therapeutic interventions from advanced practice nurses (Imhof et al., 2011a). Subsequently, we initiated an advanced practice nurse-led family community service to offer family-centred
nursing care and therapeutic interventions for families in later life, not only during family caregiving and end-of-life, but beyond (Mahrer-Imhof et al., 2014).

With this inquiry, I act upon local and international research that demonstrates the importance of family ties - either through their presence or absence - in later life. In so doing, I seek to make a systematic contribution to nurses and health professionals’ understanding of the unique context of later life families, and to lay a ground for nursing interventions with bereaved families.

1. 3. Bereaved families: What theory and research tell us

With a few exceptions, bereavement scholarship has focused on individuals. Grief is usually defined as an intrapersonal process that occurs within an individual, and to a lesser extent as an interpersonal experience unfolding between people, for instance a family (Shapiro, 2001; Walsh and McGoldrick, 2004b). Little attention has been given to the relational nature of grief and bereavement (Berger and Weiss, 2009; Gelcer, 1986; Gilbert, 1996; Kissane, 2014; Rycroft and Perlesz, 2001; Shapiro, 2001). The theoretical conceptions on grieving families most often suggest that the death of a family member is a stressful event that disrupts families in their particular situation and context, and constitutes an adversity or even a trauma when a death happens violently, suddenly, or un-timely (Berger and Weiss, 2009; Walsh and McGoldrick, 2004a). However, the evolving debate about grieving family draws heavily on theoretical ideas, and to a lesser extent on insights gleaned from systemic inquiries, which are scarce.

1. 3. 1. Current thinking about bereaved families: An overview

Three broad streams of thinking about grieving families denote the backdrop to this study. First and foremost, family is understood as a relational context in individuals’ lives. Accordingly, grief is seen as arising in-relation to others, with families denoting both the context and a resource in light of which individuals experience their grief and with which they constantly interact as they come to terms with their loss (Bloch, 1991; Gelcer, 1983, 1986; Gilbert, 1996; Shapiro, 2001). Shapiro (2001), for instance, proposed that a person’s grief is “collaboratively constructed through interpersonal, familial, and social interactions” (p. 317), whereas Gilbert (1996) maintained that such a thing as “family grief” does not exist, in contrast to grief at play within families. According to her, “grief within the family … consists of the
interplay of individual family members grieving in the social and relational context of the family, with each member affecting and being affected by the others" (p. 271). Family as context is a theoretical stance that upholds that grief is primarily experienced as an individual, yet as an individual who is constantly interacting with others in mutually co-shaping inner-personal experiences.

Second, family is seen as a structural unit holding certain roles, responsibilities and functions specific to a particular developmental stage in the family life-cycle (Detmer and Lamberti, 1991; McGoldrick and Walsh, 2004; Vess et al., 1985; Walsh and McGoldrick, 2013). From this perspective, normative ideas about family composition are of interest. The focus for research and clinical practice lies on how families regain or maintain normal function in their particular life stage and realign roles to fill in the void left by the deceased, as well as how families can be supported when grief ripples out in dysfunctional or complicated ways (Bloch, 1991; Detmer and Lamberti, 1991; Kissane and Bloch, 1994; Kissane et al., 2006; Lamberti and Detmer, 1993; Vess et al., 1985).

Third, family is framed as a system and sub-systems of interacting parts (Hayslip and Page, 2013; Walsh and McGoldrick, 2004b; Wedemeyer, 1986b). From this perspective, the death of a family member constitutes a “systemwide event” that disrupts families’ balance (Wedemeyer, 1986b, p. 338). A system perspective attends to how families interact within the larger system and sub-systems of their families to regain or maintain a balance and adapt to the new family situation (Gilbert, 2007; Hayslip and Page, 2013; Walsh and McGoldrick, 2004b, 2013). Hence, in contrast to the perspective of family as context, it acknowledges that family is a social organization that is more and different from individuals merely interacting with each other, and requires practitioners to work with family groups, rather than individuals only.

What happens for families following a death of a close other tends to be conceptualized by adopting one, or a blend of these three theoretical perspectives. For instance, in their often-cited work, Walsh and McGoldrick (2004b, 2013) combined a systemic and family life cycle perspective, and put forth a task-based conceptualization of how families adapt to a member’s death. According to these family therapists, families need to first acknowledge that the death is about to, or has indeed happened. Such a shared confrontation with the reality of the death is enabled by the presence of family members, and open communication about the circumstances of the death. Second, a “shared experience of loss” (2004b, p. 12) through funeral rites, paying respect, memorials and other habits and rituals around
commemorating the deceased is considered an important aspect of family adaptation. Again, open communication and a quest to communally make sense of the death in light of the family’s life experience and belief system as well as respect for differences in the mourning process is emphasized. Third, they posit that the family system needs to be reorganized to establish equilibrium, redistribute roles, and realign relationships so that a family can carry on with their lives. Flexibility within the family system is required if a family strives for recovery. Lastly, Walsh and McGoldrick suggest that families need to “reinvest in other relationships and life’s pursuits” (2004b, p. 14), which may require a different length of time until individual members may be open to or accept other member’s new relationships and projects. Hayslip and Page (2013) have affirmed the importance of understanding the unfolding nature of grief within families from both a systemic as well as a developmental perspective. They maintain that family communication, negotiations, beliefs, and the generational context constitute how family members and sub-systems may experience the loss similarly or differentially among members. While family system perspectives paired with structural-functional definitions of family roles (Walsh and McGoldrick, 2004a) predominate in theoretical writing about bereaved families, constructivist understandings of family as a system with unique configurations, capacities, resources, meaning-making strategies, resilience and growth have been used more recently to conceptualize what happens for families following the death of a close other (Berger and Weiss, 2009; Davis et al., 2012; Gilbert, 2007; Nadeau, 2008). Increasingly, attention is given to families’ relational process rather than to family structure or a distinct composition of people holding a certain gender, role, functions and responsibility (Hedtke and Winslade, 2004; Nadeau, 2008; Neimeyer, 2012). Such a constructivist stance acknowledges that there are manifold ways of living family and grief meaningfully. This study departed from such a relational, contextual understanding of family and grief (see chapter three for a detailed discussion). It is posited here that family is a relational web of connections that is ever-evolving and shifting, and constituted by those who feel close and live commitments in daily life (Cody, 2000b; Hartrick Doane and Varcoe, 2005a). Grief is seen to be an inherently relational process; “a lifelong experience of a changed relationship with the deceased loved one” (Thirsk and Moules, 2012, p. 108).
1.3.2. Research with bereaved families: The state of affairs

Despite a rising amount of non-research literature on bereaved families and therapeutic family work, research that sheds light on how families live with their loss in daily life, or that evaluates interventions with grieving family is, with a few notable exceptions, lacking.

**Family bereavement research:** Only a few studies investigated grief in relation to family functioning and adaptation (Kissane et al., 1996a; Kissane et al., 1997; Kissane et al., 1996b; Traylor et al., 2003), and inquired about family meaning-making following the death, focusing either on family patterns and strategies (Davis et al., 2012; Nadeau, 1998), or on family beliefs and worldviews (Black et al., 2011; Black and Santanello, 2012; Black et al., 2014) (see chapter two for a detailed review of this research). While these studies demonstrate that family processes and shared meaning-making matter in bereavement, what happens for families when an established relational matrix is shifting through a death remains little understood, and lacks a research-based foundation.

**Interventions for bereaved families:** Clinical psychotherapeutic work with bereaved families has received some research attention. One well developed and carefully devised intervention study with families “at risk” in cancer care tested a family-focused grief therapy, in which psychologists delivered a home-based family therapy to reduce grief and adverse outcomes and to strengthen family functioning and cohesion (Del Gaudio et al., 2012; Kissane and Hooghe, 2011; Kissane et al., 2006; Kissane et al., 2003; Masterson et al., 2013). Individual family members with high distress and depression at the outset benefitted from the family intervention, but family functioning remained unchanged (Kissane et al., 2006). Even though this family intervention study failed to demonstrate any effect on the family level, it mirrors insights gained from research about individual psychological or psychotherapeutic counselling and grief therapy. Several reviews have univocally demonstrated that such psychological interventions for bereaved persons yielded no benefit when delivered as part of routine care to people who did not seek help, and could even cause harm because it interrupted their individually meaningful grieving processes (Allumbaugh and Hoyt, 1999; Currier et al., 2008b; Kato and Mann, 1999; Schut and Stroebe, 2005; Schut et al., 2001). Only particularly vulnerable individuals who experience or are at risk for profound distress and clinically significant adverse mental health seem to benefit from such specialist, psychological grief interventions.
(Jordan and Neimeyer, 2003; Kissane et al., 2006; Neimeyer, 2000; Schut, 2010; Schut and Stroebe, 2005; Stroebe et al., 2007).

Interventions offered by nurses, such as supportive telephone calls, general primary care or therapeutic conversations with bereaved families, have also been investigated in a few studies (Kaunonen et al., 2000; Lyttle 2001; Moules et al., 2007; Thirsk and Moules, 2013; White and Ferszt, 2009). In a qualitative study about family nursing interventions based on the Illness Belief Model (Wright and Bell, 2009; Wright and Leahey, 2013), families reported that they had received a space for healing (Thirsk and Moules, 2012, 2013). Walking alongside with unconditional regard, active listening, enacting presence, challenging constraining beliefs, accepting families’ interpretations and feelings, and creating space for hope came up as essential for therapeutic and healing nurse-family interactions (Moules et al., 2007; Thirsk and Moules, 2013). In a bereavement context, the role of therapeutic conversations that invite families’ stories, perspectives and experiences, and attend to the beliefs that may constrain or facilitate their understanding of what is happening to them in their grief, has been well described and shown to be appreciated by and helpful for bereaved families (Currier et al., 2008a; Lyttle 2001; Morrison, 2007; Moules, 2009; Moules and Amundson, 1997; Moules et al., 2007; Payne et al., 2002; Thirsk and Moules, 2012, 2013). However, their effectiveness has not been tested to date.

The above research thus suggests that offering specialist interventions in the form of psychological, family or grief therapy to people who feel highly vulnerable, and particularly so when they seek it seems to be most effective for individuals and families alike (Neimeyer, 2000; Schut and Stroebe, 2005), although only one study tested psychological interventions with families (Kissane et al., 2006). In contrast, the premise that any form of grief therapy will be helpful for bereaved people has been seriously questioned (Currier et al., 2008b; Jordan and Neimeyer, 2003; Neimeyer, 2000; Schut, 2010; Schut et al., 2001). Thus, a consensus has evolved that a majority of bereaved family members may not need specialist grief interventions, psychological counselling, or psychotherapy, but require information about bereavement itself, opportunities to talk and reflect about their loss experience, and access to available resources and services (Agnew et al., 2010; Aoun et al., 2012; Hudson and Payne, 2011; National Institute for Clinical Excellence, 2004).
1.4. Family nursing for bereaved families: Why does it matter?

The strengthening of families through difficult life events and the provision of bereavement care are part of nurses’ mandate to promote health and healing (Registered Nurses Association of Ontario, 2006b; Victorian Order of Nurses, 2012). The death of a close other marks a particular moment in families’ lives. As nurses are concerned with family health, how families fare in bereavement, and how they can best be supported and strengthened in their communal and individual lives with loss is of relevance for them (Moules et al., 2007; Schärer-Santschi, 2012; Thirsk and Moules, 2012, 2013; White and Ferszt, 2009). Nurses work with families in that they include family members as partners or recipients of care, and they offer family nursing interventions that include health-promoting practices and therapeutic relational work with families (Bell, 2013; Hartrick Doane and Varcoe, 2005a). Family nursing is aimed at interconnected groups of persons who see themselves as family, emphasizes the relational process and contextual living situations of families, and attends to their everyday experiences of health and healing (Brykczynski, 2009; Hartrick Doane and Varcoe, 2005a; Hartrick, 1995; Hartrick and Lindsey, 1995). As nurses’ mandate is to understand, rather than to diagnose and prescribe, they are uniquely positioned to work with families in a way that honours their own perspective, and to offer nursing interventions arising from families’ priorities and views about what it is that they are most concerned with and need (Cody, 2000a; Mitchell and Bunkers, 2003; Mitchell and Cody, 1999; Naef, 2006; Pilkington, 2006; Registered Nurses Association of Ontario, 2006b; Thirsk and Moules, 2013; Victorian Order of Nurses, 2012; Wright and Bell, 2009).

1.4.1. A call to action: Constraints in caring for bereaved families

Nurses encounter bereaved families in the constraining context of today’s efficiency-driven health care system that is aimed at the individual and tends to rationalize services (Brykczynski, 2009; Cody, 2001b; Malone, 2003; Naef, 2006; Varcoe and Rodney, 2002). While families can obtain nursing support during the end-of-life, they usually lack access to nursing care in bereavement, particularly so families who are not connected to palliative or hospice services (Barry et al., 2012; Johanna Briggs Institute, 2006; Milberg et al., 2008; Victorian Order of Nurses, 2012). Hence, even though nurses work with families at the end of their ill members’ lives, and may have identified a need for follow-up care, they may hold little structural room and few resources to offer care to bereaved families after the “patient”, which is usually the
primary care recipient, has died. Thus, to better understand families’ needs, and to tailor and justify services, knowledge into families’ everyday and relational experiences of loss is required.

Deeply engrained beliefs about grief and families, and different levels of expertise in family nursing also constrain nurses’ ability to provide meaningful and helpful care to bereaved family groups (Moules et al., 2004; Thirsk and Moules, 2012; Walter, 2000). Normative ideas imply that grief is a time-limited stage-like process that one has to work through and needs to be overcome, and requires families to function in a certain way (Moules, 1998). Such an objectivist stance might hinder nurses and other health professionals to see and understand what is happening for families, and subsequently prevent them from providing relevant, family-centred bereavement care. It has been suggested that such an approach to practice ignores human subjectivity, dismisses grieving as an ongoing, meaning constructing endeavour, and is at least unhelpful, but potentially adds to persons’ suffering (Florczak, 2008; Moules, 1998; Moules and Amundson, 1997; Moules et al., 2004; Pilkington, 2006). Although nurses regularly interact with family members, they may not have the necessary training in bereavement support and how to best work with family groups. Such a lack of training and skills, paired with constraining beliefs, limited resources and rigid structures, often means that family carers do not receive the care and support they need from nurses and other health professionals (Abrahams and Moretz, 2012; Bell, 2011, 2013; Grande et al., 2009; Hudson and Payne, 2011; Moretz and Abrahams, 2012; Shields, 2010; Shields et al., 2006).

The study proposed here seeks to inform family-centred care and family nursing interventions in the context of end-of-life and bereavement care across a variety of health care settings. The absence of research-based knowledge about bereaved families is one piece of the puzzle that is needed to enhance access and quality of nursing care. To offer meaningful and helpful care and interventions, nurses need to first and foremost understand how families’ life with the loss of a close other through death unfolds in their everyday lives in the community. To increase understanding of families’ life-worlds from their own perspective, an interpretive research approach is particularly well suited (Chesla, 1995). Thus, the purpose of this phenomenological-hermeneutic inquiry is to shed light on families’ loss experiences after an older person’s partner has died. It strives to do so in attending to the relational processes that unfold for families, and by focusing on families’ meanings, actions, and concerns. This inquiry aims to generate an interpretation and rich description of families’ lived world of loss in a later life context.
1.5. Structure of the thesis: An overview

The here presented doctoral work has been undertaken to enhance nurses’ and other clinicians’ understanding of and capacity for practice with families in later life. To that end, this thesis includes an integrative review of the health sciences literature about families’ and older persons’ bereavement experiences after the death of their life partner (chapter two) and puts forth a novel conceptualization of families living with loss drawing on phenomenology and nursing theoretical perspectives (chapter three). A hermeneutic-phenomenological study was undertaken to shed light on families’ life-world after an older person’s partner has died, whose purpose and methodology are outlined in chapter four. The detailed, in-depth portrayal of the study participants (chapter five) and findings (chapter six) follow next. The findings of this interpretive study are then discussed in light of existing research-based understanding and conceptualizations about grieving families (chapter seven). Recommendations for practice, research, and health policy arising from this work map a territory for future scholarly and clinical work with bereaved families in later life (chapter eight). Concluding reflections about the essential insights and implications of the study complete this PhD thesis.
2. Review of the literature

Bereavement after the loss of an older person’s life partner:
Individual and family experiences

This chapter reports a literature review, which was undertaken to synthesize research about the family and individual bereavement experiences after an older person has died. It was guided by the question: “What is the current state of knowledge in the health sciences literature about the bereavement experience of older persons and their families after the death of an older person’s life partner?” The part of the review about the individual bereavement experience of older persons has been published in the International Journal of Nursing Studies (see Naef et al., 2013, appendix A). Thus, its findings will be presented only briefly.

2.1. Method

To synthesize relevant research, an integrative review methodology was chosen because of its explicit utility for a narrative integration of findings from both qualitative and quantitative studies around a particular phenomenon of concern (Whittemore, 2008; Whittemore and Knafl, 2005). Integrative reviews use a systematic procedure for searching the literature, and for evaluating, analysing, and synthesizing data to arrive at a comprehensive understanding of the topic of interest, which is presented in a narrative form (Whittemore and Knafl, 2005).

2.1.1. Search strategy

A systematic and iterative search was conducted. Electronic databases included Medline (1948 – February 2011), CINAHL (1937 - March, 2011), PsycInfo (1806 – February 2011), Sociological Abstracts (February 2011), and Cochrane Library (July 2011). Search terms were variously combined and included: (1) “bereavement”, “grief”, “loss of a loved one”, “death and dying”, “death of spouse”; (2) “widows and widowers”, “widowhood”, “spouses”; “family”, “family relations”, and (3) “old age”, “aged”, “elderly people”. In addition, a hand-search starting in 2005 of the journals Death Studies (to Vol. 35, Iss. 7), Bereavement Care (to Vol. 30, Iss. 2), Omega: Journal of Death and Dying (to Vol. 64, Iss. 2), and Journal of Family Nursing (to Vol. 17, Iss. 2), and a review of reference lists of pertinent articles were undertaken.
To be included, bereavement studies had to be published in English or German, and the phenomenon under study had to focus on characteristics of the bereavement experience of older persons after partner loss or the bereavement situation of families in later life. Conjugal bereavement studies were included when the mean age of the sample was 65 years or above. Studies were excluded if they investigated a narrow bereavement issue (i.e. risk factors like caregiving, quality of marital relationship, outcomes such as depression, mortality, social support etc.), focused on other populations (i.e. caregivers, adult children, siblings, families with young children), or studied the widowhood experience outside an explicit bereavement context (i.e. psychosocial health of widow/ers, loneliness etc.).

Because no research investigating family bereavement exclusively in later life was identified (i.e. families of widowed persons ≥ 65 years old), the inclusion criteria for family bereavement studies were adapted to include studies investigating bereavement experiences of families who lost an adult member. Studies needed to include more than one member of the same family and analyse the data on a family level. Studies that included only one family carer were excluded. Due to the small number of family bereavement studies identified in 2011, the search on family bereavement was rerun in June 2014.

2.1.2. Data evaluation

Critical appraisal was performed using the review guidelines for qualitative and quantitative studies developed by the McMaster University Occupational Therapy Evidence-Based Practice Research Group (Law et al., 1998 / 2007; Letts et al., 2007). These guidelines were chosen because they provide two distinct appraisal tools with appropriate criteria for qualitative and quantitative research studies in a comparable format (see Table 1, p. 33). The quality of included studies varied considerably; however, no study was excluded because it was appraised to be of low quality. Rather, level of quality was incorporated into the data analysis and considered in the interpretation of findings (Whittemore and Knafl, 2005). Hence, low quality studies were given less weight during analysis.

2.1.3. Data analysis and synthesis

Conjugal bereavement and family bereavement studies were treated as two distinctive bodies of knowledge and were analysed separately (Table 2, p. 34). All studies were read, summarized in tables, and appraised for quality.
Table 1: Criteria used for quality appraisal

<table>
<thead>
<tr>
<th></th>
<th>Quantitative Design</th>
<th>Qualitative Design</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Design</strong></td>
<td>1. Design appropriate for research question?</td>
<td>1. Design appropriate for research question?</td>
</tr>
<tr>
<td></td>
<td>2. Sample described in detail, study groups comparable at baseline if appropriate,</td>
<td>2. Clear and rich description of study context and participants?</td>
</tr>
<tr>
<td>**Sample /</td>
<td>drop outs reported, participant flow provided if required?</td>
<td>3. Sampling done until redundancy / saturation achieved?</td>
</tr>
<tr>
<td>Sampling**</td>
<td>3. Sample size justified?</td>
<td></td>
</tr>
<tr>
<td><strong>Data collection</strong></td>
<td>4. Measures valid and reliable?</td>
<td>4. Data collection strategies congruent with methodology?</td>
</tr>
<tr>
<td></td>
<td>5. Potential biases or threats to internal validity?</td>
<td>5. Researcher position and role of research-participant relationship addressed (descriptive clarity)?</td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
<td>6. Appropriate and justified statistical procedures?</td>
<td>6. Process of analysing data described adequately (auditability)?</td>
</tr>
<tr>
<td></td>
<td>7. Statistical value and significance reported?</td>
<td>7. Procedural steps used appropriate, i.e. inductive, findings reflective and consistent with data (analytical rigor)?</td>
</tr>
<tr>
<td><strong>Conclusions</strong></td>
<td>8. Research question answered, appropriate conclusions given the study methods and results, overall validity?</td>
<td>8. Research question answered and overall trustworthiness (credibility, transferability, dependability, confirmability) of findings?</td>
</tr>
</tbody>
</table>

Analysis of conjugal bereavement studies commenced by organizing all studies into four categories for data reduction and management (Whittemore and Knafl, 2005). These preliminary, analytical categories were developed in response to the included studies: (1) experiential aspects; (2) everyday activities; (3) coping strategies / strategies to live with loss; and (4) grief reactions. The extracted data from each study was then coded inductively, and codes were listed and analysed for commonalities and differences (Whittemore, 2008). Next, data were graphically displayed in a conceptual map, whereby common codes were synthesized into preliminary themes. Further analysis included a creative process of comparing and contrasting data, codes, and preliminary themes. Preliminary themes were reorganized and differentiated conceptually to arrive at main, distinctive themes around common features of the bereavement experience (Whittemore, 2008; Whittemore and Knafl, 2005). A theme was defined as a key characteristic of the bereavement experience when it was present in several studies (Naef et al., 2013). Findings of one study could be integrated into several themes.

Family bereavement studies were very few, and quantitative studies used very similar designs and measures. Therefore, the associations between and the directions among variables as well as findings from the qualitative studies were directly extracted, displayed in a table, compared and contrasted between studies, organized around the common notions that became evident, and verified with the
original articles. Congruencies and differences among variables and the phenomena of concern, respectively, as well as the study findings were identified, described, and supplemented with individual study findings.

Table 2: Data analysis used for integrative review*

<table>
<thead>
<tr>
<th>Data reduction</th>
<th>Extracting data from each primary source using overall classification system (deductive process). Remaining open to themes not yet captured within classification system (inductive process). Coding of extracted data.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data display</td>
<td>Display of coded data in conceptual map, bringing individual data sets together around particular variables.</td>
</tr>
<tr>
<td>Data comparison</td>
<td>Comparing data through a circular and repetitive process to identify themes or relationships. This involves comparing-contrasting various extracted data and regrouping them around similar themes.</td>
</tr>
<tr>
<td>Conclusion drawing</td>
<td>Derive usual and unusual experiential patterns, meanings, activities, and strategies, identification of similarities and differences.</td>
</tr>
<tr>
<td>Verification</td>
<td>Verify findings of this analysis process with primary sources for accuracy.</td>
</tr>
</tbody>
</table>

*adapted from Whittemore & Knafl, 2005, pp. 548-551; Whittemore 2008, p.153,

2.2. Search outcome

The search yielded around 2500 hits. 355 abstracts were screened, of which 64 studies were retrieved as full text for closer review. Thirty-nine studies met the inclusion criteria for conjugal bereavement, and five publications based on three studies investigated family bereavement in an adult population. Five new publications on family bereavement, based on three studies were identified when the search was updated in 2014 (Figure 1).

Figure 1: Flow chart of the literature search process
2. 3. Findings on conjugal bereavement experiences in later life

Thirty-nine studies that investigated conjugal bereavement characteristics were included in this review. Participants were on average 70.5 years old (SD 3.98, available from n=28), and a majority were women (82%, range 0-100). While half of the studies included men and women, only two studies were with men only. More than two third of studies (n=30) were conducted in North America, and one third (n=12) included widow/ers of a specific ethnic, minority or socioeconomic background (i.e. African American, lesbian partners, rural area) or from a specific clinical setting (i.e. cancer carers, hospice). Qualitative (n=17) and quantitative (n=20) designs were represented equally (mixed method n=2), and twenty-six studies were of high or good, and 14 of moderate or low quality (see Table 4 on pp. 39 -45). Findings of the conjugal bereavement studies were synthesized into six themes (see Table 3; for a detailed description see Naef et al., 2013, appendix A).

Table 3: Themes of conjugal bereavement studies

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Everyday activities and routines (n=19)</td>
<td>Strategies to live with loss</td>
</tr>
<tr>
<td></td>
<td>Leisure activities</td>
</tr>
<tr>
<td></td>
<td>Remembrance activities</td>
</tr>
<tr>
<td></td>
<td>Daily times and routines</td>
</tr>
<tr>
<td>Life as a single person in a social context (n=20)</td>
<td>Identity</td>
</tr>
<tr>
<td></td>
<td>Independence and support</td>
</tr>
<tr>
<td></td>
<td>Relationships with others</td>
</tr>
<tr>
<td></td>
<td>Relationships with the deceased</td>
</tr>
<tr>
<td>Emotions (n=14)</td>
<td>Loneliness</td>
</tr>
<tr>
<td></td>
<td>Sadness</td>
</tr>
<tr>
<td></td>
<td>Remorse</td>
</tr>
<tr>
<td>Grief intensity over time (n=9)</td>
<td>Grief over time</td>
</tr>
<tr>
<td></td>
<td>Other measures of grief over time</td>
</tr>
<tr>
<td>Coping and its relation to grief and other outcomes (n=7)</td>
<td>Coping styles</td>
</tr>
<tr>
<td></td>
<td>Coping in relation to grief and other outcomes</td>
</tr>
<tr>
<td>Health and symptoms (n=6)</td>
<td>Sleep difficulties</td>
</tr>
<tr>
<td></td>
<td>Lack of energy</td>
</tr>
<tr>
<td></td>
<td>Loss of appetite</td>
</tr>
</tbody>
</table>

2. 3. 1. Everyday activities and routines

Nineteen studies, mostly qualitative in nature, shed light on widow/er's daily lives (Anderson and Dimond, 1995; Brabant et al., 1992; Chan and Chan, 2011; Costello and Kendrick, 2000; Harrison et al., 2004; Hegge, 1991; Hegge and Fischer, 2000; Hockey et al., 2001; Holtslander et al., 2011; Holtslander and Duggleby, 2010; Jacob, 1996; Janke et al., 2008; McIntyre and Howie, 2002; Patterson, 1996; Rodgers, 2004; Shih et al., 2010; Steeves, 2002; Steeves and Kahn, 2005; Vale-Taylor, 2009). Studies showed that everyday activities and routines play an
important role during bereavement, with widowed persons using manifold strategies to live with their loss, such as keeping busy and distracted, using beliefs and religious practices, learning new skills, and finding a way to live with the pain of loss that was there to stay. Social leisure activities, along with gardening, church participation, walking or sports, reading and watching TV were prevalent among widow/ers. Remembrance activities included talking about the deceased, displaying photographs, spending time with people who were special to deceased, or revisit memorable places. Despite many helpful strategies and pleasurable activities, studies also demonstrated that widowed persons face difficult daily times, such as meal- or bedtime, during which they were particularly confronted with the absence of their loved one in a way that they could not escape. Passing the time or filling in the day was also found to be challenging, as were anniversaries or special holidays.

2.3.2. Life as a single person in a social context

Findings from twenty qualitative studies pertained to the social identity of widowed persons, the maintenance or achievement of independence, the negotiation of support, and relationships with family, friends, and the deceased person (Anderson and Dimond, 1995; Bennett et al., 2010; Bent and Magilvy, 2006; Carlsson and Nilsson, 2007; Carnelley et al., 2006; Chan and Chan, 2011; Costello and Kendrick, 2000; Harrison et al., 2004; Hegge, 1991; Hegge and Fischer, 2000; Hockey et al., 2001; Holtslander et al., 2011; Holtslander and Duggleby, 2010; Jacob, 1996; Robinson, 1995; Rodgers, 2004; Steeves and Kahn, 2005; Utz et al., 2004; Vale-Taylor, 2009; Wilson and Supiano, 2011). Studies described that bereaved, older persons found themselves confronted with a new social role as widow/ers. Their new situation required them to consciously re-find their balance and proactively shape their new identity as widow/ers. As such, widow/ers also had to negotiate their independence in the face of adversities, such as their limited health and functional impairments, financial situation, and the availability or absence of support. Most older persons were found to experience relationships with their close others, in particular with children, as a source of concrete help and comfort, except in those situations in which relationships were previously strained. Offers of help, however, were carefully weighted, and widow/ers experienced support as unwelcome when it threatened their self-sufficiency. Lastly, studies also consistently found that widow/ers remained in a relationship with their deceased partner, and experienced their continued engagement through conversations, activities previously shared, or by reliving the past through memories and dreams as comforting.
2. 3. 3. Emotions

Fourteen qualitative studies illustrated widow/ers’ feelings and emotional aspects in bereavement (Anderson and Dimond, 1995; Brabant et al., 1992; Chan and Chan, 2011; Costello and Kendrick, 2000; Harrison et al., 2004; Hegge, 1991; Hockey et al., 2001; Holtslander et al., 2011; Holtslander and Duggleby, 2010; Jacob, 1996; Rodgers, 2004; Steeves, 2002; Steeves and Kahn, 2005; Wilson and Supiano, 2011). Loneliness emerged as the most pervasive emotional issue for bereaved, older persons, which persisted despite busy lives and social connectedness. Other emotions identified included sadness, turmoil, pain or feelings of regret. Sadness itself was found to be an emotional rollercoaster for widow/ers, which entailed a loss of control while also feeling a strong need to have control over their lives.

2. 3. 4. Grief intensity over time

A total of nine quantitative studies reported how grief or other indicators of loss, such as depression, distress, mental health or personal growth developed over time. A statistically significant decline in grief intensity, depression, and distress and increase in mental health was found in all studies measuring the time course of bereavement for up to 30 months post loss. In contrast, comparisons of early versus later bereaved widow/ers showed no statistically significant difference in grief intensity, despite higher grief scores for those within 24 months since the loss (Carlsson and Nilsson, 2007; Kowalski and Bondmass, 2008; Ott et al., 2007; Sable, 1991; Thompson et al., 1991). Early bereaved (cut off at 500 days) older widowers had lower well-being, less positive, and more negative affect compared to later bereaved older men (Richardson and Balaswamy, 2001). In contrast to matched, non-bereaved controls, bereaved older adults had lower well-being over a four-year period (Richardson, 2007). Positive outcomes, such as personal strength (measured up to 4 years), as well as self-confidence, being a stronger person, and having found meaning, which were measured for up to 35 years, increased or were stable over time (Carnelley et al., 2006; Kim et al., 2011). One study devised a typology based on indicators of grief intensity, depression, and general mental health, and identified three types of responses that were termed resilient (34%), common (49%), and chronic (17%), whereby only the latter group of older persons experienced a high vulnerability for adverse health outcomes (Ott et al., 2007).
2. 3. 5. Coping in relation to grief and other outcomes

Seven of the included quantitative studies focused predominantly on coping variables derived from cognitive stress, appraisal, and coping frameworks (Caserta and Lund, 1992; Chovan and Chovan, 2006; Gass, 1987, 1988; Herth, 1990; Lalitha and Jamuna, 2004; Robinson, 1995). Studies yielded no clear pattern of coping types used in bereavement, such as emotion versus problem-focused coping, when comparing persons early versus later on in bereavement, women versus men, or bereaved versus non-bereaved groups (Caserta and Lund, 1992; Chovan and Chovan, 2006; Lalitha and Jamuna, 2004). Two studies found that the type and amount of coping strategies used depended on widow/ers’ appraisal of the event as a combination of harmful and / or threatening (Gass, 1987, 1988). When relating coping strategies to grief resolution and health function, positively connoted coping strategies were associated with good outcomes, whereas negatively associated coping strategies with difficulties in grief resolution (Robinson, 1995). Moreover, coping effectiveness, in contrast to the use of different coping strategies was statistically significantly related to more adaptive grief responses.

2. 3. 6. Health and symptoms

Six studies pertained to health concerns and symptoms of bereaved older persons, which were found to be an expression of pre-existing chronic illness and of the bereavement situation itself (Anderson and Dimond, 1995; Hegge, 1991; Holtslander et al., 2011; Holtslander and Duggleby, 2010). Insomnia or difficulty with sleep was reported in all studies. For instance, 65% of widow/ers were found to have difficulty to sleep shortly after the death, which decreased to 15% one year after the loss (Carlsson and Nilsson, 2007). Other reported health symptoms include fatigue, lack of energy, difficulty to concentrate, exhaustion from caregiving (11%-64%), as well as loss of appetite, nausea, or weight changes (22%). Only one study reported that pain was a health concern for about one third of widows included in the study (Kowalski and Bondmass, 2008).
Table 4: Overview of included conjugal bereavement studies

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Design</th>
<th>Purpose or phenomenon</th>
<th>Participants</th>
<th>n</th>
<th>Age</th>
<th>% female</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Themes*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anderson &amp; Dimond, 1995 USA Nursing</td>
<td>Qualitative study</td>
<td>Bereavement experience</td>
<td>Widow/ers within 2y after loss</td>
<td>12</td>
<td>53-89</td>
<td>58</td>
<td>Open-ended interviews at 3 weeks, 6, 12, 24 months post-loss</td>
<td>Framework analysis based on semantic-relationships after Spreadley</td>
<td>1 X X X</td>
</tr>
<tr>
<td>Bennett et al., 2010 UK Psychology</td>
<td>Mixed method study</td>
<td>Performance of instrumental tasks before and after loss</td>
<td>Widows</td>
<td>21</td>
<td>78</td>
<td>100</td>
<td>Semi-structured interviews</td>
<td>Binominal tests, McNemar test Qualitative analysis adapted from grounded theory</td>
<td>X</td>
</tr>
<tr>
<td>Bent &amp; Magilvy, 2006 USA Nursing</td>
<td>Qualitative-descriptive study</td>
<td>Bereavement experience</td>
<td>Lesbians after partner loss</td>
<td>6</td>
<td>50-70</td>
<td>100</td>
<td>In-depth, open interviews</td>
<td>Thematic analysis based on van Manen</td>
<td>X</td>
</tr>
<tr>
<td>Brabant et al., 1992 USA Sociology</td>
<td>Qualitative study</td>
<td>Thoughts, feelings &amp; behaviours</td>
<td>Widowers of women deceased in hospice care</td>
<td>20</td>
<td>65</td>
<td>0</td>
<td>Semi-structured interviews</td>
<td>Not described</td>
<td>X X</td>
</tr>
<tr>
<td>Carnelley et al., 2006 USA / UK Psychology</td>
<td>Longitudinal cohort study Americans' Changing Lives (ACL) study</td>
<td>Time course of adaptation to loss</td>
<td>Individuals after spousal loss</td>
<td>768</td>
<td>70</td>
<td>82</td>
<td>Structured Interviews: continuing involvement &amp; emotional resolution, finding meaning in loss, personal growth</td>
<td>Regression modelling</td>
<td>X X</td>
</tr>
<tr>
<td>Caserta &amp; Lund, 1992 USA Nursing/Sociol.</td>
<td>Longitudinal, case-control study</td>
<td>Comparison of expected stress &amp; coping with actual experience</td>
<td>Recently bereaved spouses &amp; non-bereaved older adults</td>
<td>108</td>
<td>85</td>
<td>78</td>
<td>Questionnaire or structured interview: perceived stress &amp; coping Likert scales at 4 weeks, 2, 6, 12, 18, 24 months</td>
<td>ANOVA</td>
<td>X</td>
</tr>
</tbody>
</table>
## Table 4 (continued): Overview of included conjugal bereavement studies

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Design</th>
<th>Purpose or phenomenon</th>
<th>Participants</th>
<th>n</th>
<th>Age</th>
<th>% female</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Themes*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chan &amp; Chan, 2011</td>
<td>Grounded theory study</td>
<td>Adjustment process</td>
<td>Bereaved Chinese older adults after spousal loss</td>
<td>15</td>
<td>74</td>
<td>66</td>
<td>Semi-structured interviews</td>
<td>Grounded theory after Glaser</td>
<td>X X X</td>
</tr>
<tr>
<td>Chovan &amp; Chovan, 2006</td>
<td>Longitudinal, descriptive pilot study</td>
<td>Nature of change in self-process</td>
<td>Early &amp; late bereaved widows</td>
<td>6</td>
<td>74</td>
<td>100</td>
<td>Clinical interviews &amp; Revised Ways of Coping Scale 1, 4, 8 weeks around self-help group attendance</td>
<td>Not described</td>
<td>X</td>
</tr>
<tr>
<td>Costello &amp; Kendrick, 2000</td>
<td>Qualitative study</td>
<td>Grief experience</td>
<td>Older persons whose partner died recently in hospital</td>
<td>12</td>
<td>74</td>
<td>67</td>
<td>Ethnographic Interviews</td>
<td>Phenomenological process of content analysis after Beauchamp</td>
<td>X X X</td>
</tr>
<tr>
<td>Gass, 1987</td>
<td>Cross-sectional descriptive-correlational study</td>
<td>Appraisal of bereavement, coping patterns, resources &amp; health functioning</td>
<td>Widows bereaved less than a year</td>
<td>100</td>
<td>71</td>
<td>100</td>
<td>Appraisal of bereavement Ways of Coping Checklist Assessment of resources Sickness Impact Profile</td>
<td>ANOVA with Scheffé post-hoc test Pearson correlation</td>
<td>X</td>
</tr>
<tr>
<td>Gass, 1988</td>
<td>Cross-sectional descriptive-correlational study</td>
<td>Similarities &amp; differences in gender in appraisal of bereavement, coping patterns, resources &amp; health functioning</td>
<td>Widow/ers</td>
<td>100</td>
<td>71</td>
<td>63</td>
<td>Appraisal of bereavement Ways of Coping Checklist Assessment of resources Sickness Impact Profile</td>
<td>T-test or chi-square test for differences Pearson &amp; biserial correlation for associations ANOVA with Scheffé post-hoc test</td>
<td>X</td>
</tr>
<tr>
<td>Harrison et al., 2004</td>
<td>Hermeneutic phenomenological study</td>
<td>Widowhood experience</td>
<td>African American widows</td>
<td>11</td>
<td>70</td>
<td>100</td>
<td>Interviews &amp; field notes</td>
<td>Hermeneutical phenomenological analysis after Cohen, Kahn &amp; Steeves</td>
<td>X X X</td>
</tr>
<tr>
<td>Author, year, country</td>
<td>Design</td>
<td>Purpose or phenomenon</td>
<td>Participants</td>
<td>n</td>
<td>Age</td>
<td>% female</td>
<td>Data collection</td>
<td>Data analysis</td>
<td>Themes*</td>
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<td>-------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Hegge, 1991 USA Nursing</td>
<td>Qualitative pilot study</td>
<td>Coping processes</td>
<td>Widow/ers</td>
<td>26</td>
<td>-</td>
<td>81</td>
<td>Structured interviews</td>
<td>Not described</td>
<td>X X X X</td>
</tr>
<tr>
<td>Hegge &amp; Fischer, 2000 USA Nursing</td>
<td>Qualitative study</td>
<td>Differences in grief responses of older and oldest-old persons</td>
<td>Widows aged 60-74 &amp; 75-94</td>
<td>22</td>
<td>17</td>
<td>100</td>
<td>Structured interviews</td>
<td>Analysis of patterns, coding, comparison of differences between age groups</td>
<td>X X</td>
</tr>
<tr>
<td>Herth, 1990 USA Nursing</td>
<td>Cross-sectional correlational study</td>
<td>Relationships of hope, coping skills, concurrent losses &amp; grief</td>
<td>Bereaved spouses</td>
<td>75</td>
<td>79</td>
<td>62</td>
<td>Questionnaire</td>
<td>Pearson correlation &amp; ANOVA with Turkey HSD post-hoc test</td>
<td>X</td>
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<tr>
<td>Hockey et al., 2001 UK</td>
<td>Qualitative-exploratory study</td>
<td>Practical and emotional challenges of sustaining a meaningful life</td>
<td>Widow/ers aged 60-74 &amp; 75 – 94</td>
<td>22</td>
<td>17</td>
<td>-</td>
<td>Interviews</td>
<td>Descriptive coding</td>
<td>X X X</td>
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<tr>
<td>Holtslander &amp; Duggleby, 2010 Canada Nursing</td>
<td>Qualitative study based on grounded theory</td>
<td>Psychosocial context of bereavement</td>
<td>Widows after caregiving for spouse with adv. cancer</td>
<td>13</td>
<td>60-79</td>
<td>100</td>
<td>2 open-ended interviews &amp; diary over a two week period</td>
<td>Constant comparative methods &amp; thematic analysis</td>
<td>X X X X</td>
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<tr>
<td>Holtslander et al., 2011 Canada Nursing</td>
<td>Constructivist grounded theory study</td>
<td>Finding balance</td>
<td>Widow/ers after caregiving for spouse with adv. cancer</td>
<td>6</td>
<td>73</td>
<td>64</td>
<td>Multiple interviews &amp; diaries</td>
<td>Grounded theory analysis after Charmaz</td>
<td>X X X X</td>
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<tr>
<td>Jacob, 1996 USA Nursing</td>
<td>Grounded theory study</td>
<td>Generate conceptual definition of grief</td>
<td>Widows whose husbands were enrolled in a hospice program</td>
<td>6</td>
<td>74</td>
<td>100</td>
<td>Interviews 1-4, 7-10, 13-16 months after loss (n=20)</td>
<td>Constant comparative method</td>
<td>X X X</td>
</tr>
</tbody>
</table>
Table 4 (continued): Overview of included conjugal bereavement studies

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Design</th>
<th>Purpose or phenomenon</th>
<th>Participants</th>
<th>n</th>
<th>Age</th>
<th>% female</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Themes*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Janke et al., 2008 USA</td>
<td>Longitudinal cohort study ACL study</td>
<td>Changes &amp; frequency of leisure activities, relationship to physical &amp; mental health</td>
<td>Widow/ers</td>
<td>154</td>
<td>69</td>
<td>90</td>
<td>Questionnaire about leisure participation before and after loss</td>
<td>Classification of change in leisure activity, ANOVA to determine association btw change or stability</td>
<td>X</td>
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<tr>
<td>Kim et al., 2011 USA Nursing</td>
<td>Longitudinal cohort study Changing Lives of Older Couples (CLOC) study</td>
<td>Trajectory of gaining personal strength</td>
<td>Bereaved older widow/ers</td>
<td>101</td>
<td>72</td>
<td>90</td>
<td>6, 18, 24 months after loss Structured interviews about personal strength, finding meaning, religiosity, social support, caregiver stain</td>
<td>Latent growth modelling based on structural equation modelling analytic framework</td>
<td>X</td>
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<tr>
<td>Kowalski &amp; Bondmass, 2008 USA Nursing</td>
<td>Cross-sectional descriptive-correlational study</td>
<td>Physical and psychosocial symptoms of grief, relationship between symptoms &amp; grief</td>
<td>Widows</td>
<td>173</td>
<td>66</td>
<td>100</td>
<td>Revised Grief Experience Inventory Demographic form</td>
<td>Pearson product-moment correlation ANOVA with post-hoc Turkey test</td>
<td>X X</td>
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<tr>
<td>Lalitha &amp; Jamunda, 2004 India, Psychology</td>
<td>Cross-sectional descriptive study</td>
<td>Psychosocial problems of adjustment &amp; coping strategies</td>
<td>Widow/ers aged 60-65 &amp; 66-70</td>
<td>120</td>
<td>60</td>
<td>50</td>
<td>Problem Inventory for Older People Health and Daily Activity Scale for Coping</td>
<td>Not described</td>
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<tr>
<td>McIntyre &amp; Howie, 2002 Australia Occup. Therapy</td>
<td>Qualitative case study</td>
<td>Meaningful occupation</td>
<td>Woman widowed twice</td>
<td>1</td>
<td>-</td>
<td>100</td>
<td>3 in-depth interviews</td>
<td>Thematic analysis with use of a coding scheme</td>
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### Table 4 (continued): Overview of included conjugal bereavement studies

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Design</th>
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<th>Data analysis</th>
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<tbody>
<tr>
<td>Ott et al., 2007 USA Nursing</td>
<td>Longitudinal cohort study Yale Bereavement Study (YBS)</td>
<td>Patterns &amp; typology of grief Bereaved spouses</td>
<td>144 70 69</td>
<td>4, 9, 18 months after loss Inventory of Complicated Grief Revised Hamilton Rating Scale for Depression SF12 for health &amp; well-being</td>
<td>Hierarchical cluster procedure with Ward agglomeration method Repeated ANOVA</td>
<td>X</td>
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<tr>
<td>Patterson, 1996 Australia</td>
<td>Cross-sectional descriptive-correlational study</td>
<td>Leisure activity and relationship to stress Widow/ers bereaved for 6-24 months</td>
<td>60 64 72</td>
<td>Interview with use of Leisure Activity Scale, Ease of Role Transition Scale, State-Trait Anxiety Inventory</td>
<td>Pearson correlation Multiple regression analysis</td>
<td>X</td>
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<tr>
<td>Richardson &amp; Balaswamy, 2001 USA Sociology</td>
<td>Cross-sectional, correlational study</td>
<td>Factors that explain adjustments during second year Widowed men</td>
<td>200 74 0</td>
<td>Structured questionnaire measuring loss- and restoration based on dual process model of coping Bradburn’s Affect Scale</td>
<td>Multiple regression analysis</td>
<td>X</td>
</tr>
<tr>
<td>Richardson, 2007 USA Sociology</td>
<td>Longitudinal case-control study CLOC study</td>
<td>Factors that explain widow/ers adjustment over time Widow/ers &amp; matched controls</td>
<td>210 83 71 72</td>
<td>6, 18, 48 months after loss Structured questionnaire measuring loss- and restoration based on dual process model of coping Bradburn’s Affect Scale</td>
<td>Multiple regression analysis</td>
<td>X</td>
</tr>
<tr>
<td>Robinson, 1995 USA Nursing</td>
<td>Descriptive, cross-sectional study</td>
<td>Relationship of resources (social support), coping processes, and grief responses Widows in second year of bereavement</td>
<td>65 65 100</td>
<td>Norbeck Social Support Questionnaire Robinson Bereavement Questionnaire Jalowiec Coping Scale Grief Experience Inventory</td>
<td>Pearson correlations Path analysis</td>
<td>X X</td>
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</table>
Table 4 (continued): Overview of included conjugal bereavement studies

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<tr>
<th>Author, year, country</th>
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<th>Data collection</th>
<th>Data analysis</th>
<th>Themes*</th>
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</thead>
<tbody>
<tr>
<td>Rodgers, 2004 USA Nursing</td>
<td>Descriptive-phenomenological study</td>
<td>Spousal bereavement</td>
<td>African American widows</td>
<td>11</td>
<td>63-94</td>
<td>100 In-depth interviews Research journal</td>
<td>Colaizzi's seven-step procedural phenomenological method</td>
<td>X X X</td>
<td></td>
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<tr>
<td>Sable, 1991 USA</td>
<td>Cross-sectional correlational study</td>
<td>Grief reactions</td>
<td>Widows</td>
<td>81</td>
<td>74% btw 50-74</td>
<td>100 Semi-structured interviews Texas Inventory of Grief Brief Symptom Inventory</td>
<td>Factor analysis with varimax rotation Correlational statistics Chi-square test</td>
<td>X</td>
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<tr>
<td>Shih et al., 2010 Taiwan Nursing</td>
<td>Mixed method study</td>
<td>Difficulties encountered, impact of religiosity on coping strategies</td>
<td>Chinese widows</td>
<td>20</td>
<td>73</td>
<td>100 Semi-structured interviews</td>
<td>Descriptive statistics Man-Whitney-U-test, Fisher exact test Critical thematic analysis</td>
<td>X</td>
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<tr>
<td>Steeves, 2002 USA Nursing</td>
<td>Ethnographic study</td>
<td>Process of bereavement</td>
<td>Elderly rural widow/ers of low socio-economic status whose spouses had hospice care</td>
<td>15</td>
<td>70</td>
<td>66 Open-ended interviews before death of spouse and thereafter up to 29 months (16 per participant)</td>
<td>Hermeneutic phenomenological analysis after Cohen, Kahn and Steeves</td>
<td>X X</td>
<td></td>
</tr>
<tr>
<td>Steeves &amp; Kahn, 2005 USA Nursing</td>
<td>Qualitative longitudinal study</td>
<td>Experience of bereavement</td>
<td>Elderly rural widow/ers of low socio-economic status whose spouses had hospice care</td>
<td>15</td>
<td>70</td>
<td>66 Open-ended interviews before death of spouse and thereafter up to 29 months (16 per participant)</td>
<td>Hermeneutic phenomenological analysis after Cohen, Kahn and Steeves</td>
<td>X X X</td>
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Table 4 (continued): Overview of included conjugal bereavement studies

<table>
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<tr>
<th>Author, year, country</th>
<th>Design</th>
<th>Purpose or phenomenon</th>
<th>Participants</th>
<th>n</th>
<th>Age</th>
<th>% female</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Themes*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thompson et al., 1991 USA Gerontology</td>
<td>Longitudinal, case-control study</td>
<td>Effect of spousal bereavement on psychological distress</td>
<td>Bereaved older persons &amp; controls</td>
<td>212</td>
<td>68</td>
<td>53</td>
<td>Structured interviews at 2, 12, 30 months after loss</td>
<td>Multivariate profile analysis of repeated measure</td>
<td>X</td>
</tr>
<tr>
<td>Utz et al., 2004 USA Psychology</td>
<td>Longitudinal case-control study CLOC study</td>
<td>Changes &amp; influences widowhood on household work</td>
<td>Widow/ers &amp; matched controls</td>
<td>202</td>
<td>75</td>
<td>73</td>
<td>Baseline &amp; 6 months after loss Face-to-face structured interview</td>
<td>Ordinary least square regression</td>
<td>X</td>
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<tr>
<td>Vale-Taylor, 2009 UK</td>
<td>Cross-sectional descriptive study</td>
<td>Post-funeral remembrance activities</td>
<td>Next of kin (spouses &amp; adult children)</td>
<td>43</td>
<td>50-90</td>
<td>65</td>
<td>Questionnaire Semi-structured interviews</td>
<td>Descriptive &amp; thematic analysis</td>
<td>X X</td>
</tr>
<tr>
<td>Wilson &amp; Supiano, 2011 USA Nursing</td>
<td>Qualitative study</td>
<td>Conjugal grief experience</td>
<td>Widows of veterans</td>
<td>6</td>
<td>69</td>
<td>100</td>
<td>Open-ended, directed interviews</td>
<td>Identification of themes, organized into coherent categories, identification of patterns and connections between &amp; within categories</td>
<td>X X</td>
</tr>
</tbody>
</table>

*Themes: (1) Everyday activities and routines, (2) Emotions, (3) Life as a single person in a social context, (4) Health and symptoms, (5) Grief over time, (6) Coping and its relation to grief
<table>
<thead>
<tr>
<th>Author</th>
<th>Design</th>
<th>Purpose</th>
<th>Participants</th>
<th>Data collection</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black et al., 2011</td>
<td>Qualitative</td>
<td>To investigate family reactions to the death of the husband and father in light of families’ worldviews and belief systems</td>
<td>n=34 families consisting of a widow (aged 69-90 years) and one to two adult children (33-68 years)</td>
<td>Two individual, ethnographic interviews with each family member using a semi-structured format</td>
<td>General approach to data analysis drawing on Mishler and Silverman: Getting a sense of what is in the data, large-level sorting with codes for broad themes and topics intra- and inter-individually, fine-grained analysis with codes for subthemes and patterns.</td>
</tr>
<tr>
<td>Black &amp; Santanello, 2012</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black et al, 2014</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>US Sociology / Aging Studies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Davis et al., 2012</td>
<td>Quantitative</td>
<td>To assess the extent to which meanings reported are similar within families, and to determine whether such congruence relates to adaptation in families</td>
<td>n=16 families of men killed in a coal mine explosion, consisting of 52 individuals (11 spouses, 3 parents, 7 adult children, other various family members, in 5 families only one member took part) 63% female</td>
<td>Individual, semi-structured interviews Open ended questions to assess phenomenological qualities of loss and its positive &amp; negative effects Closed ended questions: 10-item version of Centre for Epidemiological Studies Depression Scale CES-D, 9-item version of Bradburn Affects Balance Scale</td>
<td>Use of numerically aided phenomenology to parse data from open-ended questions into distinct theme when represented by at least 10% = constituents. Coding constituents with dummy variable 1=idea mentioned, 0=idea not mentioned Similarity analysis: Calculation of Jaccard’s coefficient (constituents) using similarity matrix &amp; ICs (depression &amp; wellbeing) Calculation of family integration score (individual’s average similarity to his / her family) &amp; family similarity score (within-family average similarity) Hierarchical linear modelling to assess integration and similarity score with depressed affect and well being Analysis limited to 14 families represented by at least 2 members</td>
</tr>
<tr>
<td>Canada Psychology</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author</td>
<td>Design</td>
<td>Purpose</td>
<td>Participants</td>
<td>Data collection</td>
<td>Data analysis</td>
</tr>
<tr>
<td>------------------------</td>
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<td>-------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Kissane, Bloch, Dowe et al., 1996  
Australia  
Psychiatry / Psychology | Longitudinal cohort study  
Melbourne Grief Study | Identify patterns of family functioning | n=115 bereaved families of cancer patients  
115 widows, mean age 57 years  
153 adult offspring, mean age 28 years  
53% female | Individual data collection  
Interview & questionnaires with spouses at 6 weeks, 6, 13 months  
Questionnaire with offspring at 6 weeks & 12 months | Use of individuals as unit of analysis (i.e. members of the same family may not belong to the same cluster)  
Taxonomic approach to cluster-analyze data. Use of Wallace information measure / minimum message length  
Use of hierarchical model to study effect of family memberships within clusters and interaction btw membership & time to (dis)confirm MANOVAs with individuals  
Use of KnowledgeSEEKER program for post hoc comparisons of cluster means |
| Kissane, Bloch, Onghena et al., 1996  
Australia  
Psychiatry / Psychology | Longitudinal cohort study  
Melbourne Grief Study | Intensity of grief, psychosocial morbidity & coping patterns in family members classified in typologies of family functioning | See above | Family clusters of study Kissane, Bloch, Dowe et al., 1996 are used as independent variables  
Measures see table 7 | MANOVA to assess main effects of cluster (btw subjects) and time since death (within subjects) and interaction between cluster effect & time to determine effect on dependent variables  
Use of KnowledgeSEEKER program for post hoc analysis |
| Kissane et al., 1997  
Australia  
Psychiatry / Psychology | Longitudinal cohort study  
Melbourne Grief Study | The influence of psychosocial variables on grief, depression, distress and social adjustment | See above | Additional variables from interviews with spouses: Experience of deceased’s illness & death, health of family members, perception of social support, overall family coping, family role change. Information about nature of spouse’s illness, caregiving | Pearson product-moment correlations  
Best subset regression analysis |
| Mayer et al., 2013  
US  
Nursing | Descriptive, narrative study | Bereavement experience of families who experienced the sudden cardiac death of a family member | n=7 bereaved families of men dying of a sudden cardiac arrest on average 2.1 years ago, consisting of 17 individuals (5 spouses, 7 adult children, 3 sisters, 1 friend, 1 niece) aged 22-60 years  
71% women | Open, in-depth interviews (7 family, 17 solo interviews) | Narrative analysis (Riessman): Structural analysis to attend to how stories were organized, thematic analysis focusing on stories’ content, using reading, coding, theoretical memoing, field notes, reflective journaling |
<table>
<thead>
<tr>
<th>Author</th>
<th>Design</th>
<th>Purpose</th>
<th>Participants</th>
<th>Data collection</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nadeau, 1998</td>
<td>Grounded Theory study</td>
<td>Process of family meaning-making of the death of one of their members</td>
<td>n=10 multi-generational, bereaved families consisting of 48 individuals aged 18 – 74 years 54% female</td>
<td>Intensive, unstructured, interviews with individuals, dyads, family groups 19 individual, 7 with family groups of 3 to 8, 7 with 2 members (siblings, parent-child or couples) 15 family members were interviewed both alone &amp; with others.</td>
<td>Based on GT (Strauss &amp; Corbin): Open coding to describe &amp; categorize data, axial coding to develop categories and relate them to one another with use of coding paradigm.</td>
</tr>
<tr>
<td>Traylor and colleagues, 2003</td>
<td>Longitudinal cohort study</td>
<td>Dynamics of relationship between family system characteristics and grief process</td>
<td>n=66 recently bereaved persons (82% adult children, 18% widowers), mean age 47 years 66% female</td>
<td>Data collected 4-5 weeks after loss &amp; at 6 months Measures see table 7</td>
<td>MANOVA to determine difference of loss of a parent versus spouse on grief &amp; family system characteristics (non-sign). Cross-lagged panel correlation (CLPC) procedures to compare correlations between grief &amp; family system characteristics Longitudinal multiple regression equation</td>
</tr>
</tbody>
</table>
2.4. Findings on family bereavement in adult / later life

Ten publications arising from six research projects on families’ bereavement experience were included (see Table 5 on pp. 46-48). Only one study targeted families of widows aged 70 years or older who had lost their husband (Black et al., 2011; Black and Santanello, 2012; Black et al., 2014). The majority included families in mid-life. These families had either lost a spouse / parent between the age of 40-65 years old from natural causes (Kissane et al., 1996a; Kissane et al., 1997; Kissane et al., 1996b; Mayer et al., 2013; Traylor et al., 2003), or a male member in a coal mine explosion (Davis et al., 2012). In one study, six of the ten families had lost a member of their oldest generation (aged ≥ 70 years), of which members of the same and / or the two following generations took part (Nadeau, 1998). Surviving spouses and adult children most often represented families; however, in three studies, other family members, such as grandchildren, in-laws, parents and siblings also took part. Half of the studies were with families whose close other had died of the same cause, such as cancer, accident, or sudden cardiac arrest (Table 6).

Table 6: Overview of samples and data in family bereavement studies

<table>
<thead>
<tr>
<th>Life-cycle</th>
<th>Family members</th>
<th>Cause of death</th>
<th>Level of data ¹</th>
<th>Level of analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kissane et al.</td>
<td>Mid-life (mean age 57y)</td>
<td>Spouses, Adult children</td>
<td>Cancer</td>
<td>Relational, Individual &amp; family</td>
</tr>
<tr>
<td>Traylor et al.</td>
<td>Mid-life (mean age 47y)</td>
<td>Spouses, Adult children</td>
<td>Various causes</td>
<td>Individual</td>
</tr>
<tr>
<td>Davis et al.</td>
<td>Mid-life</td>
<td>Various</td>
<td>Coal mine explosion</td>
<td>Relational, Family</td>
</tr>
<tr>
<td>Nadeau</td>
<td>Mixed (aged 18-74y)</td>
<td>Various</td>
<td>Various causes</td>
<td>Interactive, Family</td>
</tr>
<tr>
<td>Mayer et al.</td>
<td>Mid-life (mean age 42y)</td>
<td>Various</td>
<td>Sudden cardiac arrest</td>
<td>Interactive, Family</td>
</tr>
<tr>
<td>Black et al.</td>
<td>Later life (aged 69-90y / 33-68y)</td>
<td>Spouses, Adult children</td>
<td>Various causes</td>
<td>Relational, Family</td>
</tr>
</tbody>
</table>

¹Individual data: data from one family member; relational: data from multiple members of the same family; interactive: data from family groups

Of the six included studies, two used a quantitative, longitudinal design to analyse individual level data from one to two family members (n=66 / n=115) to make inferences about the impact of family functioning on grief and related outcomes up to one year following the loss (see Table 7 for study variables used, p. 49) (Kissane et al., 1996a; Kissane et al., 1997; Kissane et al., 1996b; Traylor et al., 2003). One study drew on both qualitative and quantitative data collected from two to five members of 14 families, to investigate the extent to which meanings made were
congruent within families, and whether such a family similarity in meanings would impact on individuals’ depression and well-being (Davis et al., 2012). The three qualitative studies focused on the family as the unit of analysis, included seven to 34 families, and explored families’ meaning-making or meanings gained of the death (Black et al., 2011; Black and Santanello, 2012; Black et al., 2014; Nadeau, 1998), or their bereavement experience in general (Mayer et al., 2013). All except one study (Traylor et al., 2003) drew on data gleaned from at least two members of a family, however, only two collected data from family groups (Mayer et al., 2013; Nadeau, 1998). Studies were of high or good quality, except for two studies whose methodological frame was insufficiently justified or unclear (Black et al., 2011; Black and Santanello, 2012; Black et al., 2014; Davis et al., 2012).

Table 7: Study variables of longitudinal, quantitative family bereavement studies

<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>Cohesion</th>
<th>Expressiven. Affect</th>
<th>Conflict</th>
<th>Family environm.</th>
<th>Communi- cation</th>
<th>Family functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kissane et al.</td>
<td>FES subs.</td>
<td>FES subs.</td>
<td>FES sub.</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Traylor et al.</td>
<td>FES subs.</td>
<td>FES subs.</td>
<td>FAM-III subs.</td>
<td>FES total score</td>
<td>FAM-III subscale</td>
<td>FAM-III total score</td>
</tr>
</tbody>
</table>

Dependent Variables

<table>
<thead>
<tr>
<th>Grief</th>
<th>Depression</th>
<th>Distress</th>
<th>Social Adjustment</th>
<th>Family Coping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kissane et al.</td>
<td>BPQ</td>
<td>BDI</td>
<td>BSI</td>
<td>SAS</td>
</tr>
<tr>
<td>Traylor et al.</td>
<td>GEI</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Legend:
- BDI Beck Depression Inventory
- BPQ Bereavement Phenomenology Questionnaire
- BSI Brief Symptom Inventory
- FACES III Family Adaptability & Cohesion Evaluation Scale
- FAM-III Family Assessment Measure
- F-COPES Family Crisis Oriented Personal Evaluation Scale
- FES Family Environmental Scale
- GEI Grief Experience Inventory
- SAS Social Adjustment Scale

The analysis of the extracted study findings yielded insights into three areas of families’ bereavement situation. First, studies focused on family characteristics and processes, and how they impact on individual family members’ bereavement outcomes (n=5); second, findings explicated families’ meaning-making strategies and meaning constructs (n=4); and third, findings illustrated the effects of time on grief intensity and family functioning (n=3).

2. 4. 1. Family characteristics and processes in bereavement

Quantitative and qualitative studies (n=5) shed light on family processes in bereavement. While conceptualizations of family processes differ, the findings suggest that family identity and cohesion, communication and sharing patterns, and
emotional closeness, measured as conflict, matter when facing the loss of a close other (Black and Santanello, 2012; Black et al., 2014; Davis et al., 2012; Kissane et al., 1996a; Kissane et al., 1996b; Nadeau, 1998; Traylor et al., 2003).

Among the many variables of family functioning or system characteristics that were investigated in the Melbourne Grief Study and by Traylor and colleagues (see Table 7), cohesion, conflict, communication, and affect were found to have an influence on individuals’ grief experiences. Both studies provide consistent evidence that cohesion, affect / expressiveness, conflict, and communication influences family members’ intensity of grief. Those family members who were close, had low conflict or good conflict-resolving skills, or communicated well, tended to experience less intense grief within the first six months post-loss (Kissane et al., 1996a; Kissane et al., 1996b; Traylor et al., 2003). Families with low to some cohesiveness and moderate to high conflict (termed „sullen” and „hostile” families) experienced more intense grief (F=8.57, p<.06) and were at greatest risk for depression (F=10.76, p<.001) compared to other empirically developed family typologies (Kissane et al., 1996a; Kissane et al., 1996b). Families who shared emotions also experienced more intense grief, yet without increased risk of becoming depressed (Kissane et al., 1996b; Traylor et al., 2003). Moreover, members of families who had a higher congruence of meanings attributed to the death were less depressed (p=.04); however, there was no effect discernible on well-being (Davis et al., 2012). A widow/er’s perception of overall family coping was found to be a predictor of bereavement outcomes. When widow/ers perceived their family to not cope well with the loss or were concerned about family members early on, their individual-level psychological morbidity was greater later on (p<.05 to <.001, depending on variable & measurement time-point) (Kissane et al., 1997), which suggests that widow/ers feel burdened when they see their families not coping well in the aftermath of their husbands’ death.

Qualitative findings point to the importance of past family patterns, rules, worldviews, and beliefs in bereavement. Findings from one qualitative study with two to three family members following their husband or father’s death suggest that families’ way of being, expressed through a shared worldview, belief and value system, and mode of communication, may become manifest as a united or fractured “we” of the family (Black and Santanello, 2012; Black et al., 2014). A confirmed, united “we” was expressed in a similar story about the death, a shared grief and desire for closeness, whereas fractions of the family “we” occurred in those families in which relationships were unresolved, or members estranged or resentful (Black
and Santanello, 2012). Families’ shared worldview gave rise to individuals’ ways of
dealing with their husband’s or father’s death. It left families and its members with
distinct ideas or expectations about how to grieve, and how to express it, for
instance during the funeral (Black et al., 2011; Black and Santanello, 2012). In a
similar vein, Nadeau (1998) discerned a spectrum of family sharing patterns that
ranged from a willingness to share everything to a reluctance to share anything with
other family members. Sharing – defined as a willingness to talk about the death as
a family – occurred most in those families who engaged in family rituals, interacted
frequently, tolerated differences, and participated together in family group
interviews. In contrast, talking about the death to find meaning was inhibited when
family rules prohibited talking about difficult issues, members were protective of
each other or felt uncomfortable to talk at all, or were cut-off from each other
through past conflicts. Meaning-making was thus enhanced when family members
shared and talked about the death with each other, and impeded when they were
unable or unwilling to speak about their loss. Davis and colleagues (2012) found
that family members shared the same meanings in about one third of their
statements, whereby a higher similarity occurred for loss-related meanings (m=.38)
than for gain-related meanings (m=.24, t=2.61, p=.015).

These family patterns of promoting or hindering shared meaning-making (Nadeau,
1998), as well as a united versus fractured “we” of the family (Black and Santanello,
2012) are potentially reflected in the quantitative findings about family cohesion and
conflict (Kissane et al., 1996a; Kissane et al., 1996b; Traylor et al., 2003). Similar to
quantitative studies that found that family cohesion and conflict impact on
individuals’ grief experience, qualitative studies indicate that families’ sense of
belonging, identity, and closeness become strengthened or are falling further apart.
Findings from five studies of various designs thus uniformly suggest that families’
patterns of interaction, closeness, and shared history and identity come to the fore
following a family death, may undergo a shift, and impact on individuals’ experience
of grief either in positive or negative ways.

2. 4. 2. Family meaning constructs and meaning-making strategies

All qualitative studies illustrate families’ meaning constructs of the death, although to
a varying extent and depth (Black et al., 2014; Davis et al., 2012; Mayer et al., 2013;
Nadeau, 1998). The meanings family assigned were of a wide range, and arose
from their previously held beliefs and values, in relation to the specific
circumstances of the death and present family situation. Meaning statements were grouped into five themes, such as positive and negative meanings, spiritual-philosophical meanings, meanings about the circumstance of the death and what was lost, and assertions about the state of meaning-making (Table 8).

Table 8: Meaning constructs

<table>
<thead>
<tr>
<th>Meaning constructs</th>
<th>Examples</th>
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| Positive meanings                                      | Lessons learned and truths realized: About myself, to focus on the moment, how to live life; gained inner strength; setting priorities, put relationships first, and not taking others for granted \(^2,^4\)  
  Brought family closer together \(^2,^4\)  
  Death became more real \(^4\) |
| Negative meanings                                      | Death was unfair, unjust, too late or too soon, simply bad \(^4\)  
  Change of philosophy for the worse: Pessimistic outlook \(^2\)  
  Shattered assumptions (i.e. about government) \(^2\)  
  Nothing good has come of it \(^2\) |
| Spiritual-philosophical meanings                       | Religious beliefs: Revelation & reunion, a test, caused by god, beliefs about an afterlife \(^1,^4\)  
  Philosophical or folk beliefs: Death happens when time is up, death is beyond control, death is part of life, continued existence of deceased other than religious beliefs \(^1,^4\) |
| Meanings arising from circumstances of the death & what was lost | Death was preventable (by deceased, family member, medical system) \(^4\)  
  Person “died” before the actual death \(^4\)  
  Attitude of deceased towards death: Un(readiness), fulfilling wishes \(^4\)  
  Death was a loss of self, a friend, a family member, something symbolic \(^4\) |
| Assertions about meaning-making                        | Did not search for any meaning \(^2\)  
  Still struggling to find meaning \(^3\)  
  Able to find meaning in loss \(^2,^3\)  
  No meaning to be found \(^4\) |

\(^1\) = Black et al., 2014, \(^2\) = Davis et al., 2012, \(^3\) = Mayer et al., 2013, \(^4\) = Nadeau, 1998

One grounded theory study provides a rich account of families’ meaning-making strategies (Nadeau, 1998). Meaning-making was embedded in families’ everyday conversations through which they brought together individual threads of meanings. Such “family speak” included agreeing / disagreeing, referencing, interrupting, echoing, finishing sentences, elaborating, and questioning and illustrate families sharing through talking about the death. Families used storytelling to create a family theme of loss, shared dreams, compared this loss with others family deaths, used coincidental occurrence around the death to make sense of it, and characterized the deceased’s life. These narrative strategies of meaning-making are similar to an in-depth qualitative illustration of family communication measured by Traylor and colleagues (2003), who found that communication was an important predictor of individual grief. These qualitative findings provide a rich portrayal of the manifold
meanings that the death holds for families, and the manner in which sharing views, stories, dreams, and memories of past events creates a web of meanings.

2. 4. 3. The effects of time on grief intensity and family functioning

The effect of time on bereavement and family functioning was considered in two longitudinal studies. Kissane and colleagues (1996a) found that family functioning was quite consistent over their three measurement time points up to 13 months post-loss; however, there was a tendency towards less conflict by 13 months post-loss. Traylor and colleagues (2003) found that family cohesion, communication, and affect (week 5) seem to be better predictors of grief six months following the loss than vice versa.

Time accounted for almost 40% of variance in grief intensity (p<.001), yet for only 10% in depression (p=.001), and had a significant effect on family coping, which changed over time (F=13.37, p=.001) (Kissane et al., 1997). By month 13, only 15% of families who were grouped into the hostile cluster were at risk for adverse outcomes compared to the earlier measurement time points (Kissane et al., 1996a). Traylor and colleagues (2003) found that family members with intense grief early on continued to have intense grief at six months.

The notion that “time heals wounds”, which finds some support from the included longitudinal studies, is somewhat challenged by one qualitative-descriptive study, in which families found their lives forever changed in an instant, as a normal day went awry after a sudden death (Mayer et al., 2013). Families felt ill prepared for the sudden cardiac death of their male members, and experienced unsettling emotions that came to the fore unpredictably and repeatedly in their lives without their close other. While they found a way to go on with their lives, they faced lasting changes in their daily routines, activities, and social context that were unwanted and challenging.

Synthesized findings about the effect of time indicate that grief intensity tends to lessen over time, in contrast to patterns of family functioning, which seem to be more stable, and might be more predictive of the family grief experience than grief intensity is of subsequent family functioning. Nonetheless, it seems that some families continue to struggle, at least from time to time, with the profound changes that the death has brought about in their lives.
2.5. Discussion

This integrative review sheds light on individual key characteristics and family processes in bereavement from mid to late life. As such, it provides an urgently needed research synthesis for clinical work with conjaguially bereaved older persons, and adds a family perspective to the bereavement literature. However, this review is not without limitations. Personal assumptions and theoretical pre-understandings will inevitably have influenced the synthesis of study findings (Whittemore and Knafli, 2005). Literature reviews can only be objective in that they follow a clearly outlined and systematic procedure (Sandelowski, 2008). Rigour needs to be ensured through transparency and evidence of critical appraisal (Whittemore, 2008). In accordance, every effort has been made to employ a transparent and systematic process for searching, selecting, appraising and synthesizing studies using established methodological procedures. Nonetheless, it may well be that the search strategy has failed to identify all relevant studies despite efforts to do so. Because of the very limited number of family bereavement research studies, this review included all identified family bereavement studies that were conducted with more than one family member after the death of an adult member. However, based on the research question, inclusion criteria for conjugal bereavement were more stringent. Thus, some of the identified thematic areas could be reviewed in an exhaustive manner, whereas other areas remain incomplete, in particular those concerned with coping and its relation to health outcomes. As the focus of this literature review was not on how older persons appraise, cope and adjust after the death of a spouse, nor on particular risks or health outcomes, some studies were excluded that could have potentially extended and added complexity and clarity to this subject area.

2.5.1. Methodological considerations

Not only the methodological limitations of this review itself, but the nature of the included studies requires careful considerations when drawing conclusions, as they determine the transferability of the review’s findings. In particular, those study features pertaining to the age heterogeneity, overrepresentation of women, and predominance of immediate family members in study samples, as well as the nature of the designs and level of study quality need to be taken into account when using this review’s thematic findings.
Study samples and representation: Despite the fact that this review used appropriate age criteria for inclusion, reviewed bereavement studies included younger widowed/ers or families among their participants. This implies that some of the identified themes may not be unique to the bereavement experience of older persons, nor to families in later life. Families consisted for the most part of widowed/ers and adult children, although other family participants were also included. Thus, findings from family bereavement studies might look different based on which families and what type of family members are included. Notwithstanding, it can be expected that some experiences are shared between adult age cohorts and among different types of family members.

The review’s findings represent to a large part a North American, female perspective, since a majority of studies included only, or more women than men and were conducted in the U.S. Such an overrepresentation of women may be a result of the fact that some consider widowhood and family caring women’s health issues due to the feminization of old age and the fact that more women than men engage in caregiving (McGoldrick, 2004; Payne et al., 2010; Perrig-Chiello and Hüpflinger, 2012; Williams et al., 2006). Thus, while some researchers focus exclusively on widows, even researchers who aim to have a mixed gender sample may be likely to recruit more women (family members) than men (male members) into their studies. Nonetheless, attention to the potentially gendered nature of bereavement findings is needed, and issues about representations within families require careful consideration.

Design and quality of included studies: Some methodological features of the included studies also warrant attention, such as how family and conjugal bereavement studies were designed, as well as the level of quality they achieved. For the most part, research with families is designed such that it collects data from several family members separately, and aggregates data to treat the family as the unit of analysis (Feetham, 1991; Ganong, 2011; Moriarty, 1990). This was also the case in the majority of reviewed family studies. In one study, quantitative data analysis was such that findings do not reflect a family as existing in reality, since members of one family could belong to different family typologies (Kissane et al., 1996a; Kissane et al., 1996b). Another quantitative study used only one person to make inferences about families, but because the measures explicitly assessed family system characteristics, it was included (Traylor et al., 2003). All qualitative studies drew on solo interviews, of which two also gleaned systemic data from
family groups to shed light on the interactive nature of family bereavement (Mayer et al., 2013; Nadeau, 1998). Although limited in their explanatory or illustrative power, individual data have the potential to provide insights about family system variables, but they do not allow us to glean insights about family interactions as they unfold in a natural setting (Åstedt-Kurki et al., 2001; Feetham, 1991; Sullivan and Fawcett, 1991). While these different approaches to research with families are important, the interactive, relational nature of bereavement – the family experience – might be better understood if research draws on transactional and interactive data, whereas in quantitative research, analysis strategies that aggregate individual data to reflect families as they exist in reality might be the best way to better understand behaviours of whole families (Ganong, 2011; Gilliss and Davis, 1992; Sullivan and Fawcett, 1991).

While 80% of family studies were longitudinal in nature, only 33% of conjugal bereavement studies collected data over time. Cross-sectional descriptive and correlational designs predominated, and only those studies that were based in large age cohort studies (i.e. Americans’ Changing Lives Study, Changing Lives of Older Couples Study, Yale Bereavement Study) had the power to describe change over time or make comparisons between various groups. Qualitative studies were mostly based on one interview, which may not be sufficient to glean an in-depth understanding of the experience even at the point in time at which it seeks it. Longitudinal research, both qualitative and quantitative, is needed to better understand how bereavement unfolds over time, and to identify individuals and families who are most vulnerable for a disabling grief experience or adverse mental or family health (Carr, 2006; Stroebe et al., 2008).

Even though 63% of studies were of good or high quality, the fact remains that one third of studies had some major flaws. In quantitative studies, small sample sizes, a lack of valid and reliable measures and inappropriate statistical analysis for the level of data were the most frequent reasons for studies’ moderate to low quality. In qualitative studies, incongruence between the design claimed, and the conducted data collection and analysis, or a lack of a sound methodological frame altogether, combined with insufficient descriptions or justifications of analysis strategies used, were the main threats to their trustworthiness. This review refrained from excluding relevant studies solely on low quality, but weighted them less when synthesizing the evidence. Nonetheless, these studies could add valuable confirmations to those thematic findings that arose from across many well designed and carefully carried out studies.
2. 5. 2. Patterns of capacity and vulnerability in later life bereavement

Individual conjugal and family bereavement studies were analysed as two separate bodies of knowledge, however, their findings complement and mutually inform each other. They propose that older persons and families hold an inherent capacity to face the loss of their close other. Persons’ and families’ inherent capacities come to the fore in the review’s findings that shed light on the nurturing and supportive nature of relationships with others, the sustaining activities and strategies that widow/ers draw on, the helpfulness of families’ emotional closeness, sense of belonging and ability to talk, the meanings collectively made of the death, and the potentially healing effect of the passing of time. The review also sheds light on the vulnerabilities that older persons and their families encounter in bereavement. On the individual level, vulnerability was evident in the many challenges that older persons encounter in relation to their health and social situation as widow/er that includes a need for support with a potential loss of independence, in their pervasive sense of loneliness and existential aloneness, the recurring emotional upheavals, conflictual and burdensome relationships, and their perception of the loss as harmful and threatening to their sense of self. On a family level, vulnerability occurred when families had a history of conflict and emotional estrangements, and when they held pronounced differences in meanings of the death.

The pervasiveness of individual and family resilience in the face of life-changing events has been well established (Berger and Weiss, 2009; Boerner et al., 2005; Bonanno, 2004; Dutton and Zisook, 2005; Greeff and Human, 1994; Landau and Saul, 2004; Stroebe et al., 2007; Walsh, 2014). Two included studies confirmed that about 17% of bereaved widow/ers and between 15 and 30% (depending the time-point of measurement) of members within families were at risk for debilitating grief and psychological distress, respectively (Kissane et al., 1996a; Ott et al., 2007). In a similar vein, a large cohort study (CLOC) yielded that about 16% of the investigated persons 65 years or older experienced debilitating grief, but almost 50% exhibited resilience (Bonanno et al., 2002; Bonanno et al., 2004). Similar to findings in this review, older persons’ trajectory of resilience was marked by initial longing and grief, and an ability to find comfort in talking and thinking about the deceased, be at peace with how things had unfolded, and to create meaningful ways to adjust to their new situation (Bonanno et al., 2008; Bonanno et al., 2004). These insights, paired with findings that grief interventions are not uniformly beneficial for all people all the time (Jordan and Neimeyer, 2003; Schut and Stroebe, 2005; Stroebe et al., 2007), shift the attention from a therapeutic focus on the negative consequences of loss to
health-promoting practices (National Institute for Clinical Excellence, 2004). Moreover, a need to better understand the constitutive factors of persons’ and families’ capacities and vulnerabilities to identify those most at risk and likely to benefit from professional attention is evident (Agnew et al., 2010; Hayslip and Page, 2013; Walsh, 2014).

(Family) relationships encompass capacities and vulnerability: Family and individual level findings establish reliably the central role and overwhelmingly helpful nature of relationships with close others and the deceased in bereavement. Qualitative research demonstrates that widow/ers find support and comfort from close others, both within and outside the family. This review thus supports previous findings that close others, and in particular children, become important sources of support in bereavement (Balaswamy et al., 2004; Benkel et al., 2009a, b; Ha, 2008; Ha et al., 2006; Miller et al., 2004; Stelle and Uchida, 2004).

The family-level review yielded consistent, but limited evidence from quantitative investigations that members of families who are emotionally close, communicate well and work with their conflicts are well able to deal with their individual grief and face less risk for adverse mental health, despite the fact that sharing emotions intensifies their grief. While reviewed studies overwhelmingly found that relationships add to persons’ capacity to manage their grief, in some situations, relationships seem to increase bereaved persons’ vulnerability and compound individuals’ grief. Individual-level qualitative findings suggest that previously strained relationships become an additional burden for bereaved widow/ers. Family-level findings purport that families marked by high conflict, low cohesiveness, and poor expressiveness face more adverse outcomes.

The importance of relationships when experiencing grief has previously been noted. Theoretical writings suggest that relationships denote not only the context within which grief unfolds, but act as a resource for individuals’ quest to come to terms with the loss (Gilbert, 1996, 2007; Ha, 2008; Shapiro, 2001). The potential negative consequences of difficult relationships have also been pointed out (D’Amore and Scarciootta, 2011; Hayslip and Page, 2013; Walsh and McGoldrick, 2004b). This review adds an empirical perspective to such theoretical claims. Despite the consistency of the family-level findings, they need to be used with caution since they are based on only a few studies, which were designed on particular assumptions about what constitutes “good functioning” families (i.e. closeness, open sharing, and absence of conflict). Such assumptions may be problematic and fall short of
capturing families’ complex and multi-layered experiences of being and doing family in light of difficult life events (Hooghe et al., 2011). While the here synthesized empirical knowledge base is too small to refute or confirm existing theoretical models, this review yielded sound evidence that persons come to terms with their grief through being-in-relation with others.

**Added vulnerability: Disruptions and challenges in widow/ers’ daily lives:**
Conjugal bereavement studies demonstrate that the death of a life partner disrupts established daily practices, social identities, and a coherent sense of lived time and meaning in life. Upsetting and painful emotions, unexpected turmoil, difficult daily times or excessive time, and a pervasive sense of loneliness bring about moments of breakdown, and denote distinct challenges for older, bereaved widow/ers.

A pervasive sense of loneliness and difficult daily, weekly, or yearly times, and a wide range of painful emotions, including sadness, remorse, and upset are known to be key feature of bereavement for older persons after the loss of their spouse (Costello, 2002; Fry, 1998; Hansson and Stroebe, 2007; Stewart et al., 2001; Stroebe, 2008; Stroebe et al., 1996). As evidenced in some studies, the loss of a spouse may also disrupt widow/ers’ sense of identity and continuity in their lives. As such, findings of this review lend credibility to the proposition that bereavement challenges the taken-for-granted life-world, disrupts life’s narrative and requires that persons “relearn their world “ (Attig, 1996, 2004). Widow/ers have to re-orient themselves in their social contexts alone. Their new social situation as widow/ers who face health and functional impairments that may require them to negotiate independence and their need for support, denotes a challenge, particularly so for frailer older widow/ers. However, how widow/ers’ health situation, independence and need for support are affected by bereavement remains unclear in this review. There is some evidence that conjugally bereaved older persons suffer from sleep difficulties, lack of energy and a loss of appetite (Carter, 2005; Monk et al., 2008; Richardson et al., 2003), but since such symptoms are pervasive in old age, they may be an expression of grief or of a pre-existing health situation (Heeb et al., 2008). Some reviewed studies suggest that women tend to be more independent in widowhood than before, but others indicate that independence is predominately constituted by age, financial resources, availability of family, and functional abilities.

It is likely that the diversity among older persons, as well as the manifold family constellations constitute widow/ers’ vulnerabilities and capacities in daily lives. What is absent to date is how a family death plays out within a family system. In particular
the ramifications a death holds for families’ concerns, caring activities, and organisation in daily life has not been investigated by any of the family-level studies. Thus, this review renders evident that widow/ers face many disruptions in daily life routines, activities, and social identity, and challenges in their lives alone for which they exhibit considerable capacities. In contrast, there is a lack of research about families’ capacities and vulnerabilities in daily family life.

**Widow/ers’ capacities: The use of strategies and activities to live with loss:**
This review shed light on the concrete manner in which older widow/ers face their lives without their spouses. Findings consistently demonstrate that older widow/ers engage in everyday activities and routines that keep them busy, increase their skills, instil purpose in their lives, and root them in their new life situation. This review brings to the fore widow/ers’ considerable resources and provides an in-depth insight about the manner in which established activities and routines provide familiarity and relief that sustain older bereaved spouses. Strategies that older persons use include everyday activities that structure their days, leisure and social activities that involve them in meaningful occupations and with others, as well as remembrance activities to remain connected with their close other and to learn to live with the difficult and painful moments. Older bereaved persons’ resilience and hardiness has been previously noted (Bennett, 2010; Bonanno, 2004; Bonanno et al., 2004). The review also adds clear support for the continuation of bonds with the deceased (Field and Friedrichs, 2004; Field et al., 2003; Klass et al., 1996; Root and Exline, 2014; Sanger, 2009; Stroebe and Schut, 2005). Bereaved widow/ers develop new relational practices through which they continue their relationship with the deceased, which denotes a source of comfort for them.

**Growing capacity: The passing of time:** The included studies provide some evidence that grief and adverse psychological outcomes, such as depression or distress, become less intense or disappear as time passes. In accordance, well-being, mental health and a sense of personal strength increase over time. In contrast, finding meaning and involvements with the deceased by means of memories, conversations, and anniversary reactions are more stable over time, and continue for many years. Changes over time occur on the individual and family level; however, the evidence base for families is small and limited to one year post-loss. For bereaved older persons, previous research suggested that depression and distress decrease over time; however, many other indicators and reminders of grief and loss continue to stay with the bereaved (Bennett and Bennet, 2000). As such,
current insights question the hypothesis that grief needs to and can be overcome (Moules, 1998; Moules et al., 2004). Rather, it suggests that individuals’ and families’ vulnerability for and experience of adverse consequences decreases over time. However, persons’ sense of loss continues to stay with people for years, as expressed in the findings about difficult yearly times, the lasting impact on meaning-seeking and personal growth, the continued interactions with or concerning the deceased.

2. 5. 3. Family functioning and individual coping in bereavement

Findings of this review uniformly suggest that family functioning and sharing patterns influence individual grief outcomes and collective meaning-making, respectively. In contrast, which type of individual coping best promotes adaptation remains unclear based on this review alone. Claims rest on weak grounds, since they are based on a couple of studies only, and studies contradict each other or use very different measures and comparison groups, respectively.

*Family functioning and sharing patterns:* Family bereavement studies suggest that family functioning is potentially a more stable feature in bereavement situations than grief itself. A family death may thus not uproot who families are and how they interact together, but bring to the fore their strengths and difficulties in distinct manners. While study designs do not allow for causal inferences, they nonetheless shed light on the manifold ways that families’ shared past, sense of identity, and previous interaction patterns serve as the background from which they negotiate their individual and family lives after the death of a loved one. In a similar vein, the meaning of the death itself is also shaped by families’ history and situated contexts, their values and beliefs, and the circumstances in which the death had happened. Only one sound, in-depth qualitative study found that established family sharing patterns matter for families’ meaning-making. Such sharing patterns were manifold and constitutive of families’ ability to actually talk about the death and to engage in a communal process of meaning-making, in particular through strategies such as ordinary conversations and storytelling (Nadeau, 1998). However, it remains unclear how the level and extent of family meaning-making affects widow/ers’ and families’ ability to come to terms with the loss.

*Individual coping:* This review entails inconclusive findings about individual coping strategies and health outcomes, mainly due to methodological weaknesses and
variability in design. However, some evidence purports that the effectiveness and fit of coping with the situation, rather than type or number of strategies used impact positively on widow/ers’ adaptation to loss. The normalizing and narrow conceptualization of successful coping used in studies may limit clearer understanding of coping with bereavement. Included studies were based on cognitive theory of stress and appraisal, where some coping strategies are considered adaptive and others maladaptive. Such an approach has been critiqued as potentially inadequate when such a complex phenomenon like bereavement is the stressor (Stroebe and Schut, 1999). More bereavement-specific frameworks, such as the dual process model of coping with bereavement (Hansson and Stroebe, 2007; Stroebe, 2010; Stroebe and Schut, 1999; Stroebe and Schut, 2010) suggest that bereavement requires a complex coping process, termed oscillation, which shifts between a focus on the loss experience itself and an attention to the everyday consequences of the loss. This review indicates that not one coping strategy per se is helpful for bereaved older persons, but the use of various coping strategies employed according to the stressor to be dealt with. Hence, the importance of an oscillating process of coping in bereavement finds some support in this review.

2. 6. Implications for research

With only six studies, families’ situation after the death of a close other in later life is clearly under-researched. In contrast, the body of research on conjugal bereavement is considerably larger. In light of the reviewed research and the fact that a majority of persons experience the loss of their life partner after 65 years of age, future research is needed. Several gaps can be identified from this review for further study.

First, there is a lack of research about the relational dimensions of loss; that is, how a family death ripples out within a family system (Hayslip and Page, 2013). To date, bereavement research tends to be conceptualized from an individual perspective and fails to acknowledge that the death of a person always affects a web of interconnected persons. Attention to families’ bereavement situation is important in light of the fact that more persons will experience spousal loss later in life, and potentially after longer times of family caregiving (Payne et al., 2010). Moreover, widowed persons tend to live longer in the community with the support of family (Perrig-Chiello and Höpflinger, 2012). Future research should explicitly address family system characteristics and relational processes, and shed light on families’
capacities and vulnerabilities in bereavement. Research designs should include at least two members, glean data from family groups, and use the family as the unit of analysis. Both qualitative and quantitative research approaches are useful to study families’ bereavement experiences, since more knowledge is needed about how family characteristics impact on family and individual health, as well as on how families' lived situation, relational activities, and interaction patterns play out in daily life (Hooghe et al., 2013). Much is theorized about how individual’s loss experience constitutes and is constituted by family groups, but little is empirically verified.

Second, there is a lack of insight about the daily consequences of spousal loss for older persons, and families’ everyday situation has not received much attention (Carr and Utz, 2002; Hansson and Stroebe, 2007; Hayslip and Page, 2013; Moss et al., 2001; Rumbold and Aoun, 2014). The intricate family caring relations and activities, subtle shifts in roles and responsibilities among generations, and the unique challenges in daily life as they play out following a family death for a group of connected persons needs considerable attention. Such insights are needed to develop a deeper understanding of older persons’ and their families' habits and practices, their capacities and adversities in everyday life to lay a basis for family-focused care. Moreover, a need for age-specific research exists that looks at the experience of participants from a narrower age range to learn about the particularities (or universal aspects) of loss in a later life context (Carr, 2006; Hansson and Stroebe, 2007).

Third, this review extends on previous findings, which suggest that a majority of bereaved older persons are resilient in light of dramatic life events, and despite their distressing and painful nature, do not suffer from debilitating or disabling expressions of grief or adverse mental health (Bennett, 2010; Bonanno, 2004). The same has been found on the family level (Kissane, 2014; Kissane et al., 1996a). However, particularly for families, a lack of insight about the constitutive elements of family resilience and vulnerability that may determine their need for professional care requires further research. Research to date has limited its investigation to functionalistic understandings of family health, which may not capture the complex and multidimensional relational patterns and family activities that constitute their ability to live with the loss of a close other (Hooghe et al., 2013).

Fourth, although this review included studies with particular ethnic, gender, or clinical groups, both on the individual and family level, it is not possible to make any inferences about particular groups of widow/ers or family groups. Moreover, with most studies conducted in North America, and with a majority of persons who had
lived in heterosexual relationships and were part of traditional family configurations, research with more diverse and non-traditional families is needed. Attention to the individual and family bereavement experience as it plays out in a different cultural context, non-traditional family relations, and unique circumstances of family life and death may add richness and complexity to current understandings.

2.7 Conclusions

In this review, empirical findings about the characteristics of spousal bereavement in later life, and family system characteristics and processes as they play out for bereaved families after the loss of an adult member have been synthesized. A considerable body of research sheds light on the individual bereavement experience, whose key characteristics were synthesized into six distinct themes. This review suggests that widow/ers face disruptions in everyday activities and routines. Paired with health concerns, shifts in social identity and self-sufficiency, and a pervasive sense of loneliness, older, widowed persons face many challenges that shape their ability to manage life alone in the community. At the same time as they experience vulnerability, bereaved older persons also exhibit considerable capacities in bereavement, find comfort and support in relationships, and use many different everyday strategies and relational activities to make themselves at home in their lives without their spouses (Naef et al., 2013).

In contrast, only six research studies on families’ bereavement situation could be identified. This small body of research consistently points to the central role of family cohesion, communication and sharing patterns, and emotions when facing a family death. Family characteristics not only affected individuals’ experiences, they also provided the background from which families made meaning of the death. The here proposed synthesis denotes only a beginning, empirically derived knowledge base for clinical practice with bereaved families and older persons in later life. Nurses and other health professionals working with bereaved families and older persons should extend their attention beyond the individual to family relations and interactions in bereavement. Families’ previous sharing and communication patterns, their sense of belonging and emotional bonds should be considered by nurses when working to support families in their communal quest to make meaning of the death. Moreover, members of families with previous conflicts and estranged
relationships may be at greatest risk, and careful attention needs to be given to their individual experience of grief.

In working with bereaved older persons, nurses need to address the disrupted and sustaining everyday and relational practices in order to support older persons to affirm or develop new activities, skills, routines, and strategies to live with the loss of their spouse. Loneliness, health symptoms and concerns also warrant attention and potential support from nurses and other health professionals. It is important that nurses realize that not particular coping strategies, but rather their fit with the loss(es) older persons face, and the meanings such losses hold for them are helpful to deal with grief. Overall, nurses should carefully discern individuals’ and families’ capacities and vulnerabilities in bereavement.

Based on this integrative review, a need for more family research and research that focuses on a variety of contexts and situations, as well as the concrete manner in which individuals and families live with their loss in daily life is needed as a basis for family-centred care. Research that sheds light on the interrelationships of grief, later life, and individual and family health is also warranted in order to identify individuals and families who are most at risk for challenging family situations. To address some of the identified areas warranting further exploration, the subsequently presented doctoral research study with bereaved families in later life was undertaken. This phenomenological-hermeneutic inquiry aims to explore family meaning patterns and everyday relational practices after an older person’s partner has died.
3. Theoretical perspective

A phenomenological and nursing perspective on grieving families

In this chapter, a phenomenological perspective and theoretical understandings of bereavement, grief and family that situated the researcher in her thinking about the subject matter, and framed the conception of the study, are elucidated. In so doing, Heidegger’s (1921/2001) ontology of human existence, and specific conceptions of grieving and family health put forward by nurses and others are discussed (Attig, 2001, 2004; Cody, 2000b; Florczak, 2008; Hartrick Doane and Varcoe, 2005a; Parse, 2009; Pilkington, 2006). The work of these scholars maps the theoretical landscape from which the researcher departed, and denotes a theoretical substantiation for the study of families’ lived world after a close other has died.

3.1. A phenomenological perspective on human existence

Phenomenology is a philosophical perspective that attends to humans’ concrete experiences as lived in their ordinary, everyday life. It seeks to understand human life from a subjective standpoint, and rejects the idea that a detached, objective gaze allows for meaningful understanding of human existence (Moran, 2000). Heidegger’s ontological philosophy of Dasein as being-in-the-world and being-with provides one lens within the phenomenological movement that sheds light on human experiences such as death, bereavement, and community with others lived as family. In order to posit a conception of death, bereavement, and family relating from a Heideggerian point of view, some of his main philosophical ideas about human existence are illuminated first.

3.1.1. Heidegger’s philosophy of humans and their relating to their world

Heidegger (1926/2001), primarily with his work Being and Time, shifted understanding of human existence as a way of cognitive knowing about the world to one of being-in-the-world through involvement and understanding (Large, 2008). He posited human existence as a situated possibility, which is constituted by a pre-existing cultural and historical world into which humans are thrown, and maintained that humans engage with their world through meaningful involvements; that is, in caring about and being concerned (Chesla, 1995; Plager, 1994).
Being-in-the-world and being-with through caring involvements: Heidegger maintained that we inherently understand ourselves and our world because we act in relation to a set of meaningful interrelationships that make up our world (Plager, 1994). As we act, we always understand our world in relation to something else and make sense of what we encounter in the everyday of our lives in relation to a whole set of interrelated meanings (Figal, 2007). The example Heidegger used is that of a hammer, in which he proposed that we understand a hammer because it serves to put in a nail, and we grasp a nail because it joins two pieces of wood together, which in turn makes a house that serves as a home (Heidegger, 1926/2001; Large, 2008). Hence, we grasp our practical world because we are engaged in it, and we make sense of entities we encounter because their functioning carries distinct purposes; they form together a relational whole that holds significance for us. However, being-in-the-world is not only practical involvement; it is also always being-with other Beings. We engage with our relational world through caring involvements with each other. Heidegger (1921/2001) posited that humans’ basic manner to be in the world is through care (Sorge), which means that people relate to things because they matter (Besorgen), and they are in relations with other human beings through concerned caring for (Fürsorge). These caring involvements are transparent and absorbed, but it is through these practical and relational involvements that we understand the nature of our Being. This familiarity of the world is primordial and precedes any cognitive reflections and mental grasps of ourselves and our surroundings. Heidegger argued that there are myriad ways to be in and relate to the world, of which the most essential one is to be aware of one’s own way of Being, which is Dasein (Large, 2008; Taylor, 2012). Dasein (i.e. being human) is distinctively different from other entities because Being (i.e. human existence) is an issue for it (Large, 2008; Taylor, 2012). This means that how to be and act within the world is a matter of choice and possibility.

Dasein’s inauthentic way of Being (fallen into the They): Dasein, as a human being, holds the capacity to grasp its own existence. According to Heidegger (1926/2001), for most of the time, humans are absorbed and subsumed in their world because they go about their taken-for-granted everydayness as any other human being does. Dasein gets pulled into the general, anonymous They (das Man). Human’s fallenness (verfallen) into the They; that is, their absorption in a general, non-distinct manner to live a life, is like a continuous gravitational pull (Geworfenheit) through which Dasein gets caught up in an inauthentic (uneigentlich) mode of being. “Inauthentic” means not one’s distinctively own, and denotes the
primordial way of being self (Figal, 2007); it is “living in the vague average understanding of everydayness” (Moran, 2000, p. 239). In this inauthentic mode of being, humans are so caught up that they do not see nor face the ever-present opportunity to choose their own potentiality to actualize their ownmost way of being (eigentlich). Rather, their potentiality-to-be is closed down and taken over by the They (Dreyfus, 1991; Figal, 2007).

**Dis-closing of the world through angst, call of conscience, and being-towards-death:** What wrestles Dasein out of the They is a moment of angst (Angst). A moment of angst about being-in-the-world not only takes away the seemingly familiarity provided by Dasein’s absorption in the They, it also renders Being a matter of conscious reflection (Heidegger, 1926/2001). Angst brings, so Moran (2000), “our personal concerns into sharp relief” (p. 239), and “leads us to drop the mask of our everyday familiarity with the world” (p. 241). The transparent everyday world becomes visible and alien. It makes persons feel not-at-home, in the sense of foreign, uneasy (unheimlich). In such anguish, “the everyday familiarity collapses” (Heidegger, 1921/2001, p. 189) in such a way that there is no “graspable possibility to be in it” (Figal, 2007, p. 76). In such a moment, the world loses significance, and Dasein “drifts past (...) unable to act, while other people go on busily” acting in their world (Dreyfus, 1991, p. 181). When such a moment of angst occurs, there is something that Heidegger names “call of conscience” (Ruf des Gewissens) that arises as a disquiet and calls from within and upon Dasein to actualize its potentiality to be authentic and face the openness of the world in making its own choices, to become its own self – to be ourselves (Figal, 2007; Heidegger, 1926/2001; Large, 2008). According to Dreyfus (1991), “anxiety serves as a breakdown that reveals the nature of Dasein and its world” (p. 177). Therefore, a moment of angst opens up the world and ways to be involved in and with it that discloses endless possibilities, it dis-closes Being as possibility (Erschlossenheit; Heidegger, p. 188). Face-to-face with the ultimate and inherently own possibility of death, humans can understand the nature of their existence. Being-towards-death (Sein-zum-Tode) brings home to humans that their life is inherently their own and no one else can live it for them, just as death is inescapably always one’s own, and no other person can die one’s own death (Large, 2008). However, in light of this radical potentiality to be authentically self, there is always the pull to fall back into the comforting, familiar, generality of being (the They).
**Dasein’s authentic way of Being (pressing into disclosed openness and possibility):** When human beings choose to make choices in a situation of angst and unfamiliarity with the world, they actualize their full potential to be a distinctive self in the face of their own impossibility to be, expressed in being-towards-death. In Dasein’s authentic mode of being, it seizes its true Being in projecting ways of being a distinct existence in the world. It is from the future possibility of death that humans press-into-possibilities (Vorlaufen in die Möglichkeit) of their ownmost possibility of existence. Face-to-face with the possibility of death, Dasein understands that it is existentially separate from the They (Heidegger, 1926/2001; Taylor, 2012). As humans seize the possibilities-to-be-themselves, they also enter into authentic being-with others; that is, their unique ways of relating with others, both living and non-living that arises from their own distinct way of being (“constituted from within one’s own potentiality-to-be”, Heidegger, p. 298). Authentic being-with others brings Dasein into its distinctively own relating with entities (besorgen), and pushes it into a concerned caring for other Beings (Fürsorge) (Heidegger, p. 298). As such, persons fulfil a “kind of potential-to-be-whole” (Moran, 2000, p. 240).

### 3.1.2. Death of another, bereavement, and family relating through a Heideggerian lens

Heidegger (1926/2001) dedicated quite some attention to death as an existential human experience. However, he was not interested in death as an actuality, but as the (im-)possibility of human existence (Large, 2008). Heidegger maintained that the death of others does not dis-close humans’ own potentiality; rather, the death of others may only confront those who remain behind with the finitude of existence, albeit never their own (Figal, 2007). Nonetheless, in *Being and Time*, Heidegger started his discussion of death with the experience of the death of others in which he elaborates on how humans relate to the death of other Beings (pp. 237-241). In so doing, he asserts that being-with (Mitsein) others who died remains a possibility even though this person is, factually, no longer (a being-) in-the-world¹: “Im trauernd-gedenkenden Verweilen bei ihm sind die Hinterbliebenen mit ihm, in einem Modus der ehrenden Fürsorge. (…) Der Verstorbene hat unsere ‘Welt’ verlassen und zurückgelassen. Aus ihr her können die Bleibenden noch mit ihm sein” (p. 238). Here, being-with others (Mit-sein als Miteinandersehnein) is not limited by the

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¹ Loosely translates as: “In a grieving-remembering abiding with the deceased, those who remain are with him/her, in a mode of honouring solicitude (…). The deceased has departed from and left our 'world'. From within that world [meaning that there is an inherent possibility arising from that world], those who remain behind can still be with him/her.”
physicality of biological existence; rather, persons’ relational world arises through concerned involvements in caring about others who matter in their lives.

Based on this assertion, the researcher came to understand situations of loss as *moments of lingering presence, which are enacted in connecting through a meaningfully remembered involvement that has moved beyond a shared factual existence*. Moreover, based on Heidegger’s account of human existence as inexplicably interwoven with others through absorbed, non-reflected habitual caring engagements (inauthentic mode of being), the death of a close other may create a moment of angst in which the world loses its transparency (authentic mode of being). Hence, bereavement can be comprehended as a *situation in which persons’ sense of being-at-home in their world that had made inherently sense is lost.*

Persons’ and families’ absorbed and engaged living in their everydayness may be interrupted as existential questions arise and throw persons into an utter alienation and unfamiliarity.

Heidegger did not write explicitly about family beyond his fundamental conception of persons as being-in and being-with in authentic and inauthentic ways of Being. However, based on Heidegger’s conceptualization of persons and their world, the author came to see family as a *being-with through caring involvements that arises from person’s facticity* (i.e. being thrown into a particular world) and is *constituted by humans’ actions and commitments that arise from their situated possibilities.* Human existence is relational, and as such, includes family relations that arise both from being born into a certain family with a certain tradition in a particular moment in time, and from making choices about how to live being-with others.

Grounded in Heidegger’s conception of human relating, a view of living with loss as *honouring being-with through a lingering, remembering involvement,* and an understanding of family as *situated, relational connectedness* can be derived.

Heidegger’s phenomenology thus provides a distinct passageway to understand human experiences, such as death, bereavement, and family relating, which are encountered by nurses and other health professionals in their daily work. Indeed, Heidegger’s thinking has been used in health care and nursing to explicate a way to researching and working with persons and families (see for instance Benner, 1994b; Chesla, 1995; Hartrick Doane and Varcoe, 2005a; Hartrick and Lindsey, 1995; Parse, 1998; Parse, 2001). Common to these more discipline-specific perspectives is their emphasis on the relational nature of human existence. They acknowledge persons and families’ unique ways to find meaning in, and appreciate that they live with their health challenges embedded in their specific contexts and situations, and
in relating with close others. Theoretical perspectives that follow from Heidegger’s philosophy are elucidated in the next section, and situated within the broader context of thinking about grief and family nursing in bereavement situations. Implications for nursing practice and research are subsequently derived to illustrate how these perspectives have shaped this doctoral work.

3.2. (Nursing) theoretical perspectives on grief and family

Heidegger’s relational and situated conception of persons in their world, their absorption in an everyday familiarity through concrete involvements and inherent understandings, their potential to make choices and actualize their own Being in making their lives creatively and distinctively their own has given rise to alternative conceptualizations about two core phenomena relevant to the researcher’s scholarly undertaking; that of grief, and that of family.

3.2.1. Living grief: Re-learning a world and unfolding (family) becoming

Thomas Attig, a philosopher working with bereaved persons, has been very explicit in articulating a different view of grief to inform professional carers to work with bereaved individuals in supporting, helpful, and respecting ways. He posited that the death of another propels a person’s world into visibility, unfamiliarity and renders it an alien and foreign place to be, which requires re-learning one’s world in new, distinctive ways, and finding lasting love with the deceased (Attig, 1991, 1996, 2000, 2001, 2004). For Attig (2004), bereavement constitutes a breakdown situation in which the familiar world, and smooth flow of pre-reflective involvement becomes undone; that is, daily life and the narratives of a person’s life story becomes disrupted, and a feeling of out of place in the larger scheme of things can arise. He maintained that grieving is an active process that includes choosing ways to be and act in the world anew; that is, how to meet the challenges brought about by the choiceless event of the death of a close other by “reengaging in the world in some old and familiar ways that still work for us and in some inevitable new and unprecedented ways” (Attig, 2004, p. 350). He suggested that the world that has to be re-learned encompasses physical surroundings (places, things, environment), persons’ social surroundings (relationships with family, friends, colleagues), and our-selves, like body, mind, and personal identities (2004, p. 350-351). According to Attig (2004), in re-learning the world, humans “strive to accomplish three things: (a)
to transcend and find meaning in our suffering, (b) to make ourselves at home once again in the local and global context of our lives, and (c) to stretch into the inevitable new shape of our daily lives and new course of our life stories” (pp. 346-347). As the lived world has to be re-learnt, the relationship with the deceased also warrants transformation. For Attig (2004), creating lasting “love in separation from the deceased” (p. 354) is an expression of a deep desire to continue to experience the caring and loving give-and-take that has marked the relationship with the deceased by holding the deceased’s legacy close, and through remembering shared involvements (Attig, 2000, 2004). Thus, Attig drew on Heidegger’s ideas about humans’ caring, pre-reflective involvements in everydayness to posit that bereavement is a situation that disrupts persons’ sense of familiarity and unreflective, absorbed manner to go about their lives, requiring them to re-learn their world. Moreover, based on Heidegger’s suggestion that a lingering-remembering involvement with the deceased is possible, Attig posited that finding lasting love with the deceased is not only possible, but desirable.

Within nursing, some have suggested that grief is a process of human becoming; that is, inherent to human and family life (Cody, 1995a; Parse, 2007, 2012, 2013; Pilkington, 2006). Parse (2009), in her family model, posited that the paradox of joy-sorrow, which includes “celebrating and grieving happiness and sadness” is inherent to living family and occurs “with the expected and unexpected in day-to-day happenings” (p. 307). As such, grieving is not limited to bereavement, but marks any moment of sadness in family life. Expressions of grieving within families may be manifold and ever-shifting, requiring that persons honour individuals’ manifestations and priorities in living joy-sorrow. Florczak (2008) posited that grieving a loss entails „persistent sorrow arising with weaving the familiar-unfamiliar anew” (p. 8). Similar to Attig’s proposition of re-learning the world, this conceptualization understands grieving as an ongoing human experience in which persons connect with those values, habits, and actions that still hold meaning, and seek to create new ways to be and act in the world in the face of the utter unfamiliarity that the parting of someone dear – or any profound loss - has brought about. Grieving the loss of a close other involves assigning particular meanings, re-creating patterns of relating with others as well as particular places, things, or values, and moving beyond in transcending to new possibilities in the course of life (Attig, 2004; Pilkington, 2006).

Nurses, together with others, have thus laid out a perspective that critiques long-standing conceptualizations of grief as a time-limited, stage-like process that ends with its resolution, which still pervades professional and popular writings about grief
In working with bereaved families, Moules and her colleagues (Moules, 1998; Moules and Amundson, 1997; Thirsk and Moules, 2012, 2013) have persistently maintained that normative and pathologizing understandings of grief that have become engrained in professionals’ practice with families add to their suffering, can even cause harm (inertia), and become the problem itself. They emphasized that common facts or myths about grief, like there is a need to say good-bye, there is a right way to grieve that ends with resolution, or moving on with life is necessary, denote constraining and problematic beliefs that inhibit individuals, families and nurses to engage meaningfully with their experiences of living through loss and providing care, respectively (Moules, 1998; Moules et al., 2004). Similarly, others also maintained that new models of loss and grieving are warranted to gain a more meaningful approach to research, and more helpful frameworks for clinical practice (Attig, 2004; Hedtke and Winslade, 2004; Neimeyer, 2001b, 2014).

Based on these (nursing) perspectives, nurses and other health professionals working with bereaved persons are called to bear witness to the suffering arising from a loved one’s absence, and to walk alongside in a supporting manner as bereaved persons meet the challenges in re-creating their world and lasting love. As Attig (2004) suggested, professionals caring for grieving persons should appreciate diverse ways of finding meaning in life, and “help grievers as they choose how to respond to the challenges they face (…) [and] to carry the pain of missing those they mourn, reshape their daily lives, and redirect their life stories (p. 353). Unique meanings and diverse ways of living grief within and between families should be respected. For research, these theoretical perspectives warrant attention to persons’ experiences as distinctively lived in the everyday context of their lives. It requires approaches that respect human complexity and diversity, and seek to understand in-depth the concrete manner in which people make sense and re-shape daily and relational life patterns.

3.2.2 Living family: A situated, relational connectedness

Drawing on Heidegger, among others, nurses have put forth a view of family as an inherent relational and situated connectedness (Cody, 1995b, 2000b; Hartrick Doane and Varcoe, 2005a; Hartrick, 1995; Hartrick and Lindsey, 1995; Parse, 2009). For example, Hartrick Doane and Varcoe (2005b) suggested that family is a “complex relational process” that is contextually situated and continually shifts and
evolves (p. 11). As such, family can be seen as a “multiplicity of voices and consciousness (…) engaged in a dialogic relationship”, with “a wealthy source of traditions, stories, characters, and values that offer plenty of raw material that they shape into a life through their own creative fashion” (Hartrick, 1995, p. 143/144). They maintain that “seeing family as a ‘relational experience’ assumes and draws attention to how people, situations, contexts, environments, and processes integrally connect and shape each other” (Hartrick Doane and Varcoe, 2005b, p. 11).

In a similar vein, Parse (2009) suggested that “family is an indivisible, unpredictable, everchanging connectedness with close others” (p. 305). Who is family, therefore, is a question of individual meaning (Cody, 1995b). In her family model, Parse (2009) put forth three essences of family becoming; that is, of living family health. First, in living health, families structure meaning in situations through revering intentions. In so doing, they honour family members’ personal significances, and confirm-not confirm family values, priorities, and individual members’ experiences. Second, families configure rhythmical patterns of relating; a process through which communion and solitude arises “with the ebb and flow of attending-distancing” (Parse, 2009, p. 307). As such, being together and being alone denotes a paradoxical pattern of family relating. Third, families co-transcend with the unfolding possibilities that are inherent to their family, and which arise “with the comings and goings of those persons named a family by individuals” (p. 308). Such comings and goings initiate different ways of seeing family that are familiar and unfamiliar all-at-once, and liberates new configurations, patterns, and possibilities in living family.

Such an understanding of family as situated, relational connectedness engaged in an experiential process of unrelenting and ever-changing becoming is unbounded by ideas about family structure, functions, or systems; rather, family is about meaningful connections that are lived with close others present or absent. Rather, an individual’s or a group’s idea of family is constituted by a particular culture, specific contexts, and shaped by the interrelated meanings, beliefs, values, habits and customs that bring them together or moves them apart (Cody, 1995b, 2000b; Hartrick Doane and Varcoe, 2005a; Hartrick Doane and Varcoe, 2005b; Hartrick, 1995; Hartrick and Lindsey, 1995; Parse, 2009).

When working with and researching families, nurses and other health professionals are called to attend to the lived relations and caring practices that arise from the situated connections of persons in focusing on their meanings, beliefs, habits, capacities, and restrictions. As Hartrick Doane and Varcoe suggested, family nursing – as a relational process of inquiry - “involves getting and staying 'in sync',

inquiring into a family’s health and healing experience, following the lead of families, listening to and for, self-observation, letting be, collaborative knowledge development, pattern recognition, naming and supporting capacity and emancipatory action” (2005a, p. 228; 2005b, p. 18). For research, these perspectives warrant an understanding of family that is open to individuals’ points of view and moves beyond functional or structural definitions of family. Because of the multidimensional and shifting relational connections that family means to any given individual, it is not necessary to recruit all family members to obtain understanding of family health and becoming (Cody, 1995b, 2000b; Hartrick Doane and Varcoe, 2005a). However, recruiting more than one person defining themselves as family adds multiple perspectives and diversity to the understanding of family health and bereavement, even though it can never bring to the fore a complete and final picture of a family’s experience. Moreover, family research from this point of view attends to families’ meanings, beliefs, caring practices, limitations and possibilities, rather than merely their functions or their organization of roles and responsibilities.

3.3 Implications for the study of families’ bereavement situation

In this chapter, an alternative view of grief and family relating has been put forward that is rooted in Heidegger’s philosophy of human existence as elucidated in Being and Time (1926/2001), and which was translated into a bereavement and nursing context by others (Attig, 1996, 2000, 2001, 2004; Cody, 2000b; Florczak, 2008; Hartrick Doane and Varcoe, 2005a; Hartrick Doane and Varcoe, 2005b; Hartrick, 1995; Hartrick and Lindsey, 1995; Parse, 2007, 2009, 2012; Pilkington, 2006). From this viewpoint, the death of a close other is seen as a situation that may bring about an unfamiliarity in one’s habitual world, requiring individuals and families to re-learn their daily and relational patterns (Attig, 2004; Pilkington, 2006). Although death denotes an ultimate parting and deprives those alive from a loved human presence with whom they were closely connected, it is suggested that families cherish the community they have lived with the deceased through honouring and remembering his or her place in their lives (Attig, 2000; Hedtke and Winslade, 2004; Moules, 1998). Cherishing, which is a “being-with” the close other, involves re-creating ways of relating in different and new forms to those possible when the person was still a living human presence “in” the world (Heidegger, 1926/2001). Such a view of loss and grief departs radically from the dominant, western conceptualization of grief that has pervaded most thinking in the health sciences (such as medicine, psychology,
nursing, and others) and have heavily influenced popular ideas about grief (Attig, 1991, 1996; Florczak, 2008; Moules, 1998; Moules and Amundson, 1997; Walter, 2000).

While the close other who is lost is often a literal family member, the experience of loss and grief is not bound by traditional family membership. Indeed, with a literal definition of family, an individual’s experience of grief may be marginalized and disenfranchised, or conversely its absence judged as denial, and persons’ experiences as abnormal if feelings of loss are absent (Attig, 1996; Moules, 1998; Moules and Amundson, 1997). Thus, a notion of family as a group of persons engaged in an experiential and inter-relational process of close connections has been chosen as a useful way to think family when nursing the bereaved (Cody, 2000b; Hartrick Doane and Varcoe, 2005a; Hartrick, 1995; Parse, 2009). From this perspective, the death of someone to whom a person is closely connected is a moment of changing relational connections that brings about a new situation for those who feel as family.

In summary, for this study of family bereavement in later life, Heidegger’s phenomenology and the theoretical conceptualization of the above discussed authors, have not only shaped the researcher’s thinking, but informed the purpose, conception, and conduct of the henceforth presented doctoral research project. From such a theoretical standpoint, the researcher inquired about families unfolding relational connections within their new situation; a situation into which they were thrown by the death of their close other and which arose from their own family and individual histories and specific contexts, constituted by culture, society, and time in history. Families’ concrete, caring involvements with their world, that is, with other persons and non-living entities, such as places, time, things, and values, became of interest to the researcher. She was curious about the ways that the death of a close other questioned families’ habitual and relational actions, and how their loss – if at all - unfolded in their meaningfully lived world of family connections.
4. Research purpose and methodology

A hermeneutic-phenomenological inquiry with bereaved families

The research purpose, methodology and research strategies used to investigate the family experience of loss are described in the following chapter. First, the research purposes and question are outlined. Then, the hermeneutic-phenomenological approach to the study is introduced and justified. Next, the study context, procedures for data collection and analysis, the role of the researcher in the study, and ethical issues are delineated. The chapter concludes with considerations around the study’s quality.

4.1. Research purpose and phenomenon

A paucity of research exists that explores the loss of a partner as a family experience within the unique and specific contexts that older persons and their families encounter in later life. What happens for families; that is, how the loss affects family relations and practices, and how various family members interact as they go about their daily lives following the loss, has not been previously investigated. To address this existing knowledge gap and to inform practice, this study sought to disclose families’ lived world of loss after an older person’s life partner has died. The research purposes included:

- To disclose patterns of meanings of families’ experience of living with loss.
- To generate a full description and interpretation of everyday actions, concerns, and relational practices that arise for families after the death of their close other.

The research question to guide this inquiry was: “What is families' experience of living with loss after a close other has died late in life?”

The researcher chose to name the phenomenon under study living with loss to move beyond established, and potentially limiting ideas associated with the conception of grief, and to achieve an open stance towards families’ experiences after a close other has died. It was assumed that grief itself, which includes “intense sorrow”, and is defined as “a kind, or cause, of hardship or suffering” (English Oxford Dictionary, 2013), or the “distress” that ensues from bereavement (Ayers et al., 2004; Stroebe, 2010), accounts only for one specific aspect of families’ life-world
following a death. *Living with loss* was understood to be a broader phenomenon that allowed the researcher to inquire about families’ overall experiences relevant to their lives after a death, which may encompass, but are not limited to grief (Ayers et al., 2004).

4.2. Methodological frame of the study

A research approach based in hermeneutic phenomenology was used to study families’ lived world of loss (Gadamer, 1975/1989; Heidegger, 1926/2001). Research drawing on hermeneutic phenomenology seeks to gain an in-depth understanding of the meanings and everyday actions through the study of persons’ and families’ descriptions of their practically lived world (Benner, 1985, 1994b; Chesla, 1995; van Manen, 1990). Health researchers working from this framework embark on such an inquiry from their own situated context, and co-create interpretations of humanly lived experiences through a dialogical relationship with the persons and families who serve as informants (Chesla, 1995, 2011; Plager, 1994; van Manen, 1990). The textual data consists of concrete, rich, and authentic descriptions of families’ lives and narratives about actual events (Benner, 1994b; Chesla, 2011). Through an abiding engagement with the text by “carefully listening, hearing the voices” (Benner, 1994a, p. xviii), the meanings and actions in the particular contexts of families’ lives are elucidated (Chesla, 2011; Plager, 1994). The ensuing interpretive account should “disclose what is at stake for the family” (Plager, 1994, p. 75), and illuminate families’ relational worlds, meanings, concerns, and practical actions in a manner that opens up insight and increases understanding (Benner, 1994a; van Manen, 1997). Interpretive findings should be conveyed in an “evocative text” that is oriented to families’ contexts, and provides the strongest interpretation in a rich way, accounting for the fullest variation across families’ experiences (van Manen, 1990).

4.2.1. Hermeneutic phenomenology to study families’ life-world

Hermeneutic phenomenology has been put forward by nurse scholars as a fitting approach to gain understanding of families’ experience of health and illness, and has been previously used to study families or couples’ lived experiences (Butt and Chesla, 2007; Chesla, 1995; Eggenberger and Nelms, 2007a; Gudmundsdottir, 2009; Gudmundsdottir and Chesla, 2006; Plager, 1994; Racher et al., 2000; Thirsk
Interpretive research arising from hermeneutic phenomenology is suited for the study of family experiences because it presumes that all understandings and actions are inter-subjective, and arise from within a particular world of which human beings are an inseparable part (Benner, 1994b; Chesla, 1995; Plager, 1994; Taylor and de Vocht, 2011). Other qualitative approaches, in particular ethnography, denote alternative frames of inquiry into the experience of groups, such as families. Hermeneutic phenomenology and interpretive ethnography have in common that they attend to people’s meanings and actions, and strive to better understand what happens in particular, culturally and historically situated contexts. Both do so by means of talking with and observing people to elicit a rich description of their lived or cultural world, respectively (Benner, 1994b; Madden, 2010). What differs is that ethnography attends to culturally defined meanings and practices to better understand social interactions and group interrelations (Madden, 2010; Parse, 2001; Speziale, 2007), for example, how practices are culturally inscribed, or how illness experiences are made sense of in light of cultural (dominant) understandings and definitions of diseases (Benner, 1994b; Doolittle, 1994). Ethnography therefore focuses explicitly on cultural, social worlds and its members, and the meanings that actions and events have for members within, or of a particular culture. In contrast, hermeneutic phenomenology presupposes culture and suggests that a shared culture enables understanding because it forms part of the world in which humans live with each other (Large, 2008; Plager, 1994). The focus of hermeneutic-phenomenological inquiry is therefore not the culture of the group per se and how meanings, actions, or events, such as a death, are expressions of a culture. Rather, it attends to individual as well as shared meanings that arise from the situated context and a shared background, from persons’ being-with (Plager, 1994; Taylor and de Vocht, 2011). Although the focus of this study lies on a group of people who do indeed share the culture of their family, the intent of this study was not to understand family bereavement as a cultural experience and to attend to how it is shaped by the meta-narrative of a particular cultural tradition (Madden, 2010). Rather, the intent was to disclose the practically lived world of a group of persons; that is, to learn about the manner in which such a group of persons who are committed to live family create inter-subjective meanings and actions as they live with the loss after a family death. Thus, hermeneutic phenomenology provides a fitting philosophical background and scientific strategy particularly well suited to understand families’ shared concerns, actions, and meanings.
4.2.2. Methodological underpinning to this study

Martin Heidegger’s (1926/2001) ontological analysis of human existence, and Hans-Georg Gadamer’s (1975/1989) hermeneutics of textual interpretation denoted the philosophical background to the study. Due to their consistency with the study’s philosophical underpinnings (Dowling, 2007; Laverty, 2003; Naef, 2011), Patricia Benner’s (1985, 1994b) analytic strategies and Max van Manen’s (1990) research activities were deemed most appropriate to guide the data gathering and analysis. Both these authors acknowledge that there is no method within phenomenology in the form of procedures or steps, but rather an interpretive engagement with the data that is informed by the philosophical ideas that underpin the research project (Crist and Tanner, 2003).

Heidegger (1926/2001) and Gadamer (1975/1989) have rejected the idea of Edmund Husserl that human experiences can be disclosed through consciousness. They suggested that understanding is more fundamental than human consciousness of, or human knowledge about the world (ontological versus epistemological view of being human) (Moran, 2000; Palmer, 1969). In contrast to research within descriptive phenomenology that seeks to describe the universal essence of a phenomenon through transcendental subjectivity for which the researcher is required to bracket pre-understandings to achieve a pure mental consciousness (Palmer, 1969), hermeneutic phenomenology seeks to understand or interpret what discloses itself through involvement with a phenomenon. Since philosophical tenets not only framed, but underlined the concrete strategies and decisions in this study, they are briefly delineated.

Humans are situated and involved in a shared and pre-existing world with others: Dasein, which is a basic tenet of Heidegger’s philosophy (1926/2001), suggests that humans are thrown into a pre-existing world with which they are continuously involved. World is not a place, but a “meaningful set of relationships, practices, and language that we have by virtue of being born into a culture” (Leonard, 1994, p. 46). Dasein, however not only means “being-in-the-world”, it also means “being-with”, as Heidegger explained (1926/2001): “Auf dem Grunde dieses mithalten In-der-Welt-seins ist die Welt je schon immer die, die ich mit den Anderen teile. Die Welt des Daseins ist Mitwelt. Das In-Sein ist Mitsein mit Anderen.” (p. 118). In fact, human beings understand the nature of their being only because they

2 Loosely translates as: “Based on such a being-with in-the-world, the world is always already the one that I share with others. The world of Being [Dasein] is a world-with others. Being-in is being-with others.”
are continuously involved with the living and non-living entities that make up their world and in the context of the referential whole within which Dasein is situated (Heidegger, 1926/2001; Taylor and de Vocht, 2011). Thus, human beings are not separate entities, but form an integral part of a shared world with communal meanings and understandings (Taylor and de Vocht, 2011). The phenomenological conception of persons situated in context and in relation to others warrants a mode of investigation that seeks to understand persons embedded and engaged in their life-worlds. Insights about family experiences can therefore not be abstracted from the context of their lives and concrete, everyday activities that make up their world.

**Humans constitute and are constituted by their world through understanding:**

The phenomenological conception of person further suggests that understanding is not a way to know about the world, but a manner of being in the world (Laverty, 2003). Humans comprehend their world because of an inherent familiarity that is handed down to them through culture, language, and practices. Understanding of self, others, and the world arises from a shared background world and through constant, concerned involvements and practical engagement with others in the particular context of humans’ communal lives (Heidegger, 1926/2001; Leonard, 1994; Plager, 1994). All intentional interpretation that seeks to disclose the world presupposes such an implicit, non-reflective comprehension of the matter of interpretation, which Heidegger (1926/2001) calls the fore-structure. The fore-structure consists of an inherent understanding arising from the persons’ situatedness in the world (fore-havings), an anticipating idea, or sight about the phenomenon of interest from which it is approached (fore-sight), as well as an initial grasp and expectation that is constituted by conceptual and established thinking about the subject matter (fore-conceptions) (Heidegger, 1926/2001; Leonard, 1994; Plager, 1994). This threefold pre-condition to all interpretive understanding denotes the possibility to comprehend anything at all, as Heidegger (1926/2001) asserted:\(^3\): “Auslegung ist nie ein voraussetzungsloses Erfassen eines Vorgegebenen” (p. 150). Thus, formal inquiries about human existence within phenomenological thought become possible because the interpreter holds a fore-structure of understanding of the world. Thus, a shared background world of family members, and of participants and researcher are a precondition for understanding within interpretive, scientific inquiry.

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\(^3\) Loosely translates as: „Interpretation is never a presuppositionless capturing of something that is already given.”
**Achieving right understanding through a spiralling movement:** In interpretive research of text based in Heideggerian philosophy and as further explicated by Gadamer, the aim is therefore not to escape human's fore-structure to achieve an illusionary objectivity; rather, what is required of the interpreter is to work with this fore-structure in relation to the subject matter, scrutinizing it constantly in order to come to a “right understanding” revealed from the “things themselves” (Gadamer, 1975/1989; Heidegger, 1926/2001). According to Heidegger (1926/2001), what is decisive about any interpretive efforts is to enter the hermeneutic circle the right way, which can only be achieved when one has realized⁴ “dass ihre erste, ständige und letzte Aufgabe bleibt, sich jeweils Vorhabe, Vorsicht und Vorgriff nicht durch Einfälle und Volksbegriffe vorgeben zu lassen, sondern in deren Ausarbeitung aus den Sachen selbst her das wissenschaftliche Thema zu sichern” (p. 153). Gadamer (1975/1989) used the term horizon to elucidate how interpretive understanding, which he situates in language and dialogue, is achieved. He maintained that each person’s situation within a tradition has a horizon, which is a “range of vision that includes everything that can be seen from a particular vantage point” (p. 301).

Getting into the hermeneutic spiralling movement the right way means asking questions (“acquiring the right horizon”, p. 302) that allow one to remain oriented to the phenomenon under study (van Manen, 1990), or in Gadamer’s words, to “keep one’s gaze fixed on the thing throughout all the constant distractions that originate in the interpreter himself” (p. 269). Fixing one’s gaze on the subject matter involves anticipation and projection arising from the person’s situation or fore-structure, and continually evolves. Gadamer (1975/1989) describes this hermeneutic movement with text in the following succinct way (p. 269):

> A person who is trying to understand a text is always projecting. He [sic] projects a meaning for the text as soon as some initial meaning emerges in the text. Again, the initial meaning emerges only because he [sic] is reading the text with particular expectations in regard to a certain meaning. Working out this fore-projection, which is constantly revised in terms of what emerges as he [sic] penetrates into the meaning, is understanding what is there. (…) every revision of the fore-project is capable of projecting before itself a new projection of meaning; rival projects can emerge side by side until it becomes clearer what the unit of meaning is; interpretation begins with fore-conceptions that are replaced by more suitable ones. This constant process of new projection constitutes the movement of understanding and interpretation.

Interpretive understanding therefore crystallizes through a movement that departs from the interpreter’s fore-structure, which needs constant explication, and the

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⁴ Translates as: “that our first, last, and constant task in interpreting is never to allow our fore-having, fore-sight, and fore-conception to be presented to us by fancies and popular conceptions, but rather to make the scientific theme secure by working out these fore-structures in terms of the things themselves.”
researcher’s strong orientation to the “thing itself” of the subject matter (Benner, 1985, 1994b; Conroy, 2003; Gadamer, 1975/1989; Plager, 1994; Smith, 2007; Spichiger and Prakke, 2003). For any scientific interpretive endeavour, becoming aware of one’s fore-understandings is a prerequisite to engage in an in-depth exploration and to enter the hermeneutic movement the right way (Spichiger and Prakke, 2003), and it remains essential over the course of the analytic enterprise to resist the danger of premature interpretation of the nature of the phenomenon under study (Finlay, 2002b; Geanellos, 1998a). It has been proposed that “real understanding” can only occur when the interpretive researcher is challenged in his or her frame of thinking, and has to move out of his or her established frame of reference (Benner, 1994b; Chesla, 1995, 2011). Moving out of one’s familiar sphere of thinking can be seen as an expression of vigilant attending and continuous scrutinizing of pre-projections to secure the scientific theme (Geanellos, 1998a). In interpretive research, this is achieved through an ongoing, self-reflective practice that becomes part of the interpretive process (Finlay, 2002a, b).

In this continuous movement of interpretation, the question becomes how to know that “right understanding” has been achieved. Within phenomenology, truth is seen as partial and never complete, it arises “from the perspective of the person making the assertion” (Taylor and de Vocht, 2001, p. 1581), and thereby precludes final interpretation of any subject matter. However, as Gadamer (1975/1989) maintained, the hermeneutic movement enables a “most fully realized” understanding that arises from the interpreter’s fore-understandings and anticipations (p. 293). In most fully realized understandings, “a real fusing of horizons occurs - which means that as the historical horizon is projected, it is simultaneously superseded” (Gadamer, 1975/1989, p. 306). Right understanding, albeit partial, incomplete, and determined by the interpreter’s fore-structure, is achieved when previous ideas are surpassed in referring to the past, but moving to something new.

4. 2. 3. Explicating fore-understandings

Because fore-understandings can be facilitative or blocking, making them explicit is a way to maximise their facilitative potential, because „they allow the interpreter to examine their origin, adequacy and legitimacy in relation to: (i) the phenomenon under investigation; and (ii) textual interpretation” (Geanellos, 1998b, p. 243). Therefore, in this study, the researcher explicated her fore-understandings by adapting a strategy described by Geanellos (1998a, b) (see Table 9). The
researcher wrote stories about her experiences, delineated her beliefs about the phenomenon under study, and wrote an essay about her theoretical ideas of the subject matter, which she then analysed and reflected on to bring to light her own situation and pre-reflective grasp of the study matter. In the following, a short synopsis of this reflective enterprise is given in a first person account.

Table 9: Strategies used to explicate fore-understandings

<table>
<thead>
<tr>
<th>Fore-understandings</th>
<th>Question</th>
<th>Mode of explication</th>
<th>Explication process</th>
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</table>
| Fore-havings        | How does being-in-the-world as family member and nurse shape the approach to the study, data generation and textual interpretation? | Stories of involvement with phenomenon of loss in professional and personal life. | Writing stories about experiences. Coding stories & synthesizing codes into themes to order text. Reflective writing around thematic notions using the following questions:  
  - How am I involved with loss and grief in my professional and personal life?  
  - What are the reasons for my interest in the phenomenon?  
  - What do the stories reveal about my thinking? |
| Fore-sights         | How do beliefs and assumptions about loss in a bereavement context construct data gathering and textual interpretation? | Statements about beliefs around nature of phenomenon, i.e. loss in the context of conjugal / family bereavement in later life. Analysis of statements to bring forth fore-structures. | Writing down beliefs about:  
  - Death of a family member in later life  
  - Grieving  
  - Living with loss  
  - Family and loss  
  - Nursing  
Reflective writing around beliefs using the following questions:  
  - Why do I believe this?  
  - How is it significant for my current understanding?  
Synthesizing limiting and enabling beliefs. |
| Fore-conceptions    | How does theoretical thinking and expectations co-construct data gathering and textual interpretation? | Conceptualization of phenomenon by drawing on theoretical / research literature. | Writing an essay that defines the phenomenon, synthesizes traditions in understandings and conceptual definitions within nursing, puts forth theoretical ideas that shaped the researcher’s thinking, reflects on the naming of the phenomenon of interest. |


My fore-havings: I came to this study as a nurse who had worked in acute care, where the possibility of facing death and dying, and witnessing family members’ experience of loss was ever present in my daily work. Because the death of a patient usually meant the end of my mandate to provide nursing care, my involvement with families was limited to the first hours or days after the death of their loved one. However, family members did often not receive the care they needed for two reasons. First, to face the profound suffering of family members was
immensely challenging for myself and other nurses, and it happened that we turned away from families’ need to talk about their situation. Second, there was no structure or support for follow-up care to bereaved family members. For instance, in my role as care coordinator for persons and their families following a lung transplant, I was providing care for families over the years, which ceased abruptly when the “patient” died. While I did provide care to some bereaved family members, the majority of my clinical experience left me with a lingering sense that inadequate or no care was provided for families during early and later phases of their loss.

I also embarked on this project as a wife, mother, daughter, sister, in-law, and aunt. I encountered a family death for the first time as a 14-year-old adolescent. My grandfather had died very suddenly, and I still remember vividly the shock I felt when we went to see his body at the morgue. My other grandparents died when I was already an adult, and I experienced those deaths as rather removed, not only physically because I lived abroad at that time, but also because I felt it did not happen to me as a grandchild. Rather, I was like a relative of other family members (my parents) who were closely involved and shaken by the deaths. My personal experience with death is not one of loss, but one of seeing it happen to others rather than to myself, either turning towards or away from the suffering inherent to grief, or dwelling with it in a few instances, for instance when my mother felt pained by the agony that surrounded her father’s death.

**My fore-sights:** Some of the beliefs and assumptions that I held about death, grief, and family turned out to constrain understanding of families’ experiences, whereas others enabled me to grasp what was happening for families (Geanellos, 1998b). For example, my belief that death denotes a loss of a valued and loved person became challenged, and did indeed become a barrier to understanding what happened to families when I encountered a family to whom life following the death denoted a gain.

**My fore-conceptions:** My beliefs were also shaped by theoretical ideas that denoted the departing point for this study, and which were delineated in the previous chapter. Over the course of my nursing career, I have come to take a very critical stance towards prevalent views of grief as a time-limited phase with distinct stages that one has to move through until grief is resolved. I think that much harm can arise when practitioners’ approach to individuals and families is informed by such a normalizing view of grief. Rather, it is my understanding that loss needs to be
acknowledged as a significant event and theme in a person’s life that permeates the whole human being with his or her relationships to other persons, things, and events. It marks a critical point in the lives of families when they lose their spouse, partner, parent, or sibling, no matter the circumstances or felt time(un)liness of death. It is about learning to live with the physical absence of the close other, and the fact that there will be no new, shared experiences or activities. I believe that grief can never be an individual experience alone. While it might affect surviving persons in various and diverging ways, grief is inherently communal, and a sense of loss shared among persons who see themselves as family. I assume that it changes how family members relate to each other, and what they do to acknowledge the loss, remember the deceased, and to rearrange, compensate or fill in the family role and activities previously held by the deceased.

4. 2. 4. Methodological implications for the study conception

The above elucidated philosophical underpinnings of this study enabled the researcher to seek understanding, departing from her own historical and cultural situatedness as a nurse and family member, about families’ lived world of loss through engagement and participation. The linguistic nature of understanding gave rise to the possibility of seeking insight through dialogical conversations with individuals and family groups to learn about shared and distinctly different meanings and actions (Butt and Chesla, 2007; Racher et al., 2000; Taylor and de Vocht, 2011; Valentine, 1999). Because understanding occurs through persons’ practical engagement with their world, it was of interest in this study to glean families’ accounts of their life- worlds and examples of practical involvements through textual data that not only describe, but illustrate such practices-in-action (Benner, 1994b; Chesla, 1995, 2011). Arising from the hermeneutic situation, an interpretation of families’ lived world of loss was thus sought through a spiralling movement that shifted between the involved persons, pre-understandings, questions, the textual data and emerging ideas (Benner, 1985, 1994b; Gadamer, 1975/1989; Plager, 1994; Smith, 2007; Spichiger and Prakke, 2003). Interpretive efforts attempted to disclose the thing itself by securing the scientific theme through constantly explicating fore-understandings as they evolved in relation to the phenomenon under study and the emerging textual interpretation (Geanellos, 1998a). To achieve “right” understanding, it was important for the researcher to remain open to different lines of inquiry throughout the research process until an interpretation was gleaned that was first, true to the data and second, the most plausible and compelling.
illustration and rich description of the loss experience as lived by families (Finlay, 2002b; Spichiger and Prakke, 2003). The use of research strategies based in hermeneutic phenomenology thus allowed the researcher to find out about families’ shared meanings, and to hear about the differences that existed in individual member’s interpretations and meanings (Taylor and de Vocht, 2011). It denoted a fitting approach to study family bereavement from a nursing perspective as it aims to study families’ “ways of being in the world, habits and practices, meanings, and concerns” (Chesla, 1995, p.64).

4.3. Study participants and procedures

In this interpretive study, community-dwelling persons aged 75 years or older whose life partner had died within the two previous years were eligible to take part together with their families. A minimum age of 75 years for widowed persons was used because the study aimed to understand the particularities of the loss experience late in life, and to unearth the specific issues for families in a later life context. The time limit was set at two years after the death for pragmatic reasons and to achieve homogeneity in recruited families. It was assumed that the closeness of time to the death and the still relatively new situation as a family would help to ensure that participants’ descriptions would be vivid accounts of their still unfolding lives with loss. To address diversity of family constellations and to acknowledge that persons of a family may have different views about who is family (Cody, 1995b, 2000b), family was understood to be “a group of individuals who are bound by strong emotional ties, a sense of belonging, and a passion for being involved in one another’s lives” (Wright and Bell, 2009, p. 46), from the perspective of the older person. At least one additional family member, such as adult child, grandchild, sibling, friend or other, who was 18 years or older (or who had obtained consent from the legal guardian) had to agree to take part. Individuals had to be able to speak German and to cognitively understand and take part in the study. Families had to self-identify to experience the phenomenon under study, and they had also to express their willingness to talk about their experiences with the researcher as a family. Exclusion criteria were institutionalization in an acute, long-term, or mental health facility, dementia or a serious mental illness.
4. 3. 1. Recruitment

Families were recruited in an urban centre in Switzerland between October 2011 and May 2013. Twenty different health and social care organizations, such as home nursing care services (n=8), day clinics for older persons (n=3), church-based social services (n=3), hospital-based social and pastoral services (n=2), or other organizations providing social programmes and counselling for older persons (n=4) agreed to help with recruitment. The researcher had access to these organizations through pre-existing research-practice collaborations (n=10), personal contacts (n=2), or via a local collaborative network of health and social care organizations providing services to older persons (n=8) in which she acted as the representative of her employing university. The person who recruited widow/ers within these organizations was either a nurse (n=12), social worker (n=4), or minister (n=4) who knew eligible widow/ers personally, and who were most often the managers of the teams that worked at the point of care / service. The researcher met face to face or held meetings over the phone to explain the study purposes, inclusion criteria, and study processes, provide instructions about the recruitment process and ethical considerations, and to answer questions. She handed a study brief and a recruitment algorithm to gatekeepers, and provided them with information leaflets and participant information sheets (see appendices B-F). The recruiting person within each organization identified potential participants based on the inclusion criteria and their clinical appraisal of the cognitive ability of the older person (home care nurses only). Some organizations also displayed information in waiting areas, published an announcement in their newsletter, or sent out study information with a recommendation letter.

Of the twenty organizations willing to help with recruitment, only nine identified older persons who met the inclusion criteria regarding age and time since death. Sometimes, the exact age of surviving partners was not known to home care agencies because they did not obtain demographics of the family members on a routine basis. The recruiting person of each organization actively contacted the identified potential participants by phone and told them about the study. If a potential participant was interested and agreed, the recruiting person gave the researcher the contact details. The researcher phoned the interested older person to provide information about the study, to answer questions, and to listen to personal considerations. At this point in time, detailed, written information was sent out by mail. When the widow/er agreed to take part, s/he identified to the researcher who could be further invited into the study from his or her family (Ganong, 1995; Gilliss
and Davis, 1992). The widow/ers acted as the linking person between family members and the researcher, asking family members for their permission before giving contact details to the researcher. The researcher contacted each family member personally to explain the study and answer questions. Usually, at least three phone calls were necessary before families could be enrolled in the study. Only when each family member had given oral consent to the researcher, a first interview appointment was scheduled, most often via the widow/er. Upon the first interview, the researcher explained the study and what it means to take part for the family and answered questions that families had. Written informed consent was obtained from each family member, and a copy was given to each person.

4. 3. 2. Sampling and sample size

A purposive sampling strategy was used to include those families who did indeed experience everyday life with loss (Creswell, 2013; Marshall, 1996; Morse, 2007). In practice, purposive sampling was difficult to steer since the researcher relied on the recruiting organizations to make decisions, based on the inclusion criteria, about eligible clients. Moreover, each organization identified only a few, or no eligible clients. Thus, sampling aimed to be purposive in that it was guided by the inclusion criteria, yet there was also an element of convenience sampling present because only those identified as eligible by clinicians and those who agreed to participate did indeed do so (Morse, 2007).

The study aimed to include at least ten, and a maximum of 20 families. In the absence of clear criteria that guide decisions about the adequacy of sample size in qualitative research, the number of families needed in this study to answer the research question was difficult to discern in advance (Baker and Edwards, 2012). While data saturation, defined as including new participants or data to satisfy emerging analytical categories to their completion and replication, denotes one of the most established concepts used for decision-making, its origin lies in grounded theory and is as such not necessarily applicable to other qualitative approaches (Bowen, 2008; O'Reilly and Parker, 2013). Rather, within hermeneutic phenomenology, the completeness of cases and the redundancy of data obtained to achieve the purpose of the study denote important considerations about sample size (Benner, 1994b). Conducting several interviews per case is a useful strategy to increase the interpretive potential of a phenomenological study (Benner, 1994b; Smith et al., 2009). Moreover, a detailed account with a “concentrated focus on a
smaller number of cases" (Smith et al., 2009, p. 51) is usually more appropriate for the interpretive undertaking than having a larger number of participants. In addition, the heterogeneity of included families, the amount of data collected with each family, the strategies used to obtain and the depth of the data also warrant attention (Creswell, 2013; Morse, 2000; O'Reilly and Parker, 2013; Smith et al., 2009). What is of concern within hermeneutic phenomenology is to gather enough data to discern the full scope of the study phenomenon in-depth (Benner, 1994b; Smith et al., 2009).

Many phenomenological studies include around ten participants, yet there are also studies that include only a few or many more (see for instance Butt and Chesla, 2007; Gudmundsdottir and Chesla, 2006; Mahrer-Imhof, 2007; Naef and Bournes, 2009; Racher et al., 2000; Taylor, 2014). Some argue that larger numbers of participants aid the researcher to uncover patterns of meaning with greater clarity and a higher confidence compared to studies with only a handful of participants (Benner, 1994b; Chesla, 2011). In contrast, ethical and pragmatic considerations warrant qualitative researchers to enrol only as many participants as necessary to answer the research question (Ayers, 2007; Francis et al., 2010; Marshall, 1996). The amount of data should not surpass the researcher’s ability to engage with its full breadth and depth during analysis to avoid shallow interpretations (Ayers, 2007; Morse, 2000). In light of these considerations, the decision about sample size in this study was guided by the number of cases, concerns about the heterogeneity of included families, and the number of interviews conducted. The size of the gathered data was appraised in its completeness and richness in relation to each family case, and judged in its redundancy that started to evolve across family cases.

4.4. Data collection

To arrive at a full description of families' life-world, family group and solo interviews were carried out, and field-notes were written after each interview. Demographic information was collected with a short questionnaire. Several interviews were held with each family because a prolonged engagement with participants provided the opportunity to gain rich data over time (Benner, 1985). Repeated points of contact enabled participants and the researcher to reflect on interview interactions during intervals, and then to elaborate on already gathered family narratives and reflections of everyday life following the loss (Benner, 1985, 1994b; van Manen, 1990). A combination of family group and solo interviews was used in this study because
using both interview types allowed the researcher to learn about shared interpretations and practices related to families’ collective lives with loss, while also discerning the differing, individual meanings and actions in-depth, either with other family members present or in a one-to-one interview situation (Bell et al., 2000; Chesla, 1995; Feetham, 1991; Gilliss, 1991; Taylor and de Vocht, 2011).

Family group interviews set up a “natural communicative context” (Benner, 1994b, p. 109) in which families could speak about their experience alike they might do in everyday life without a researcher present, and allowed the researcher to gain insights about how families interacted together in a given situation (interactive data) (Feetham, 1991). This enabled the researcher to attend to a family’s way of telling their experience and to see in action how they co-constructed their shared understanding of the loss (Taylor and de Vocht, 2011). During group interviews, participants were invited to tell their story and speak about their family experience. Family members were also invited to talk about their own individual meanings and actions. Participants were asked how individual members, as well as other non-participating family members experienced the loss (Nadeau, 1998; Wright and Leahey, 2013). Such questions to obtain observational information about absent family members added their perspective as perceived by participating members to the data, and multiple views could be gained from each family (Dumont and Kissane, 2009; Kissane and Dumont, 2014). Family group interviews enabled families to reveal particular matters, concerns, and actions that had unfolded within their relationships.

Solo interviews sought to understand how individual members understood family processes (relational data), and to learn about their individual experiences as family members (individual data) that may be different from the family’ understanding of loss (Feetham, 1991; Moriarty, 1990; Taylor and de Vocht, 2011). In this study, individual interviews were used to further explore the distinct perspective of family members, or when the researcher had a sense that family members would be more comfortable or reveal different aspects of their experiences with only the researcher present. Circular questioning was used to ask widow/ers and their family members how they think their close other lives with the loss (Nadeau, 1998; Wright and Leahey, 2013). This allowed the researcher to increase the interactive nature of the data even with only one interview partner present.

Families’ reflections and narratives were sought during interviews to gain their views, perspectives, and thoughts, as well as to learn about their concrete concerns and actions as they played out in distinct situations. To obtain narrative data,
participants were invited to relate concrete examples of everyday life in the form of anecdotes, stories, or incidences. Family narratives, such as the events surrounding the death, what had since happened, and how their everyday life had unfolded, enabled the researcher to understand families’ experience of loss through their everyday practices (Chesla, 2011; Kesselring et al., 2009; Leonard, 1994). Reflections about families’ loss were also explored, such as what they missed most about the deceased person, what had been particularly difficult, and how the death of their member affected family relations. Such reflective data included in-depth descriptions of experiences, and disclosed participants’ beliefs and thinking about their experience (Chesla, 2011; Kesselring et al., 2009; Leonard, 1994).

Field-notes were used to capture initial, intuitive grasps of families’ stories and descriptions. They were useful in several ways. First, they denoted an essential reflective tool for the researcher about her comportment during the interview and her reactions to families’ stories. Second, initial observations, impressions and grasps of the gleaned descriptions and stories were written down and aided the analytical process later on because they captured what stood out vividly from the interview shortly after it had taken place. Moreover, as data collection advanced and more families were included, field-notes also represented one place to note common thematic threads that the researcher started to see and realize during a particular encounter with one family or individual.

4.4.1. Data gathering processes

Interview dialogues took an open, unfolding form (Benner, 1994b; van Manen, 1990). Even though the researcher used a topic guide (appendix G), there was no fixed order of questions to be asked. Rather, the researcher was guided in the interview situation by a strong orientation towards the phenomenon of loss and the research question (van Manen, 1990). Interview encounters developed according to families’ stories and descriptions, and discussions were moved along by encouraging persons to tell more, to further illustrate something they had said, or by seeking more depth and clarity about the experience (Parse, 2001). In family group interviews, the researcher involved all members by taking a stance of non-partiality, and attended to multiple, potentially conflicting views (Bell et al., 2000; Moriarty, 1990). When some family members were talking more than others, questions and invitations were directed especially to those family members who had been less vocal, to either provide them with an opportunity to talk or to further understand their
situation by asking for more depth and clarity. However, the researcher did not attempt to change families’ way of interacting, and enacted a facilitative presence with families to hear not only families’ overall narrative, but the perspective of each individual member (in particular when no individual interview was possible). The dynamic nature of families’ habitual manner of interaction that unfolded during family group interviews, especially so when more than two members participated, became an essential part of the data.

The first interview began with an invitation to families to talk about the death and to portray their close other and their family. A family genogram was drawn to understand family configurations (Nadeau, 1998; Rempel et al., 2007; Wright and Bell, 2009). In addition, the researcher invited participants to tell what had happened for them since the death, and how they experience life without the loved one.

Follow-up interviews served to further explore and complement families’ and individuals’ unique stories and experiences. To start, the researcher asked participants if something had stayed with them from the last encounter that they wanted to take up, or if something had happened in the meantime that they considered relevant. This way of beginning follow-up interviews helped to re-enter relationships, and it opened a space for participants to bring up their reflections or concerns they had in relation to their experience and/or participation. Based on the analysis of previous interviews, the researcher also brought particular areas that she wanted to further explore or clarify with participants to the table. Towards the end of each interview, the researcher asked participants if there was something else they wanted to add or elaborate on, and if there was something that had not been asked but which they found important. These questions often yielded essential aspects of their experience, or added important details to things they had previously said. Each interview lasted up to two hours and ended either after a previously agreed upon time span had passed, or when the researcher had nothing more she wanted to explore and when participants felt that they had exhausted their stories and reflections.

Usually, two family group interviews were held because one alone was insufficient to hear the whole story and exhaust families’ accounts of their experiences, and complemented with solo interviews. Solo interviews took place most often with the widow/er, but were also conducted with other family members when their perspectives warranted further exploration to understand the diverse views within families. The researcher and family member(s) made decisions about the type, order, and number of interviews together; that is, whether a next interview would
take place, and with whom. Practical scheduling issues also influenced decision-making. The dialogical engagement with families ended after two to five interviews, depending on families’ preferences, and the number of members who participated and took part in solo interviews.

Field-notes were written after each interview. The researcher made note of her observations and impressions of the interview, the interaction, her own role, and things that stood out from the family’s story and reflections (Finlay, 2002a, b; Munhall, 1994, 2007). The researcher reflected about and analysed each interview before meeting the family or individual for follow-up interviews. Analysis included listening to and reading the transcript at least once, and writing reflective notes to synthesize and organize data. In addition, reflective writing was useful to develop further questions for data gathering and to explicate early interpretive ideas.

Demographic information (Table 10 and appendices H & I) was collected with a short written form that was handed to participants at the first interview, which they either returned by mail or upon one of the following interviews meetings.

Table 10: Demographic information

<table>
<thead>
<tr>
<th>Demographic data of participants</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Widowed person</td>
<td>Age, gender, years of marital relationship, living arrangement before and after death of spouse / partner, former occupation, socioeconomic status, self-perceived health</td>
</tr>
<tr>
<td>Each family member</td>
<td>Type of relationship with widowed person and deceased, age, gender, marital status, occupation, socioeconomic status, self-perceived health</td>
</tr>
<tr>
<td>Deceased family member</td>
<td>Date, cause &amp; place of death, age at time of death, gender, living arrangement prior to death</td>
</tr>
</tbody>
</table>

4.4.2. Transcription and data management

Data were collected in Swiss German (a spoken dialect) and transcribed by research assistants in Standard German. Transcriptionists were nursing students at the Bachelor or Master level with previous experience in transcribing qualitative interviews. Each student transcribed interviews of two to three families. Due to the demanding nature of interactive group interview transcription, and the parallel participation of families, the use of several transcriptionists became necessary to ensure a timely return of the transcripts before follow-up encounters.

Transcription is not simply a translation of spoken words into written language (Bird, 2005; Lapadat and Lindsay, 1999; Oliver et al., 2005; Tilley, 2003). Thus, decisions about what and how to transcribe, and the role of the researcher in use of transcriptionists were made in light of methodological considerations. First, rules for
the transcription were defined (see Table 11 and appendix J). Second, the researcher communicated with each transcriptionist and checked transcriptions (Easton et al., 2000; MacLean et al., 2004). The researcher gave feedback about transcriptions, answered questions about rules and specific interviews, and offered support in situations in which interviews were emotionally difficult, or challenging to transcribe. Because transcriptionists had no previous experience with family interviews, most required some support. The researcher checked each transcript by listening to the full audio-recording to check its accuracy; that is, errors and omissions, the consistency with rules, translations of particular sayings or words, and anonymization (Poland, 1995). Because one researcher conducted all interviews, she was able to ensure consistency among transcriptionists.

Table 11: Rules for transcription

<table>
<thead>
<tr>
<th>Transcription rules*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Semantic record of everything said.</td>
</tr>
<tr>
<td>2. Noting of non-verbal utterances, such as laughing, crying, or pauses in brackets.</td>
</tr>
<tr>
<td>3. Indicating talking over each other and interruptions with //.</td>
</tr>
<tr>
<td>4. Removal of all identifying information, such as names and places</td>
</tr>
</tbody>
</table>

* adapted from Smith et al., 2009, Kvale and Brinkmann, 2009, Chesla, 2011

All identifying information was removed from verbatim transcription of audio-recorded interviews to ensure anonymity. Study numbers and code names were used for families and individual persons throughout the research process. Data were kept separately from consent forms. Identifying information was stored on a password-protected computer and in a locked filing cabinet. Those documents that matched participants with study numbers or code names were secured with a password, which was only known to the main researcher. Checked and anonymized transcripts and field-notes were entered into Atlas.ti Version 7, a qualitative data analysis software package used to assist in handling and organizing qualitative data (Bournes, 2001; Seale and Rivas, 2012). Demographic information was inputted into SPSS Version 19 for descriptive analysis.

4. 5. Data analysis

The aim of data analysis was to discern thematic meaning notions and patterns across families to provide an insightful and compelling interpretation of families’ loss experience, and to account for the commonalities as well as the variances inherent in the gathered data (Benner, 1994b, Chesla, 1995, Spichiger and Prakke, 2003, van Manen, 1990). Families were the unit of analysis (Bell et al., 2000; Feetham,
1991; Gilliss, 1991; Racher et al., 2000; Thompson and Alker, 1982). Textual data for each unit included transcribed interview text and audio-recording, field-notes, and demographic information about the family and each participating member.

Data were examined using thematic and narrative approaches to analysis. Thematic analysis was employed to disclose thematic meaning notions across families, whereas narrative analysis helped to understand families’ practical lived worlds in-depth by attending to concrete situations and stories that stood out as particularly illustrative (Benner, 1994b; Chesla, 1995, 2011; van Manen, 1990). The aim of thematic analysis was to discern what the data of each case and the data as a whole revealed, which brought forward in a salient way thematic notions within families’ experience (Chesla, 2011). Thematic analysis included the complete text and occurred through a recurring process of reading and writing, developing interpretive questions and refining emerging lines of inquiry through moving among parts and the whole of the text until the thematic meaning notions that denoted the study’s findings were specified (Benner, 1994b; Leonard, 1994; van Manen, 1990).

Narrative analysis was carried out with selected family cases and focused on the stories that stood out as particularly strong illustrations of families’ life-worlds after a close other has died (Benner, 1994b; Chesla, 2011; Leonard, 1994). The aim of the narrative analysis was to aid the interpretive undertaking through examining those cases which stood out as paradigmatic for emerging thematic meaning notions (paradigm case) or as exemplary for particular actions and concerns (exemplar) (Benner, 1985, 1994b; Leonard, 1994). According to Benner (1985) paradigm cases and exemplars are “strong instances” (p. 10) that stand out vividly and distinctively among other cases or smaller examples of concrete situations. Whereas thematic analysis was an essential mode to disclose commonalities among families’ experience of loss, narrative analysis allowed for the distinct to be revealed through the in-depth analysis of a whole narrative case, which illustrated some core meanings and patterns particularly well. As such, it allows to account for the variances and particularities inherent in families’ lived worlds (Benner, 1985).

4. 5. 1. Data analysis processes

Thematic and narrative analysis occurred simultaneously, and included a spiralling movement between parts and whole of the text, as well as the research question, emerging understandings, and the data (Benner, 1994b; Chesla, 2011; Smith, 2007; Spichiger and Prakke, 2003). This hermeneutic movement unfolded through
repeated reading, reflection, writing and re-writing (Spichiger and Prakke, 2003; van Manen, 1990). First, each interview was read several times. The researcher used questions such as: “What is the main twist of the story told by each member and family?”, “What is a story / description about, and why is it told in the way it is?” to penetrate gleaned interview text, and wrote reflective notes to synthesize the interview around topics such as “illness time and caregiving”, “the death”, “family relations and interactions”, or “sense of loss on individual and family level”. This interpretive effort included attention to the things said and not said, the interview context and sequence in which a story was told or experiences related, and how families interacted (i.e. separate, complementary, parallel etc.). When data collection was completed with a family, all interviews were read again with attention to what the text disclosed; using interpretive questions (Table 12). Families’ stories and descriptions were then synthesized in a written case summary.

Table 12: Interpretive questions for thematic analysis

<table>
<thead>
<tr>
<th>Questions for thematic analysis*</th>
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</thead>
<tbody>
<tr>
<td>1. What has changed in their lives and relationships following the loss?</td>
</tr>
<tr>
<td>2. How and why do individual family members experience their lives and relationships the same or different from each other?</td>
</tr>
<tr>
<td>3. What happens to and for them?</td>
</tr>
<tr>
<td>4. What actions do they take following the loss?</td>
</tr>
<tr>
<td>5. What matters to them following the loss?</td>
</tr>
<tr>
<td>6. What does the death mean for their lives following the loss?</td>
</tr>
<tr>
<td>7. How do they make sense of the death?</td>
</tr>
</tbody>
</table>

*adapted from Gudmundsdottir and Chesla, 2006, Chesla, 2011,

Repeated reading of parts and the whole text yielded further interpretive questions that formed together with the conceptual grounding of the study early lines of inquiry (Leonard, 1994). Emerging lines of inquiry included, for example ideas such as “sense of emptiness, gain, relief”, “re-creating life without the living presence of the other”, “witnessing death”, or “practicalities of widowhood”. Interpretive writing about those ideas was used to explicate and refine such early interpretive insights and to map out the terrain for further interpretive endeavours.

Each family case was read once again in light of the refined lines of inquiry, and new thematic ideas that further evolved from the data were added to the interpretive undertaking (Leonard, 1994). Ambiguities, contradictions, and variances that evolved were incorporated and taken forward together with the commonalities that became evident (Benner, 1994b). Hence, text was named and retrieved from individual interviews and family cases and organized around the refined thematic lines of inquiry like “family sharing-not sharing”, “re-negotiating relationships”, “integrating death”, or “sense of loss”. In so doing, questions such as “How do
thematic ideas arise across families?”, “How is it the same or different for each family?”, “Is there a family whose experience stands out as being paradigmatic, i.e. illustrates thematic threads particularly well?” guided the interpretive focus.

Narrative analysis was also conducted with particular family cases and stories to further penetrate the particular manifestations of the interpretive ideas, using the questions listed in Table 13.

Table 13: Interpretive questions for narrative analysis

<table>
<thead>
<tr>
<th>Questions for narrative analysis (from Chesla, 2011)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is the situation’s context and background? How did the situation unfold?</td>
</tr>
<tr>
<td>2. What matters to the family? What are the concerns apparent in the narrative? What larger concerns (for-sake-of-which) show up?</td>
</tr>
<tr>
<td>3. What calls their attention (solicits them)? What is the breakdown? What helps to go back to smooth flow / resolve breakdown?</td>
</tr>
<tr>
<td>4. What happened? What did the person do? What actions addressed their concerns?</td>
</tr>
<tr>
<td>5. What are the narrators’ emotional tone and expression throughout the narrative? How does it shift? What emotions did the person experience during the situation, and looking back?</td>
</tr>
</tbody>
</table>

Interpretive engagement continued through reading the text retrieved around the thematic lines of inquiry and through writing about the emerging commonalities, differences, and distinct manners in which those ideas unfolded in families’ practically lived world until the thematic meaning notions that denoted the study’s findings were specified (Benner, 1994b; Leonard, 1994).

Throughout the interpretive endeavour, reading was an analytical strategy to familiarize and become immersed in the text, as well as to move and remain close to the data in an ongoing, dialogic engagement (van Manen, 1990). According to van Manen (1990), reading and writing is a way to create a consciousness necessary for an interpretive undertaking and to attain “a certain distance and tension between understanding and experience, reflection and action” (p. 124). Writing was the essential strategy through which understanding and interpretation was moved forward in this study, and did indeed turn “into a complex process of rewriting (re-thinking, re-flecting, re-cognizing)”, as van Manen (1990) suggested, which became necessary in order “to do justice to the fullness and ambiguity of the experience of the lifeworld” (p. 131). Different forms of writing were used in this study to aid the interpretive process, such as personal notes to reflect on the researcher’s personal response to participants and data, reflective notes to organize and summarize family cases, theoretical notes to distil how data relates to theories, concepts, and pre-understandings, and interpretive notes to develop interpretation of the data (Chesla, 2011).
Although the interpretive work was predominantly an individual effort, a team consisting of four researchers was involved throughout data analysis (Chesla, 1995; Crist and Tanner, 2003). Regular bimonthly to monthly meetings with supervisors, and occasional meetings with a local advisor familiar with the study context and methodology were held. During such meetings, analytical strategies were discussed. Emerging lines of inquiry were reflected on, with supervisors questioning the researcher’s insights in a manner that invited reflections, enabled refinements, and grounded the researcher in her interpretive endeavour. Such meetings not only denoted a methodological and analytical tool, but were moments during which the primary researcher could bring to light the manner in which her own background and position in the world, as well as her questions and intuitive grasp of the text co-created her interpretations.

The spiralling movement in interpreting the text continued until the team of researchers could not discern any new insights. Through the primary researcher’s immersion with the data over several months, which had created an intense familiarity with the text, she was assured that there was nothing that she had missed that pertained to the analytical questions that had framed the entry point into the hermeneutic movement. On the level of intuitive knowing, the researcher felt that she had pushed through in her interpretive endeavour and had gained an insightful and compelling understanding of families’ lived world after a close other had died, alike Gadamer’s (1975/1989) description of the fusion of horizons. The specified thematic meaning notions and family patterns brought forward the commonalities in experiences but also accounted for variances within families, and across families in a way that accounted for the breadth and depth of the available data.

4. 5. 2. Enacting reflexivity

To reflect on her responses to families, their stories, particular situations, and the textual data, the researcher engaged in ongoing reflexivity. During data collection, the reflective field-notes helped the researcher to discern her assumptions and beliefs and how they played out in interview interactions.

For example, when I interviewed a grandchild, I realized that my own experience of my grandparents’ death was so different that I had come to believe that losing a grandparent did not really denote a loss. During the interview, I was surprised upon seeing the pain, which challenged me to turn my reflective attention towards that matter. Another such situation occurred when I interviewed a family who was very
close. The intensity of their shared loss was difficult to grasp as my own experience was not one of such intense family closeness and connection.

In a few situations, I felt touched by families’ stories of suffering and tragedy that had occurred in their lives, and even though I was used to witness suffering from my clinical practice, the manner in which families talked about their lives lingered. There were several such points in times during which it was necessary to reflect on my experiences and ideas about loss or family interactions in order to understand my own response to family participants, as well as the manner in which my understanding of loss shaped my initial grasp of their experiences. Families’ stories also invited reflections about myself as a family member, and death and dying as a reality of human existence. Writing field-notes and having regular meetings with supervisors set up a context for support in situations during which I felt affected by the suffering or tragic stories of persons’ lives.

Second, during data analysis, reflections about the researcher’s personal responses were written out in form of personal or theoretical notes and discussed during team meetings.

For example, I could understand some experiential descriptions around the manner family members reached out or withdrew from each other around their loss instinctively because they mirrored something that I had also experienced in relation to a new health challenge that occurred during the course of the study. Here, reflections showed that my own experiences of an existential situation enabled me to be immediately attuned to and to understand the significance of some of families’ experiences with greater clarity.

Moreover, over the course of the study, my framing of the phenomenon became challenged as I encountered one family who did not experience the death of their close other as a loss in the sense of having lost someone dear. It became clear that although I had attempted to frame this study more broadly to remain open to families’ lived experience, there was a pre-conceived assumption inherent in the formulation of the study phenomenon that potentially restricted me from understanding what happened to families. In qualitative approaches, the unfolding nature of the research phenomenon is an inherent feature, and changes are consistent with the frame chosen for this study in those situations in which the initial framing of the research question threatens the researcher’s access to participants’ worlds and inhibits understanding (Benner, 1994b). As a consequence, I clarified
the denotation of the study phenomenon of living with loss to mean *living with the absence of someone after his or her death*.

Such ongoing explications of the researcher’s shifting fore-understandings, responses to, affectedness by, as well as grasps of families’ situation through the means of reflexivity served to keep the researcher’s gaze on the phenomenon of loss as it became disclosed in the life-world of families (Gadamer, 1975/1989). While it is impossible to be aware of every way the researcher’s fore-understandings and role in the interpretive undertaking co-shaped findings, enacting an ongoing reflexivity when things puzzled her or withstood disclosure sheds light on her footprints, and denote one essential research strategy that contributed to the study’s trustworthiness in securing the scientific theme (Gadamer, 1975/1989; Geanellos, 1998a; Heidegger, 1926/2001).

4.6. Ethical approval and considerations

The responsible Cantonal Ethics Committee in Switzerland (KEK-ZH-NR: 2011-0300, approval date 29.07.2011), and the Research Ethics Committee at the University of Manchester (approval date 29.09.2011) approved the study. The Swiss Ethics Committee issued a “declaration of innocuousness”, which stated that they were unable to issue a formal approval due to the fact that the study sample would consist of a “non-clinical” population, and did therefore not fit the criteria for a “clinical study” as defined by the law. However, the Swiss Cantonal Ethics Committee did review the study and found no ethical concerns in carrying it out. The research team adhered to the ethical procedures and standards for clinical studies in Switzerland.

Several ethical concerns are specific to this family study of bereavement (Cook, 2001; Parkes, 1995; Rosenblatt, 1995), including family dynamics in decision-making about participation, changes in person’s willingness to participate over time, confidentiality and anonymity with whole families taking part, and potential emotional turmoil and family distress.

4.6.1. Attending to family dynamics in decision-making for participation

In family research, the risk exists that family members talk each other into participation (Moriarty and Cotroneo, 1993; Rosenblatt, 1995). To address this
concern, the researcher had at least one phone conversation with each interested member to explain the study in detail and to provide an opportunity for questions (Moriarty and Cotroneo, 1993). Potential participants received the time they needed to make a decision about participation. Some family members did not take part from the outset, but made a decision to join the study after one or two interviews. Despite these efforts, some family members’ primary reason for participation was because their widowed member wanted to take part in the study and had invited them.

4.6.2. Obtaining continued consent over time

In studies that involve more than one time point of data collection, experiences of previous interviews or reluctance to commit more time might alter persons’ comfort or willingness to continue with the research (Cook, 2001; Rosenblatt, 1995). The researcher used the concept of “processual consent”, whereby each participating family member had the opportunity to renew or withdraw consent at any point of contact (Rosenblatt, 1995). After the first encounter, families made, without being explicit about it, decisions about their continuation in the study based on their comfort with the researcher during the interview. In this study, widow/ers were often keen to take part and open to as many meetings as the researcher suggested. Family members had often more specific ideas about the number of interviews they wanted to take part in, mostly out of time concerns.

Families and individual members made not only decisions about the number, but also about the type of interviews. While the researcher made suggestions based on methodological considerations, families’ preferences and decisions always took precedence. For example, one family felt that a third interview was not necessary because they had already been able to speak about everything they had to say, and in two families, widowers did not want to take part alone.

4.6.3. Protecting families’ identity

Confidentiality and anonymity were of concern for several families. This was particularly the case for those families whose deceased member used to be a public figure. Such issues were discussed with families when they arose, and the researcher took up their concern, and illustrated how the data was managed to ensure that their personalities and family identity were protected. In the presentation of findings, distinct or recognizable features of families were altered to protect their identities.
4. 6. 4. Working with potential emotional turmoil and family distress

The participation in interviews about personal experiences of loss and death may lead to unexpected emotional turmoil, or unanticipated family situations (Cook, 2001; Rosenblatt, 1995). To address potential emotional turmoil and family distress, a threefold strategy was put in place (Parkes, 1995). First, the researcher was prepared, based on her expertise in working with families, to provide initial support during interviews should emotional turmoil arise. Second, the researcher would clarify with families their need for follow-up care. Third, families would receive the contact information of a professional who they could contact for further care, or the researcher would establish a contact if wished so by the family (Rosenblatt, 1995).

There was no single interview situation during which the interview had to be stopped, or during which the researcher had to switch into a therapeutic role or make a referral. Nonetheless, a majority of families experienced painful moments when speaking about how their loved one had died, when sharing particular vivid memories, or when describing their life without their family member. These moments mirrored individuals’ and families’ experiences, and were not unusual, or out of the ordinary for them. During such situations, the researcher remained oriented to the phenomenon under study and rooted in her role as a researcher while also offering her human and attentive presence and concerned way of engaging in the interview, for instance by acknowledging the suffering, letting a painful moment pass or moving on with something that was easier for participants to talk about. The fact that the first interview was always a family interview allowed participating family members to support each other, either during the interview or after the researcher had left the house.

4. 6. 5. Reflections on the researcher’s presence in families’ world

For families in this study, it was important to get to know the researcher whom they had made a decision to confide their experiences and allowed a glimpse into their worlds. For example, during interview encounters, families made conscious efforts to learn more about the researcher as a person, including her professional background and affiliation, family situation, or of her own experiences of deaths in the family. These conversations happened aside the “official” interviews and when the audio recorder was switched off, and served to build up the relationship and to establish trust. Once families knew the researcher, some persons also revealed their initial hesitations and concerns about participation, stating that not knowing the
researcher and what she would ask had made them cautious. Getting to know the
researcher had the potential to facilitate interview interactions. For instance, the fact
that the researcher was a nurse, as well as a mother and daughter herself, was
often important for families in this study to instil trust and to share their experiences.
The researcher’s experience as family member was something that served as a
connection across age differences and varying life circumstances.

Even though the researcher’s involvement with families was solely for research
purposes, about which she was clear with families, interview participation gave
individuals and families an opportunity to sit down together and talk about their
experiences, with someone listening attentively and respectfully (Bravo-Moreno,
2003; Cook and Bosley, 1995). Some participants revealed experiences, or
particular occurrence and decision points in their lives that they had not previously
talked about. Based on her theoretical knowledge and clinical expertise as a nurse,
the researcher had an understanding that listening and asking questions to invite
reflections per se have the potential to be helpful.

Because interviews took place over several months, changes happened for families.
Families attributed some of these changes to the passing of time. However, it also
became evident that some changes happened because of the research. Participants
reflected about their situation or things they had spoken about during the interview,
as well as about things they had heard from their family members. Some
participants told the researcher that it had been helpful for them to take part in the
study. The experience in this study confirms previous reports that the participation in
bereavement research, albeit at times painful, may also be beneficial for
participants, since it denotes a rare opportunity to tell their story (Beck and Konnert,
2007; Cook and Bosley, 1995; Williams et al., 2008).

4.7 Ensuring quality and scientific merit

A plethora of criteria to judge quality in qualitative research exists (Davies and
Dodd, 2002; de Witt and Ploeg, 2006; Sandelowski, 1993), among which the
framework proposed by Whittemore and colleagues (2001) denotes a useful
approach to assess the quality of this hermeneutic-phenomenological study.
Whittemore and colleagues (2001) used the well-established quality criteria put
forward by Lincoln and Guba (1985), together with others that were suggested in
more recent times, to propose primary criteria that account for the need for a unified
set of quality criteria applicable across qualitative approaches, while acknowledging that other criteria, which they termed “secondary”, may apply to some qualitative approaches more than to others (Table 14). The authors claimed that validity is a justified term that can be used within interpretive research to refer to the quality and scientific merit of qualitative inquiries. For them, “assuring validity (emphasis in the original) becomes the process whereby ideals are sought through attention to specified criteria, claims to knowledge are made explicit, and techniques are employed to address the most pressing threats to validity for each type of inquiry” (pp. 527-528).

Table 14: Quality standards used in this study*

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Definition</th>
<th>Questions for appraisal (p. 534)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary validity criteria in description &amp; interpretation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Credibility</td>
<td>“Effort to establish confidence in an accurate interpretation of the meaning of the data” (p. 530).</td>
<td>Do the results of the research reflect the experience of participants or the context in a believable way?</td>
</tr>
<tr>
<td>Authenticity</td>
<td>Efforts to &quot;reflect the meanings and experiences that are lived and perceived by the participants” (p. 530).</td>
<td>Does the representation of the emic perspective exhibit awareness to the subtle differences in the voices of all participants?</td>
</tr>
<tr>
<td><strong>Primary validity criteria of design &amp; truth claims</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Criticality</td>
<td>Effort to critically structure all aspects of the investigation through “reflexivity, open inquiry, and critical analysis” (p. 531).</td>
<td>Does the research process demonstrate evidence of critical appraisal?</td>
</tr>
<tr>
<td>Integrity</td>
<td>“Evidenced in the process to assure that the interpretation is valid and grounded within the data” (p. 531).</td>
<td>Does the research reflect recursive and repetitive checks of validity as well as humble presentation of findings?</td>
</tr>
<tr>
<td><strong>Secondary validity criteria applicable to hermeneutic phenomenology</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explicitness</td>
<td>Ability to follow interpretations and track down interpretive judgements made (p. 532).</td>
<td>Have methodological decisions, interpretations, and investigator biases been addressed?</td>
</tr>
<tr>
<td>Vividness</td>
<td>“Presentation of thick and faithful description with artfulness, imagination, and clarity” (p. 531).</td>
<td>Have thick and faithful descriptions been portrayed with artfulness and clarity?</td>
</tr>
<tr>
<td>Thoroughness</td>
<td>Informants and their situations have been adequately sampled and interrogated; data was adequately analysed to ensure comprehensive read (Chesla, 2011).</td>
<td>Do the findings convincingly address the questions posed through completeness and saturation?</td>
</tr>
</tbody>
</table>

*from Whittemore et al., 2001

Within this framework, the primary criteria of credibility and authenticity are a measure of validity in description and interpretation. Credibility pertains to the closeness and accurateness of interpretations to the experience of participants. Authenticity is achieved when shared meanings and nuanced differences in voices of participants show up in the findings, and attends to the “authenticity of person, phenomenon, or situation” (Whittemore et al., 2001, p. 530). To achieve credibility and authenticity in this study, different voices across family participants were brought to the fore in the formulation of the interpretive findings. For instance,
meaning notions capture commonalities that arose from all families, whereas family patterns bring forward the variations that existed. Moreover, not only families, but family members’ voices were represented in the findings. With an extensive use of quotes, presentation of interpretive claims is illustrated with concrete data, with all families represented in the presentation of the findings. A prolonged and repeated engagement with participants’ world by means of multiple interviews and the inclusion of enough participants to achieve redundancy and completeness also add authenticity and credibility to this study (Benner, 1985, 1994b; Crist and Tanner, 2003). The use of analytical strategies, such as the hermeneutic circle and interpretive writing, was essential to achieve depth and closeness of the study’s interpretation to families’ life-worlds (Benner, 1994b; Spichiger and Prakke, 2003; van Manen, 1990). This study is based on the acknowledgement that multiple interpretations are possible, with each interpretation being tentative (Gadamer, 1975/1989; Geanellos, 1998a). To render transparent the ways the study’s interpretation evolved and was chosen as the most compelling and plausible among various lines of inquiry, the analysis process was described in some detail.

The primary criteria criticality and integrity pertain to the validity of design and truth claims. Whittemore and colleagues suggest that criticality requires a critical engagement in all aspects of the research process as well as that the researcher’s background and role in the study is made explicit through means of reflexivity and critical analysis. Integrity includes efforts undertaken to demonstrate that interpretations are valid and grounded in the data. To ensure criticality and integrity in this study, the researcher explicated her fore-understandings and engaged in ongoing reflexivity, whose insights were made transparent in this chapter (Finlay, 2002b; Geanellos, 1998a, b; Plager, 1994). Not only reflective accounts, but a research log was used to record decision points during data collection and in the analysis process, and to justify these decisions (Cutcliff, 2003; Finlay, 2002b). An interpretive team discussed emerging insights and decisions made (Benner, 1985). With the use of interpretive descriptions, family exemplars, and quotes across all participants, findings are presented in a way that ground the interpretive claims made (Benner, 1994b; Chesla, 2011; Leonard, 1994).

Some of Whittemore and colleagues’ secondary criteria are highly relevant for phenomenological research, such as explicitness, vividness, and thoroughness. Explicitness refers to the auditability of the research process and the manner in which “the interpretive effort of the investigator” (p. 531) can be followed. It is pertinent in interpretive studies because it is essential to render visible the
researcher’s unique imprints on the research findings. In this study, the researcher’s first person accounts provide an insight into her fore-understandings and how they shifted throughout the study process in a way that makes explicit her presence in families’ world, and her footprint in interpretive claims.

**Vividness** concerns the representation of the findings in a thick and artful way. It resonates with van Manen’s (1997) emphasis on evocative texts that open up a space in which understanding can disclose itself: “Phenomenological texts aim to enchant, to turn mundaneness into transcendence and familiarity into strangeness” (van Manen, 1997, p. 354). Vivid texts allow the researcher to enter the life-world of participants in a way that invites insight and imagination (Chesla, 2011; van Manen, 1997; Whittemore et al., 2001). In this study, the description of study findings aims to bring to the fore the concreteness and everydayness of families’ experiences in a compelling way in order to enable transformative understandings for the reader.

Lastly, **thoroughness** involves that the phenomenon of study has been explored in-depth and full scope, that ideas have been fully developed, and that connections among themes have been attended to so that the research question can be satisfactorily answered (Whittemore et al., 2001, p. 532). In this study, analysis ended when all data was explored in-depth, and emerging lines of inquiry could be formulated into a coherent overall to answer to the research question. Three interrelated thematic meaning notions form together the study’s interpretive claim.

While not developed for phenomenological studies per se, Whittemore and colleagues’ (2001) framework does mirror well the methodological considerations that are relevant within interpretive research (de Witt and Ploeg, 2006). For example, the criteria authenticity acknowledges that while there are common threads in humanly lived experiences, variances exist and are relevant to understand the phenomenon of concern. The criteria of integrity is highly relevant within phenomenological inquiry since the subjectivity of interpretive efforts may bring forth unique interpretations and needs to be accounted for with repeated verifications of interpretations with the data. The secondary criterion vividness, for example, points to the importance of the interpretive power that a phenomenological text can unleash if it represents findings in an evocative way. These seven quality criteria denote a useful set of standards against which the validity of this study can be appraised; in particular its soundness, trustworthiness, and scientific merit. The study’s merit also needs to be judged in relation to its potential to expand understanding of families’ life-world and enable meaningful clinical practice with families after a death of a close other late in life.
5. Study findings part I

Family participants

The study findings are presented in two parts. Part one introduces family participants and collected data; part two, which follows in the next chapter, entails a detailed presentation of the study’s thematic findings. In this chapter, family participants are portrayed and demographic characteristics, family configurations, and life situations delineated. An overview of the collected textual data with family groups and individual members concludes the chapter.

5.1. Participating families

Ten traditional, nuclear families spanning up to three generations took part in this study. They were represented by two to four members, including widow/ers (n=10), adult children (n=14), grandchildren (n=3), and in-laws (n=3). In three families, the widow/er and one child participated (ID 2, 3, 9). In further three families, the widow/er and two or three children took part (ID 1, 7, 8), whereas in four families, two to three different family members participated in addition to the widow/er (ID 4, 5, 6, 10). Even though widow/ers were free to ask whoever they wanted, they invited predominantly their daughters for a variety of reasons. Most often, the daughter was the closest confidant among the children (ID 7, 9, 10). Widow/ers also felt that their sons did not have time (ID 2, 3, 4, 5, 6, 7, 10). When a son took part, all children did (ID 1, 8); however, in most families, at least one child declined participation.

Six widow/ers were recruited through home care nursing (n=3 general home nursing care, n=2 specialized palliative home care, n=1 health promotion home visiting programme), and two through a minister of the local evangelic-reformist church. One widow contacted the researcher directly after she had received a recommendation letter sent out by one ministry. Another widower was recruited through the family clinic for older persons run by the University where the researcher is employed.

Among those invited to take part, a number of widow/ers chose to not take part because they did not want to talk about their experience, were afraid that the study participation would „stir things up“, or did not have a family member or friend willing to participate. Some widow/ers would have liked to take part, but were unable to. Reasons included their young age and the unavailability of family members due to estrangement or lack of time.
5.2. Demographic characteristics of individual family members

Participating widow/ers were on average 80 (75-88), and their children 51 years old, although adult children ranged quite a bit in their age, from 42 to 61 years (Table 15). In-laws were slightly younger than their widowed family members. The three granddaughters were between 17 and 25 years old. Widow/ers used to be married on average for 54 (47-60) years. Only one of the adult children had recently separated, all others were married (n=11) or lived in a partnership (n=2). The in-laws were also married, of which two to each other. One granddaughter had a boyfriend, and the oldest cohabited with her partner. All 14 adult children were parents themselves, with children ranging in age from 4 to 32 years.

Table 15: Overview of individual participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Total n=30</th>
<th>Widow/ers n=10</th>
<th>Children n=14</th>
<th>In-laws n=3</th>
<th>Grandch. n=3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years</td>
<td>mean (range)</td>
<td>60 (17-88)</td>
<td>80 (75-88)</td>
<td>51 (42-61)</td>
<td>77 (73-80)</td>
</tr>
<tr>
<td>Female gender</td>
<td>n (%)</td>
<td>23 (77)</td>
<td>6 (60)</td>
<td>12 (86)</td>
<td>2 (66)</td>
</tr>
<tr>
<td>Marital status</td>
<td>n(%) (n=20)</td>
<td>17 (85)</td>
<td>-</td>
<td>13 (93)</td>
<td>3 (100)</td>
</tr>
<tr>
<td>separated / divorced / single</td>
<td>n(%) (n=20)</td>
<td>03 (15)</td>
<td>-</td>
<td>01 (7)</td>
<td>-</td>
</tr>
<tr>
<td>Number of children</td>
<td>n(%) (n=27)</td>
<td>17 (63)</td>
<td>5 (50)</td>
<td>9 (64)</td>
<td>3 (100)</td>
</tr>
<tr>
<td>&lt;2 children</td>
<td>n(%) (n=27)</td>
<td>10 (37)</td>
<td>5 (50)</td>
<td>5 (36)</td>
<td>-</td>
</tr>
<tr>
<td>&gt;3 children</td>
<td>n(%) (n=27)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Self-perceived health</td>
<td>n(%)</td>
<td>21 (72)</td>
<td>4 (40)</td>
<td>13 (93)</td>
<td>n=2</td>
</tr>
<tr>
<td>good to excellent</td>
<td>n=29</td>
<td>6 (38)</td>
<td>1 (10)</td>
<td>6 (43)</td>
<td>-</td>
</tr>
<tr>
<td>neither good nor bad</td>
<td>n=29</td>
<td>08 (28)</td>
<td>06 (60)</td>
<td>01 (7)</td>
<td>-</td>
</tr>
<tr>
<td>Education in years</td>
<td>n(%) (n=28)</td>
<td>11 (38)</td>
<td>6 (60)</td>
<td>1 (7)</td>
<td>n=2</td>
</tr>
<tr>
<td>≤ 9 years</td>
<td>n=29</td>
<td>08 (28)</td>
<td>1 (10)</td>
<td>6 (43)</td>
<td>-</td>
</tr>
<tr>
<td>10-12 years</td>
<td>n=29</td>
<td>10 (34)</td>
<td>03 (30)</td>
<td>7 (50)</td>
<td>-</td>
</tr>
<tr>
<td>≥ 13-16 years</td>
<td>n=29</td>
<td>14 (48)</td>
<td>07 (70)</td>
<td>5 (36)</td>
<td>n=2</td>
</tr>
<tr>
<td>Financial situation</td>
<td>n(%)</td>
<td>10 (35)</td>
<td>1 (10)</td>
<td>6 (43)</td>
<td>1 (50)</td>
</tr>
<tr>
<td>easy to very easy</td>
<td>n(%)</td>
<td>05 (17)</td>
<td>2 (20)</td>
<td>3 (21)</td>
<td>-</td>
</tr>
<tr>
<td>rather easy</td>
<td>n(%)</td>
<td>05 (17)</td>
<td>2 (20)</td>
<td>3 (21)</td>
<td>-</td>
</tr>
<tr>
<td>difficult; from time to time</td>
<td>n(%)</td>
<td>05 (17)</td>
<td>2 (20)</td>
<td>3 (21)</td>
<td>-</td>
</tr>
<tr>
<td>Living situation before death</td>
<td>n(%)</td>
<td>05 (17)</td>
<td>2 (20)</td>
<td>3 (21)</td>
<td>-</td>
</tr>
<tr>
<td>own flat</td>
<td>n(%)</td>
<td>3 (30)</td>
<td>3 (30)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>own house</td>
<td>n(%)</td>
<td>4 (40)</td>
<td>4 (40)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>rented apartment</td>
<td>n(%)</td>
<td>3 (30)</td>
<td>3 (30)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Change in living situation</td>
<td>n(%)</td>
<td>2 (20)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Sixty percent of widow/ers felt that their health was neither good nor bad since most had some health concerns that affected their daily lives, like pain, limits in movement, or breathing difficulties. In contrast, adult children felt overwhelmingly healthy (93%, n=13). While about two third of the oldest generation had nine or less years of education, 93% of the second generation had completed more than nine years of education, of which about half (n=7) even more than 13 years. Almost half
of family members found their financial situation easy to very easy, which was even
the case for 70% of the widow/ers (n=7).

5.3 Family characteristics of illness, caregiving, and dying

For nine of the families, their close others’ death was expected and occurred after
an illness time during which spouses had cared for their husbands and wives for up
to 4.5 years (n=4); a period of family end-of-life care lasting up to two months (n=3);
or a time of profound uncertainty about the illness course (n=2). The illness and
caregiving time preceding the death was strenuous for all involved, but in particular
for the spouses, and involved a lack of sleep, constant worry, seeing the other
suffer, an inability to go outside the house for more than what was absolutely
necessary, and a profound uncertainty about the future course of the illness and
moment of death. Half of the widow/ers said that they received help from at least
one child. With the exception of two families, participants used regular (n=4) or
specialized home nursing care (palliative n=2, oncology n=1, wound care n=1).

Five family members died at home (Table 16, p. 119). One death at home was
sudden, and one simply happened during the night, whereas three occurred after a
few days to a couple of weeks of end-of-life care that families had provided with the
support of home nursing care. Another five family members died in respite care
(n=2) or after a few days in hospital (n=3). Deceased family members were on
average 81 (76-87) years old and died of cancer (n=4), chronic obstructive lung
disease (n=2), heart failure (n=2), acute infection (n=1), or Alzheimer’s disease
(n=1).

Eight widow/ers continued to live in the same flat or house after their spouses’
death. One widow moved into assisted housing about six months following the
death, and one widower relocated into a senior’s home while he was participating in
the study, about one year after his wife’s death. The son of one widow continued to
live in the parental house; otherwise, widow/ers lived alone following the death. All
widow/ers had at least one family member living in the same city or a neighbouring
town (travel time around 20 minutes). The children of two widows even lived in the
same neighbourhood. However, five widow/ers had also children who lived one to
two hours away, and one daughter and granddaughter lived abroad.
5. 4. Description of conducted interviews

Data were collected between November 2012 and October 2013. The first interview with family groups was held six to 23 months after the death. Second interviews were most often group interviews, whereas the third to fifth interviews were mostly solo interviews. On average, 3.7 (2-5) interviews took place with each family spanning over 15 (10-23) weeks, with one to three groups, and up to four solo interviews per family.

The final data set included 37 interviews with more than 50 hours of interview time, ranging from 2:39 hours to almost 8 hours per family. Interviews lasted on average 82±23 (15-129) minutes. With a mean of 86 (44-129), minutes, family group interviews lasted slightly longer than solo interviews with 78 (15-114) minutes. All but one encounter were face-to-face and took place in the homes of the widow/er or a family member (n=30), at the work place (n=1), or in a quiet room at the local university (n=5).

5. 4. 1. Family group interviews

Family group interviews (n=21) involved two to four members. Together with the widow/er, one adult child (n=11), two adult children (n=3), a grandchild (n=2), and in-law (n=1), an adult child and a grandchild (n=1), or an adult child and one to two in-laws (n=2) participated. One group interview was with an adult child and grandchild only. During one interview, an adult family member with a learning disability was also present. With the exception of one daughter, all family members took part in at least one family group interview. However, the first family group interview did not necessarily include all participating family members because some made a decision to join the study only after the first interview had already taken place (ID 1, 4, 5, 6, 8).

5. 4. 2. Solo interviews

Solo interviews (n=16) were held with widow/ers (n=9), adult children (n=5), and in-laws (n=2). Of the 30 family participants, 14 took part in one (n=5 widow/ers, n=5 children, n=2 in-laws) or two (n=2 widow/ers) solo interviews, whereas 16 family members did not take part in solo interviews at all.
Table 16: Overview of family participants

<table>
<thead>
<tr>
<th>Participants</th>
<th>Characteristics of the deceased</th>
<th>Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>Cause of death</td>
<td>Age</td>
</tr>
<tr>
<td>Brown (ID 02)</td>
<td>Alzheimer’s Pneumonia</td>
<td>84</td>
</tr>
<tr>
<td>Clarke (ID 01)</td>
<td>Cancer</td>
<td>87</td>
</tr>
<tr>
<td>Ferro (ID 10)</td>
<td>Heart attack</td>
<td>76</td>
</tr>
<tr>
<td>Fisher (ID 05)</td>
<td>COPD</td>
<td>82</td>
</tr>
<tr>
<td>Ford (ID 08)</td>
<td>Uraemia due to prostate cancer</td>
<td>80</td>
</tr>
<tr>
<td>Gibson (ID 03)</td>
<td>Lung cancer</td>
<td>81</td>
</tr>
<tr>
<td>Graham (ID 06)</td>
<td>Heart insufficiency</td>
<td>78</td>
</tr>
<tr>
<td>Mendes (ID 09)</td>
<td>Bladder &amp; prostate cancer</td>
<td>81</td>
</tr>
</tbody>
</table>

¹ Time since death (in months) upon first interview
² Mean (range) in minutes, total in hours
Table 16: Overview of family participants (continued)

<table>
<thead>
<tr>
<th>Participants</th>
<th>Family members</th>
<th>Age</th>
<th>Characteristics of the deceased</th>
<th>Interviews</th>
<th>Total</th>
<th>Group</th>
<th>Solo</th>
<th>Place</th>
<th>Time</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patterson</td>
<td>Isabelle (widow)</td>
<td>81</td>
<td>Enteral infection</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>Home</td>
<td>11</td>
<td>85.3</td>
<td>(68 – 110) Total: 4:16h</td>
</tr>
<tr>
<td>(ID 07)</td>
<td>Brigitta (daughter)</td>
<td>49</td>
<td>Open wounds</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Uma (daughter)</td>
<td>42</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Richard</td>
<td>Rosa (widow)</td>
<td>75</td>
<td>COPD</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>Home</td>
<td>17</td>
<td>67.4</td>
<td>(49-84) Total: 5:37h</td>
</tr>
<tr>
<td>(ID 04)</td>
<td>Maria (sister-in-law)</td>
<td>77</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stella (daughter)</td>
<td>50</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 Time since death (in months) upon first interview
2 Mean (range) in minutes, total in hours
6. **Study findings part II:**

**Family meanings, patterns, and practices in bereavement**

The following chapter presents the findings of this inquiry into families’ lived world of loss after the death of a close other late in life. Three interrelated thematic meaning notions were identified in the data, which bring to light, at the most abstract level the common ideas around families’ experience of loss (see Figure 2 and Table 17, p. 120). Families revealed their understandings and actions in looking back by reflecting on and narrating the death, in focusing on the now by speaking about their loss, and in moving forward by recounting how family life after the loss had unfolded for them. Past - present - future denoted families’ lived time in which their collective meanings, patterns, and practices unfolded.

**Figure 2: Meaning notions and family patterns of living with loss**

In looking back, families assigned meanings to the death of their close other through the family pattern of *weaving the death into their family narrative*. Families strived to find peace with how death had happened within their family, and grasped it as an existential family moment. Meaning-making of the death occurred in light of their history and identity as a multigenerational family, and the shifting configurations that had become apparent with the close other’s death.

Focusing on the now pertains to families’ interpretation of, and their daily lives with loss. *Sharing-not sharing* arose as an oscillating pattern of living with loss for families. While individuals within families predominately either converged or diverged in their sense of loss, they all-at-once connected and did not connect in their daily lives with loss at various moments in time and in myriad ways.

Moving forward captures families’ collective lives without their deceased member. Two family patterns were evident. The pattern of *continuing* encapsulates how families carried on with their lives and were left with a perception of an unchanged
sense of family. The absence of their close other had little repercussions, with only minor concerns and shifts that occurred in families’ everyday being and doing. The pattern of reconstructing captures families’ upheaval and turmoil that ensued from the deceased’s absence in their family interactions. These families had to consciously re-create their everyday lives around the concerns related to widowhood and later life through changes in their practical involvements, and their lives became more intertwined.

Table 17: Detailed overview of findings

<table>
<thead>
<tr>
<th>Notion of time</th>
<th>Family meaning-making (1th theme)</th>
<th>Family living with loss (2nd theme)</th>
<th>Family transitions (3rd theme)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Themes’ focus</td>
<td>Looking back</td>
<td>Focusing on the now</td>
<td>Moving forward</td>
</tr>
<tr>
<td>Pertains to (level of sub-notions)</td>
<td>Death</td>
<td>Loss</td>
<td>Family life</td>
</tr>
<tr>
<td>Circumstances of the death</td>
<td>Interpretation of loss</td>
<td>Reverberations of deceased’s absence</td>
<td></td>
</tr>
<tr>
<td>Other family deaths &amp; existential events</td>
<td>Moments in time with loss</td>
<td>Family matters around widowhood &amp; later life</td>
<td></td>
</tr>
<tr>
<td>Family generations</td>
<td></td>
<td>Doing family through involvements</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Being family though sense of belonging / closeness</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family pattern(s)</th>
<th>Weaving the death into the family narrative</th>
<th>Sharing-not sharing</th>
<th>Continuing Reconstructing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manifested in / as (level of sub-notions)</td>
<td>Interpreting to mean good</td>
<td>Converging or diverging</td>
<td>Effortless flow-confident-steadfast-unchanged</td>
</tr>
<tr>
<td></td>
<td>Comprehending distinctiveness</td>
<td>Connecting-disconnecting</td>
<td>Upheaval-concerned-increased-strengthened</td>
</tr>
<tr>
<td></td>
<td>Discerning rippling effects</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The three thematic notions capture families’ meaning-giving understandings that arose across families within the first couple of years after the death, and bring forth the distinct family patterns that highlight figurations in families’ caring practices. In the following, each thematic notion with sub-notions will be presented, accounting for the communalities as well as the differences that existed between families. Family exemplars and quotes are used to illustrate the breadth and depth of families’ lived world of loss. The henceforth-presented findings will focus on the family experience. Therefore, the results around individual family members’ experiences of loss are not included unless they are relevant to families’ overall experience, for example to illustrate differences within families, or divergences across types of family members.
6. 1.  **Weaving the death into the family narrative** (first thematic notion)

*Weaving the death into the family narrative* captures families’ speaking about the death, and the meanings they created to embed it comfortably into their family history and identity; that is, their narrative. A family narrative was defined to include families’ fabric of intermingled lives that had evolved over time, the situation from which they assigned meanings, and a continually evolving frame of reference into which they integrated the meanings they gained. As such, the theme focuses on the close other’s death. It evolved from families’ reflections about the death, and it showed up in the stories that they told during the interviews. *Weaving the death into the family narrative* denotes essentially the manner through which families assigned their shared and distinct meanings to the death itself, and arose as a family pattern that was common to all participants.

**Table 18: Sub-themes related to death**

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Families’ assigned particular meanings to the death in three ways (Table 18). First, families strived to interpret the death of their close other to be a good death, which helped them to find peace with the manner death had happened. Second, families aligned this particular death with other existential situations and previous deaths to grasp the vulnerability and immediacy the death unfolded for them. Third, families discerned changes in their generational constellation as a consequence of the death, with the oldest generation who was fading away, and the generation of adult children who were moving to the brink of becoming the oldest generation.

6. 1. 1. **Interpreting the death to be a good death** (first sub-notion)

Families’ meaning-making about the death enabled them to find peace with the way death had come about for their close other. *Weaving the death into the family narrative* showed up in families’ storytelling about the good way death had occurred. *Storytelling* denoted the family practice through which families got a grip on what had and how it had happened, and with which they created a family story of a good death. Although some families had members who lived with lingering doubts or held different views about the circumstances of the death, they told a mutually created story of the death as a good death. These families interpreted ambiguous
circumstances such that they received a positive slant in the overall context of their family. When families had created a communal story of a good death, they could embed the death into their family narrative in an effortless way. Families’ story of the death unfolded around four assertions of the good.

**Anticipating the death:** A good death meant for families that they had found time to prepare. With one exception (ID 10), all families came to anticipate the death. In some families, individual members had started to expect (3PW, 5FWa, 6PW, 6FWc), see signs of (4FWb), or await the death (5PM, 2FW)\(^5\). In those families, differences existed in members’ awareness about the impending death even though they knew as a family that the end was near. In other families, a moment in time occurred during which they realized that it was now about dying (ID 8, 9). Knowing that their close other felt ready to die helped families to find comfort that death occurred in full awareness, as the following interview excerpt with Gerard and his father George Clarke demonstrates (P1: 456-465):

Gerard: [She said:] “It’s good, I’ve had it all, it’s okay now”. And she said: “I would like to switch it off”, right (to his father), this is what she said: “I would like to switch it off”. “You can’t do that, you’ll need to wait”. “Well, yes” but that was it for her. The only thing that she would have loved to see is her grandchildren to get married. That she said too.

George: Yees (laughs).

Gerard: I never had a bad feeling when I went to see her. She made it easy for us, she was fulfilled with her life, and content.

Going through a time of preparing for or communally acknowledging the impending death was seen as a good death because families could make choices, and had an opportunity for farewell. In contrast, the Ferro family lacked such a time to prepare, which left them struggling with the immensity of being hit by the brutality of loss, as Marlene and her father Louis illustrated (P30: 273-277):

Marlene: Yes, it is just this inconceivability, basically all around. It is because, (seeks words) - how should I say this – you don’t expect; if someone is older, you always have to reckon with it. But she was not kind of, if someone is ill, when you know: „Well here“. Or given the age, old, old, you might say: „Yes“. But it happened so // suddenly. //

Louis: // Yes, exactly, // that’s been the problem. That’s the point, that she didn’t need care when you would know, or maybe those who think it is a relief, when they can pass away, right?

Marlene: // Exactly. //

When a time of anticipating and preparing for the death was lacking, the suddenness, rather than the preparedness for, was at the forefront of families’ story.

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\(^5\) Individual participant identification: Numbers 01-10 = family identification; Uppercase letters refer to type of family member and gender: P = widowed person, F = family member, W = weiblich (female gender), M = männlich (male gender); Lowercase letters a, b, c are used to distinguish different family members of the same family.
**Fitting time-point:** Families came to see their close other’s death as good because it was fitting in the time-point it occurred. The time-point of the death late in life was understood as an expression of the natural order of things, and prevented families from having to come to terms with a disquieting fact of an un-timely death, as Sophie Mendes, a daughter, explained (P22: 581): “But I have to say though that we’ve had him for long. After all, we were allowed to have him for a long time”. The fact that family members were old when they died allowed families to acknowledge that death not only concluded a life lived into old age, but also ended a time of worries and of heavy responsibility of looking after an ill member. Families found that the time-point of the death spared them from worse, as Rosa Richard, a widow, explained (P9: 585):

I do have to say that he was spared a lot. I don’t know if I would have; how long I could have continued [to care for him]. And then I do feel: „Oh if he would“ – he was alright in his head until that particular night – if he would have been dead in his head and I would have had to admit him to a home. I don’t know if I would have had a quiet second, right, I would have always felt that he thinks: „She’s getting rid of me, now“ – and that is indeed because I could have him at home for so long and that he did not have to go somewhere else, that is also a thing for me, right.

The death at the point it happened prevented families, and in particular widow/ers from meeting the end of their strength to provide care at home, and from making a difficult decision about long-term care placements (ID 2, 3, 4, 5). Moreover, it spared their close other and themselves from further suffering and facing ongoing uncertainty about the illness course (ID 2, 4, 5, 6, 7, 8). With the exception of the Ferro family, for whom death was not fitting in time as it happened amidst their close other living an active and full life despite her advanced age, families’ framing of the death as fitting in time contributed to their view of a good death. Their close other had died at a moment in time from which families could derive positive meanings.

**Peacefulness of the death:** All families framed their close other’s death as peaceful. In their detailed narratives, families stressed that their loved one did not suffer in dying. Because families had witnessed suffering in illness, it was a comfort for them to see that their close other’s death was serene. Marcus Fisher and his daughter Keira gave a typical illustration of a peaceful death (P14: 95-103):

Keira: She could simply fall asleep. Well this is of course, seen from that point; [brother’s name] was here, my brother, // right and //
Marcus: Yes her features afterwards were, were relaxed; and her breathing was absolutely regular, she // then simply //
Keira: // it went just slowly downwards //
Marcus: There were larger intervals, yes.
Keira: Well from that point; if it had to happen it could not have been better.
When some members (ID 3, 9) were uncertain about the peacefulness of the death, families tried to accommodate their doubts and regrets. For Ona Gibson, for instance, her disquiet arose from the fact that she had not been called in time, and was not present when her husband Arthur died in hospital (P7: 480): “I would have liked to know how he died, if he did indeed suffocate”. When Ona went to view his body, she not only felt alienated and was disappointed to see her husband’s face in a bloated and unfamiliar look, it also nurtured her disquiet about the way Arthur had died. Her daughter Emma could not take away Ona’s disquiet, but she respected her upset, and they created a story of the good death together that embedded Ona’s regrets (P5: 389-405):

Emma: At the end, I had the impression that you found it a pity that you did not get there [the hospital] earlier.
Ona: Yees, that was real bad. It was a pity that I did not get to the hospital in time.
Interv: For the last hours?
Ona: Yes, I would have liked that.
Emma: I’ve once heard, well, a colleague told me. Most people who pass away like want to be alone, so that they can pass away. I don’t know if that is true, if that’s so.
Ona: I’ve heard that too. //
Emma: // that it happens mostly when someone is away; that it happens then. //

While most families felt univocally assured that their close other’s death was peaceful, those families whose members had lingering doubts created ways to accommodate them into their story of a good death.

**Fulfilling the deceased’s wishes:** Families took their close other’s death to be a good death when they were able to or did everything possible to fulfil their close other’s wishes, in particular in relation to the place of death. Families found great comfort in the fact that their close other could remain at home until a few days before the death (ID 1, 2, 3, 4, 7), or could even die in their own beds as they had wished (ID 5, 6, 8, 9). Families whose loved one died in hospital or respite care found great satisfaction in eschewing placement in long-term care, or a prolonged stay in hospital (ID 1, 2, 3, 4, 7). Some families were apprehensive about their ability to face death at home (ID 2, 3, 4) and were relieved that their close other died in hospital even though their closed other had hoped to die at home. Yet other families had tried everything to fulfil their close other’s wish and the fact that they could not impinged on their story. Gerard Clarke, for example, was haunted by his bad conscience about admitting his mother into respite care against her explicit will. However, together with his father George, he came to frame their decision as the right and only possible thing for the family to do (P1: 467-473):
George: But then, she got angry because we brought her there.
Gerard: Yes, that did not suit her at all. But we had to simply stick it out. We were all; we also had to protect father.
George: And you were going away; I would have had to do it all alone.
Gerard: There was simply no other way. We urgently needed a break. (...) But it did not suit her at all to go into [name of respite care].

Gerard focused on the positive side as he felt that "she could probably like let go in [name of respite care]" (P1: 509). What counted for the Clarke family for their positive story of the death, as with other families, was their determination and actions to make dying at home – potentially – possible. Families were thus extremely grateful when they had been able to actively contribute to fulfil their close other’s wishes.

**Summary of sub-notion:** Without exception, the need to interpret the death as imbued with positive meanings around having had a time to prepare, fitting time-point, peacefulness of the death, and fulfilling the deceased's wishes permeated families' stories. Weaving the death into the family narrative, which became manifest through *interpreting the death to be a good death*, served at least two purposes. First, it gave families a peace of mind about the manner death had happened to their close other. Second, mutual storytelling brought about conciliation and fortification for families about the ways they had worked together during caregiving and end-of-life care, and handled the dying itself as a family, which enabled families to conclude an intense period in their family lives on a positive note. During interviews, families provided vivid examples of the ways they engaged in a communal endeavour to create a family story of a good death through agreeing, complementing, filling in details, or by adding individual, differing perspectives (please see appendix K for a longer family exemplar). It became evident in the data that *storytelling* denoted an essential family meaning-making practice to weave the death into the family narrative.

6. 1. 2. Comprehending the distinctiveness and existentiality of the death (second sub-notion)

Families' meaning-making around the death enabled them to comprehend the distinct and existential implications of the death in light of their family narrative. Weaving the death into the family narrative arose through comparing the current situation to other family deaths and contrasting the death to other extraordinary family events. *Comparing-contrasting* denoted the family practice through which...
families put into words their existential vulnerability and insights that arose from witnessing a family death.

Previous deaths within and close to the family denoted the backdrop from which participants grasped the distinct and different meanings that this current death held for them (ID 3, 6, 7, 8, 9, 10). Although previous deaths had provided some family members (2FW, 3PW, 6PW, 7PW, 8PW, 8FW, 9PW) with a familiarity with the physicality of dying, and helped break some taboos that surround death and dying, the death of their close other was experienced as utterly different; that is, more immediate, consuming, and incisive. Marlene, who had previously experienced the death of her parents-in-law, found that the death of her mother was affecting her profoundly, as she explained in interaction with her father Louis (P26: 1467-1475):

Marlene: (…) It's something else when a neighbour or someone else you know dies than when it is someone in the family. Well I have, professionally I experienced a lot that people died. And that's something completely different. This amazes me again and again.

Louis: Yes, yes.

Marlene: When someone in the family dies, it's a total difference.

Louis: It is totally different.

Marlene: Or even now. I work as a postie and it happens a lot that you’re told out of the blue: This woman suddenly died. Yesterday, I talked with her at the mail box and such. Yes, you are also sad, but it’s completely different, isn’t it?

Sophie Mendes, another daughter, experienced this difference from other deaths as vulnerability, which she explained with the fact that she felt “deeply connected” (P22: 1021) to her father, so much so that it was hard to find some distance to her raw emotions (P22: 981-985): “I've seen a few people pass away. But it astonishes me how raw you can feel, over how long a time (trembling chin) when it is someone so close to you”. Comparing the current death of their close other with previous deaths allowed families to grasp the unique- and profoundness of this death.

Families comprehended the death as a breaking or rupturing moment in family life that split their lives up in a before and after, alike other extraordinary family events, such as a birth or divorce, during which they had to re-learn daily life anew. They used other extraordinary family events to crystallize the unfamiliar and disrupting turn the death denoted in their lives, and to exemplify the existential implications that witnessing the death held for them. The two daughters of the Patterson family, Brigitta and Uma, for example, contrasted their father’s death with the births of their daughters in an attempt to put into words the different way they perceived their lives following the death (P16: 1566-1580):

Brigitta: On the one side, you feel this vulnerability, on the other side; over time you tend to be a bit calmer, don’t you. Well, that does help me sometimes.
Isabelle: Yes, yes.

Uma: Everything’s a bit relative. You say this too when you get children, don’t you? You see everything in a different perspective //

Brigitta: // everything in a different light. //

Uma: In a different light. And when someone dies, perhaps in a different light. The big happenings, hu? And then, everything is a bit different.

Brigitta: That’s something you can really say. If you would draw a scale of your life, to note where there were turning points and alike. This is one, of course, this has been one.

Similarly, the siblings of the Ford family, through contrasting their father’s dying with birthing or becoming a parent, explicated its authentic and existential nature that set the moment apart from daily life, as Sara explained: (P37: 144): “Yes this is a bit like when you are birthing a child, energy wise. It is so dense, and so, so different from daily life. You really enter something and we don’t have rituals for such things, don’t we.” Moreover, the death within their family shifted life alike becoming a parent, as Sebastian asserted (P17: 1572):

Also with the birth, the first time it was so up close, a bit too much, you were lost. And it has been too much quite a bit this past year, with the feelings, the many factual issues, and with, you know, my new role within our clan; it is always the first times during which, yes.

For the Ford siblings, comparing end-of-life care and death to their experience of becoming a parent or birthing was a fitting image to express the extraordinariness of the moment in time, and the utter novelty in family life that followed the death.

**Summary of sub-notion:** Comparing this death with previous deaths, and contrasting it to other existential family events was a manner through which families expressed and explained their vulnerability and the extraordinariness of the moment that death and dying denoted in their lives. Families came to see the death as a turning point in their family lives, which shifted the everyday and called them to re-learn their lives, alike for example, the birth of their children, the parent’s divorce, or when the children left home. Weaving the death into the family narrative, manifested as comprehending its distinctiveness and existentiality, allowed families not only to grasp the immediacy of this death that made it special within their family, they also came to see the existential moment it was for their family life. What became evident was that comparing-contrasting was a family practice through which families wove the death into their family narrative by understanding the death within the broader context of their family lives and in line with other significant and existential family moments. Within their family narratives, death became one of the few, but not the only extraordinary event that had shifted their family lives.
6. 1. 3. Discerning the rippling effects of the death across family generations
(third sub-notion)

Families’ meaning-making about the implications of the death for their multigenerational family enabled them to discern the shifting nature of their family configurations and differing ramifications the death held for each generation. Weaving the death into the family narrative surfaced through situating the death in the generational context of their family. *Generational situating* denoted the family practice through which families discerned the sameness and difference that the death implied across members and generations.

For families, the very experience of a family death moved the factuality of death closer into their lives, and brought forward perceptions about the changing nature of their family configurations. It made them realize that they had entered a phase in their collective life in which the composition of their family was shifting (ID 3, 4, 6, 7, 8, 9, 10). In interviews, families talked about their oldest generation who they saw fading away (ID 4, 5, 7, 8, 9, 10), as Marcus Fisher said (P33: 552): “Yes, you simply slip into this age, don’t you, in which people around you suddenly start to die, one after the other”. The thinning of their ranks was particularly notable for the oldest generation, as Isabelle Patterson, a widow illustrated (P24: 1050): “Yes, but not because I think: ‘You’re next in line’, but more so: ‘You are still here from that generation’. Right? And my husband is not here anymore, more like this, like this”.

Not only the oldest generation, but those to follow reflected about the changing nature of their family generations. Adult children saw themselves moving to the brink of becoming the oldest generation. The Mendes said, for instance (P22: 987-991):

**Edith:** And for the children too, one of the parents is gone. They have only me left, so to say. And when I’ll go, nobody is left, then they are the-

**Sophie:** We’ll move up.

**Edith:** Yes. I felt this real strongly when my father died first and then my mother: “Now, no one’s around anymore, now you do have to stand on your feet all alone”.

For families, the fact that members of their oldest generation had started to die meant that they faced changes not only in their lineage and composition of their family, but they expected to lose the last person who embodied part of their family history and identity, and personified a home for the second generation. Families sought to make sense of the death in light of the multigenerational families they were. Participants realized that they had now reached a time in family life during which the oldest generation was waning, and would be soon lost forever, with the next generation in line taking on their succession.
Weaving death into the narrative also meant that families interactively discerned an understanding that the death held different implications for each generation. From families’ descriptions it became evident that each generation’s outlook on their individual life following the death depended not only on who had died, but also on the particular age and life situation family members were in when the death happened. What was common to each generation was that the death of their close other became an invitation to ponder the meaning of life, and to evaluate their own life priorities and actions within their given life circumstances.

**Oldest generation (widow/ers, in-laws):** For the oldest generation, their own death and possible widowhood (in-laws) arose into their consciousness and become a matter of reflection, as Isabelle illustrated (P23: 1063):

I’ve started now too, when; when I hear some news that announces what will be in 2025, then I’ve started to think: “You will probably not be around by then”. But somehow, I don’t know, it seems that death is beyond the imaginable, as long as you live, you are here and you are hungry, you have; it is, well yes.

For widow/ers, while remaining unintelligible, the prospect of dying had moved closer into their lives, as Ona exemplified (P5: 316): “It will be my turn someday. I simply hope that, like everybody does, that you don’t have to suffer, and that you don’t have to wait for too long until you can finally pass away”. Some widow/ers felt less attached to their lives because their spouse was not with them anymore, and struggled with a loss of meaning and purpose, at least from time to time (2PM, 5PM, 7PW, 8PW). Henry Brown, a widower, explained for example (P6: 609): “And you don’t see it as hard anymore, when you know your time comes. It does not get at you anymore; I wouldn’t call it fear; you don’t chase it away anymore and you do know, it is not far away anymore”. However, other widow/ers looked forward to a few more good and enjoyable years (i.e. healthy) to come (ID 1, 3, 4, 6, 9, 10), as Rosa said (P9: 623): „And I always do think, despite everything that I kind of would like to live for a bit still, right, because if possible, I would like to go on a holiday...“. For widow/ers, the death of their spouses changed their stance vis-à-vis their own death. While hoping to remain well for their time alive, widow/ers expressed both an awareness of, as well as certain equanimity towards their own death (ID 1, 2, 5, 6, 7, 8, 9). While some felt apprehensive about the uncertainty that their future held, others tried to flow with the unfolding nature of their lives.

Other members of the oldest generation started to think about or gained some new insights about their own potential widowhood (4FWa, 10FM). Through the experience of the death of his sister-in-law, Harry Ferro was stricken by an insight
that he would be utterly helpless without his wife, who ran the household and cooked for him. His utter helplessness was brought home to him when he returned one day from church to find his wife Helen passed out on the floor (P21: 61-73).

Harry: (...) I was thinking immediately about, about being lost. I was thinking: „I couldn’t do this, I couldn’t do that“. I would have been flat on my back; I would have had simply one alternative, the [name of long term institution]. And (pause, emotional), and then it occurred to me that; you can read it, here (unfolds paper).

Interv: At the bottom?

Harry: Yes, that is it.

Interv: (Reads from the paper): “When I had to bring my wife into emergency, the thought of my own lostness captured me. I felt helpless. That is why Louis’ determined actions surprised me, how he took everything purposefully in his hand and brought it to a good end.” Yes

Harry: Well, I would not have been able to. I would have relied on help. Even already then when she had slumped down there.

Upon seeing how Louis Ferro purposefully met the difficulties and pain of his widowhood, Harry realized the strain he would encounter, at the same time as he wanted to learn from Louis’ experience. For participating in-laws, the death of their family member meant that they attempted to prepare for their own potential widowhood.

**Second generation (children):** For the second family generation, the death of their parent invited reflections about their own later life, and brought about some insights about their lives’ priorities in light of their own finitude. For example, Victoria Brown, throughout caregiving for her mother who suffered from Alzheimer’s disease, felt acutely the ramifications for her own life, and thought about her own preferences for caregiving-receiving, living arrangements, and hopes for her future (P10: 80):

Well, and as for myself, there is evidently, with everything, the ramifications for my own life, because our children have now moved out and I mean, I will be the next one in line. That is simply a fact and this gives me a lot to think about. What will we do, are we doing this in a different way so that our children won’t have it as we did, or will we burden them as well? That is quite at the forefront, yes (pause). Well, and probably we’ll do it the same way (laughs). I don’t know.

Not only their later life, but their own finitude became an issue. For example, the children of the Ford and Mendes family felt like they learnt a lesson about dying, as Sophie Mendes said (P22: 103): “What I had been thinking afterwards: He has like taught us a bit how you can die at peace (raw voice)”. Sophie also noted that the death of her father brought about a “different awareness of life” (P27: 305), which one daughter, Sara Ford explained in the following way (P37: 144):

And the whole dying phase was extremely intense and I think that this was a very formative experience, looking back. To experience this once again, this, how should I say, this finitude, you know, and all these stupid things we worry about. This is
The death of their first parent left children with a conscious new awareness about their own finitude, and created a moment in their lives in which they reflected about their own current as well as phases in their lives during which they will be older themselves.

**Third generation (grandchildren):** For the third generation in the family, the death of their grandparent denoted the first time they encountered the death of a close other, which created for them an opportunity to learn about the existential nature of death through an immediate involvement. Grandchildren in the study struggled with the utterly unfamiliar experience of death during a particular sensitive and formative time in their lives (5FWb, 6FWa, 6FWb). For instance, Charlotte Graham felt that the death of her grandfather aggravated the raw emotionality she already experienced as an adolescent (P29: 713 / 729-733):

> I assume that it does have to do with my age. But I would also say that I would not be, (reflects), not be so emotional in the manner I am if that would not have happened. (…) I have the impression that I am rather more irritable (…). Well like; someone says a word and I am either completely pissed or immediately very sad. It may be that this is part of adolescence, but I have the feeling that it has gotten, like amplified with grandfather’s death. And I’ve reacted to certain things differently than I would have reacted otherwise.

In contrast to adolescent and adult grandchildren to whom the death of their grandparent happened during a stressful time in school or during transitions that determined the future course of their education, leaving them feeling raw and vulnerable, families (ID 7, 8, 9) with younger children below the age of ten found that their youngsters had met their grandparent’s death with an inquisitive and natural way, as the Patterson family illustrated (P16: 742-764):

> Uma: And they take it quite naturally, well, [4-year old daughter’s name] or so, they are so close to it. Death was something she talked a lot about when Daddy died. All the time: “When do we die? Do you die? When do you die?” Talking about it, always talking about it.

**Brigitta:** // Yes, but often. //

**Uma:** // It comes back up // it comes back up a bit when someone else dies. //

**Brigitta:** On the one side, they have a bit more distance, on the other side; they deal with it much more // naturally. //

**Uma:** // Yes much so. //

**Brigitta:** Which helps us too, I have to say. //
Uma: Yes, well // she looks up to the sky, to her granddad, [daughter’s name] // and so, well she does! //
Brigitta: // Also with my daughters, // who are a bit older.
Uma: For her, this is; today for example, she said: “Granddad came by when we said goodnight.” Such things, [daughter’s name] says // sometimes. Well, I think that this is really interesting. //
Brigitta: // Well yes, from this point of view... // I do think that they;
Isabelle: // Well inspiring. //
Brigitta: // do not suffer as much. //

The Patterson family found that their youngest integrated their grandfather’s absence quite easily into their thoughts, dreams, and actions, but were also “one generation further away” from the pain (Brigitta, P16: 740). The first family death enabled grandchildren to learn about one of the existential issues in life, which was for young children a life experience they happened to make, and for adolescent or adult grandchildren a rather painful and formative experience during a moment in their lives during which they felt particularly sensitive.

**Summary of sub-notion:** For families, the death’s significance ripped out across family generations and created awareness for families about the changing generational configuration of their family. The death within their family brought to light for each generation distinct insights and shifted their own situatedness vis-à-vis death as family members of the oldest, next to follow, or youngest generation. This situation meant that they were either moving closer to death, thinking about and gaining insights about their own lives, or were confronted with the finitude of life for the first time, respectively. Weaving the death into their narratives, which became manifest through discerning the rippling effects, left families with two distinct insights. First, they saw how their family’s composition was changing. Second, it created an altered, authentic awareness for their own lives that was shaped by their generational situation within their family. Thus, generational situating arose as the distinct family meaning-making practice through which families integrated the death into their shifting family narrative.

6. 1. 4. **Synthesis of the first thematic meaning notion: Sharing a world through looking back to the close other’s death**

The thematic meaning notion of weaving the death into the family narrative reveals that families’ experience of loss involved making sense of the death. Making sense allowed families to let the death become part of their factual world and embedded it within their lived context. Meaning-making arose from families’ past lives and
unfolded in light of the multigenerational families they were at the present moment in time. The narrative that families came away with encompassed shared meanings of the death: A positive family story of the death as a good death, an insight about the uniqueness of this death in light of other existential family moments, and an awareness of the lasting changes within their multigenerational family configurations that brought about reflections about their own way and meaning of life.

From a Heideggerian (1926/2001) frame of reference, the death of their close other rendered their transparent world, which families inherently understood through acting in it, a matter of deliberation, alike other previous family events such as becoming a parent. Storytelling, comparing-contrasting, and generational situating were families' practically engaged ways of relating to their world and with each other, and through which they let the death, and their own family caregiving and witnessing dying fall back into the obscure and transparent of the everyday. This regained transparency of the death was achieved through the sense the death made for families in relation to their contextualized family situation, and arose as "peace with". Families' peace with death came about as they were interpreting the death to be a good death, comprehended the uniqueness of the death for their situation, and discerned the distinctive generational implications.

Witnessing a family death confronted some members with their own potentiality to be open to the yet undetermined and unfolding possibilities in their lives (Figal, 2007; Heidegger, 1926/2001). This arose as family members' felt awareness of their own finitude, new freedom to stand in full vision of their own end-of-life, and shifting priorities in their individual lives. For those family members, their sense of life was altered, and became "authentically their own", whereas others remained absorbed in the familiarity of going about their established ways of life.

In summary, the meaning notion of weaving the death into the family narrative captures families' interactive manner through which they let the death become part of their world. Having moved through caregiving and witnessing a family death made up families' new facticity, their already-being-in-a-world through their relational interconnectedness as a family – their family narrative. While death became part of every family participant's world, only some participants felt an authentic awareness of their own potentiality to be. Some family members heard, through their confrontation with dying, a call to face their own potentiality to be an "authentic" self (Heidegger, 1926/2001), and to actualize their own distinct way of living their lives. It made them understand "something" about human's existence; that is, their very own lives.
6.2. Sharing-not sharing the loss as a family (second thematic notion)

Sharing-not sharing the loss as a family is a theme that captures families’ converging and diverging interpretation of the loss, and families’ enacted community and aloneness during various moments of family and individual life. It focuses on the loss as interpreted and lived with by families. The theme arose from families’ descriptions and examples that illustrated their interpretations and portrayed the concrete manner in which families engaged or disengaged from each other in daily life with loss. Sharing-not sharing denotes the central way in which families interpreted and lived with the loss as a family, and emerged as a distinctively, oscillating family pattern of living with loss in daily life.

Table 19: Sub-themes related to loss

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Families shared and did not share their loss in two ways (Table 19). First, families converged or diverged in the interpretation of the loss. Second, families connected and disconnected around their loss during various moments in time of their family life. While families either overwhelmingly converged or diverged in their sense of loss, all families shared some moments in their lives with loss at the same time as they did not share others.

6.2.1. Converging or diverging sense of loss (first sub-notion)

Family sharing-not sharing was a pattern that showed up in relation to families’ converging or diverging interpretation of the loss. Families’ interpretation of the loss varied depending on the closeness they experienced before the death within their dyadic relationships with the deceased.

Converging sense of loss as painful missing: Families who converged in their sense of loss interpreted the significance that the loss held for their individual lives in the same way (ID 1, 4, 7, 8, 9, 10). Their sense of loss involved for some a painfully felt emptiness (ID 7, 9) or a glaring void amidst their ranks (ID 10), while other families were also filled with a sense of thankfulness (ID 1, 8) and relief (ID 4) about their close other’s end of suffering. Families with a converging sense of loss had lost a member who had welded them together, either through an anchoring (ID
4, 8), unifying (ID 7, 9), or connecting presence (ID 1, 10). For the Patterson family, for instance, their world felt entirely changed, as Brigitta pointed out (P16: 1004 / 1020 / 1024): “Well, basically, everything is different, isn’t it. For me, I feel that way, I do. It happens already when I enter the front door, it is different. He simply is not here anymore”. For Louis Ferro and his daughter Marlene, it was most difficult to lose the person who had always been around and had cared for them (P30: 167-171):

**Louis**: Yes (short laugh), the most difficult thing is that you don’t have a partner anymore, in this very sense. You have friends, good and very good friends, but no partner anymore with whom you are together all the time, who is here. This is, of course difficult when you’re old.

**Marlene**: That this person is not here anymore to ask things. I asked my mother quickly, she knew stuff. I can’t do this anymore somehow, right? It comes to mind, that you think: “She knows that, she would have known that”, or so. // This is. //

**Louis**: // It is // of course, she did, didn’t she, when I, she said: “You’re limping” “Yes, my knee hurts or such.” She had a health book and said of course: “You might wanna try this out.” This is of course, well, such things do not happen anymore. Yes.

Families with a converging sense of loss did not only miss their close other within their family ranks, but also in their individual lives. Families acknowledged that the death was most disruptive for the widow/ers. Widow/ers in these families had lost a spouse with whom they had shared decades of married life, and who had provided them with assurance, security, love and affection until the moment of death. As Rosa Richards said (P9: 581 / 585): “Yes, (pause) what goes through my mind? (Pause) That we’ve had good times (pause, crying) and that I miss him again and again. When I sit here on any given evening and can’t talk with anybody”. Widow/ers’ daily lives underwent profound shifts, and they suddenly had to spend their days alone, whereas before, they used to be together, particularly since retirement and during caregiving. There were many little things that happened, or that widow/ers encountered in their daily lives that reminded them of their loss and brought about a painful longing. Isabelle Patterson explained (P17: 322):

**There is so much that goes through your hands. We, well, just recently (cries) a ballot paper, or something; a newspaper article about some educational policy, when something undergoes a change in one of the universities and such, then I think: “Yes!” Then I catch myself thinking (still cries): “I have to talk with him about this (becomes incomprehensible).” It is then that my children get it instead.**

The abounding absence of their spouse left widow/ers longing for his or her presence to share particular moments in their days, like sitting in the sun together (7PW), spending the evenings reading on the couch (9PW), sitting down to have a home cooked meal and a bottle of wine (10PM), someone to talk to, ask for advice (4PW) and pass decisions through (8PW), or having someone around at home who
infused it with a cosy and homey atmosphere (1PM, 10PM). Widow/ers of these families had lost their closest confidant, which they felt in manifold ways.

The children within these families longed for their mother’s deep interest in their lives and the place one could always return to that their mother had embodied (1FM, 1FW, 10FW), or ached for their father’s encouragement and incessant support that had helped them to become the persons they were (4FWb, 7FWa, 7FWb, 9FW). For example, the Ford children missed their father because he had embodied a place of contemplation and openness that had grounded them, as one daughter, Kirstin said: (P17: 1184): “I realized that I could easily rest with Alfie. That his nothingness; it was simply so recuperating”. Her sister Sara also missed her father most as the person to turn to for reflections (P37: 160-164):

Sara: This vastness of space, you know, when I’m thinking about this and that, I could go to him and say: „What do you think about this?“ Or when people make a fuss about something or talk about certain things: „I don’t understand it, what do you think about this?“ And then he would say a couple of sentences; and that is what I miss. I do find this in my husband too but I am in a different rel--; he is much closer to me. He had given me that; I did appreciate this very much in him.

Interv: Like a place to go to, to a bit...
Sara: Yes, to get an advice: „How do you appraise this?“ Or to tell him something and then he would say: „Well, you know, that will work out, just wait a bit longer“. You know this, this not having to rush into action and such, I think that is what I will miss the most, and what I already miss. Not during my daily life, but this, this outside authority, who said somehow something and you would think: „Oh yes, it is, it will be alright“. And that was what he was for us, right.

In contrast, the daughters of the Patterson and Mendes families profoundly missed their father in daily life and felt very vulnerable for much longer than they had expected. Their vulnerability meant that sadness and crying overcame them in unexpected ways, for instance when gathering and having fun times with friends (9FW), or they felt vulnerable and unable to stand their grounds as they used to in challenging situations unrelated to the death, for instance with their children (7FWa, 7FWb). Brigitta Patterson explained (P16: 1504-1526):

Brigitta: When you have experienced such a thing, like this loss of someone who is so immensely dear to you, you react at times quite unpredictably (…) tears well up when others can’t understand why. Simply that you are // (…)
Uma: But that others can’t understand why; why you have to cry, is it that what you mean?
Brigitta: Yes. (…) That you have, maybe in this past year, and maybe not only for this one year, right? When something profound like this happens, you are. //
Isabelle: // More sensitive. //
Brigitta: raw, yes

While the children missed their parent as a person who embodied, in some way or other, a person to turn to, the three participating in-laws who participated in two
families did not. They felt that someone was missing among their ranks very distinctively, but did not feel that they lost a person they shared daily life with, or a person to turn to as did the widow/ers and children in these families.

**Diverging sense of loss ranging from contentment, relief, and missing:**
Families who diverged in their sense of loss derived varying significance for their individual lives (ID 2, 3, 5, 6). Some members experienced a painful emptiness and missed their close other (2PM, 5FWa, 5FWb, 6FWa, 6FWb), whereas other family members did not because they felt relieved (2FW, 3FW, 6FWc), or grateful for their ability to contribute to a good end of their marriage (3PW, 5PM, 6PW). Albeit some dyads within these families shared an interpretation of the loss, families’ overall sense of loss diverged because of the different kind of relationships they had had with the deceased.

Widow/ers (3PW, 5PM, 6PW) in these families had lost their spouse as a partner they loved and could turn to while s/he was still alive, as Ida Graham summarized succinctly (P15: 459 - 463): "I've been alone long before my husband died because during these last years, he's been so infinitely far away (pause). That is why I say that you can be lonely when you are together. And I've, I've felt alone, but not lonely". The marriages of these widow/ers had been strained for various reasons, as Ida continued to explain (P15: 431):

> For me, the dilemma was always between my ill son and to be a wife alongside, and mother and so forth. At one moment, I realized that. This has strained the relationship just as well. And today I have to say that despite everything I am very glad that I did see it through. Until the end. (Pause). It has simply not been; because I could prepare myself over such a long time, it has not been a shock. Rather, it has come as a release. Well, for him and for me. I have to say, if I would not have had my family physician, I don't know what would have happened. I've been once well beyond everything, with my strength, right.

Alike Ida, the other widow/ers had also gone through a time of intense caregiving (ID 2, 3, 5) and constant worry (ID 2, 3, 5, 6). The death of their spouse released them from a strenuous and worrisome time during which they had focused their lives on the care of their spouse. However, they felt not only disburdened, but thankful for their ability that had allowed them to provide care to their spouse, and to conclude their marriages with caring ways and actions. Marcus Fisher, whose marriage had been strained by his wife’s mental illness explained (P23: 205-209):

> Marcus: I could do something for her sake, and she appreciated it. In that sense, it was not: „It is self-evident or I can expect this, you could have done this and that“, as it used to be sometimes maybe, in the earlier times. She was real thankful that I was around and looked after her.
Interv: And that knowledge is something good for you now, did I understand that right?

Marcus: Yes, well, it gives me, it gives me certain gratitude. I would say, I would say – because I caused her a lot of great pain, psychically (…). And now it is maybe such that I can say: “I could now compensate for this a bit by looking after her well, and no third person had to come to do it”, like this, yes. That’s maybe the reason why I say that I am thankful that I was able to do it yes.

For these widow/ers, death concluded their strained marriages in a good way. Not only widow/ers, but most daughters within these families felt relieved and were at peace with the death of their parent (2FW, 3FW, 6FWc). Not only did they see the death coming, they desired it for their parent. Susan Graham said (P29: 77 / 519):

I felt sorry. Well, yes, you don’t wish anybody to die. But somehow I found: “It’s not really a life either, if you’re around, but you are not really here”. That’s what I felt sorry for a lot, for him mostly. (…) I can deal with it well because I know that it’s the right thing. It’s alright like this, everything else would have been simply worse.

The daughters also appreciated that their surviving parent was disburdened from providing care, and were glad that their parent could dedicate their energy to themselves. Emma Gibson, for instance, said about her mother (P11: 79 / 83): “She flourishes and is on the go all the time (…) I think it’s a good thing. I think it’s great (…) Well [I am] glad that she’s doing so well.

The participating grandchildren of the Fisher and Graham families, in contrast, felt the loss of their grandparent painfully in their lives, in particular during meaningful moments, as Chloé Fisher said when talking about the conclusion of her exams (P32: 295): “I always think, in big moments I always think of grandma because I want to tell her, I want to tell her how I feel”. Although the grandchildren felt that over time, their happy memories of their grandparent had started to move into the foreground and pushed the sadness away, they continued to face moments of profound sadness. Charlotte Graham explained (P29: 615-627):

That’s the dilemma for me. Well it does, I don’t know, maybe once a month it bubbles up, or at a family get-together. Not that I am sad for a month and that’s it. It requires some more time for me. I don’t know how much longer, but I still need time. (…) It is still the same feeling that I had at the funeral. (…) Well it is; when she [mother] told me, it didn’t seem real. It was simply: “He is dead”. And then at the funeral, I had this sense; what came up was: „He’ll be absent for the rest of my life” (raw voice). And that has been more or less the sense that has been with me since then.

All three participating grandchildren missed the good times they had had with their grandparent, and felt pained by their absence, in particular during those times in their lived that denoted a cross-road for them.
Summary of sub-notion: The deceased's role in family life and the previous nature of relationships among family members provided the background from which families assigned the particular meanings the loss held for them, such as missing the close other's presence, contentment, or relief. Sharing-not sharing, manifested through a converging or diverging sense of loss, thus unfolded in light of their previous family lives. Families who overwhelmingly converged in their sense of loss, in some way or another, had lost in their close other a person they relied on and had found a partner in love, or a caring parent until the moment of their death. Thus, they missed their close other's anchoring, loving, or connecting presence in their lives, both as a family and individually. In contrast, for families who overwhelmingly diverged in their sense of loss, the death of their close other had ended some sort of restriction for all, or parts of the family. Their contentment about the manner in which they could conclude their strained marriages, and their relief about the end to their close other's suffering and a strenuous time of family caregiving prevailed.

6. 2. 2. Connecting-disconnecting during various moments in life with loss
(second sub-notion)

Family sharing-not sharing was a pattern that occurred as connecting and disconnecting in daily life with loss. Families enacted community during various moments of shared family life during which their loss was at the forefront. Through community, families provided comfort and alleviated aloneness. Families cared for each other through creating awareness about each other's wellbeing and situation around the loss, and by living availability to each other to share the burden of the loss through concrete actions. However, reaching out and being together to share was not always possible, and situations of aloneness could not always be averted, which denoted moments of disconnection. Families' community and aloneness unfolded during particular moments in time of their family life, such as during daily life as a family, during special family moments, and in everyday life alone.

Family connecting in daily life: Families connected in their daily lives in different ways, for various reasons, and on manifold occasions (see Table 20, p. 144). One way of family connecting happened through taking note and talking. Taking note and talking were family caring practices that allowed families to create awareness about each other's wellbeing and feelings around the loss. For instance, Victoria, a daughter, illustrated how she made inferences about her father's situation through talking (P10: 92):
When he is not so well; or when I ring him up and ask him this standard question: “How are you?” He basically always says: “I am doing a bit better”. Once I asked him: “What do you mean, better? Were you not well before?” He says, it’s funny, he always says: “It seems that it slowly gets better”. And then I don’t know for sure what he refers to, to the physical or else. Sometimes I ask back and sometimes I don’t. But basically I think; he is doing relatively well.

Victoria learnt about her father’s wellbeing based on the conversations she had with him (talking), but also by observing his actions during the time they spent together at the ski cottage (taking note). Another child, Sebastian Ford, gave an example of how he learnt about his mother’s wellbeing by taking note (P28: 156):

She gets herself out of these lows, which she always used to have, right, with an activism and tackling things, and if it’s only that she thinks the house is not clean enough. You see this all the time. Well, when I go to visit her I basically know right away what kind of week she had, because you can eat from the floor, yes.

Family connecting through talking and taking note was not only a manner through which to learn about each other’s situation, but it was also enacted to find and provide comfort. Charlotte Graham gave a description of how she felt comforted upon observing how others in her family faced the loss (P29: 473-479):

Charlotte: Well I think it would have been bad for me when she [her mother] would not have done a thing or could not have done anything for a week or so. Also grandma, for instance, when she could not have laughed or talked anymore, then I think it would have been much worse for me because I would have lost a certain normality. And then it would have been in my face the whole time what change has occurred. And I found it extremely good that I had people around me. For instance my father could also deal with it well. That I had people around me (seeks for words) who knew and who had already dealt with it before. And that is why I was not so, well, I was sad, but I was not pulled down so much, I was rather comforted: That something is now missing, but that the basic bricks are still the same as before, let’s say it like this. And that has helped me the most. And she [her mother] was very grounded and pragmatic. Well, I don’t know if she cried, but I am glad that I did not see her because I can’t-

Susan: // That I do for myself. //

Charlotte: / /Because // it pulls you down when you see that everybody around you is sad // and you are sad //.

Susan: // That's for sure. //

Ida, Charlotte’s grandmother, led the way for her because she remained firmly grounded in her life and talked with Charlotte about her experience in a positive way. Through talking with her family members and taking note of their comportment, Charlotte felt carried through her pain and found an assurance in family connecting.

Another manner through which families connected to provide comfort and alleviate aloneness was by enacting presence and spending time to live with the painfully felt loss together. The Mendes family gave a rich illustration of how connecting – embodied as enacting presence - denoted a great source of comfort for them (P22 / 1103-1107 / 1147-1163):
Sophie: What is really important - we noticed it a lot – is when you can stand by each other a bit; this is unbelievably helpful.

Edith: Mhm (confirming).

Sophie: That and your net as well. I have also a family who needs me and that is simply what helps you to go on. It does continue and that carries you. (....) When you are feeling alone, you can go to the other. I do think that it is the presence.

Edith: Yes or simply when someone says some words that you have not thought about, thought about, that calms you. That happened a lot to me with you three [daughters] (…). I only remember that I was thinking to myself: „Look, you did not get that idea on your own, but it does you good. It calms you“ (…)

Sophie: Simply, to be able to share this.

Enacting presence to receive and find comfort was an important manner through which families connected and consciously reached out to each other (ID 5, 6, 7, 9). Another way families connected was through spending time. Spending time was a family practice enacted with the purpose to alleviate widow/er’s aloneness (ID 1, 4, 8). For instance, the Clarke siblings took turns to spend Sundays with their father, and Stella Richards made an effort to be with her mother as often as she could, in particular during holidays, birthdays, or anniversaries because she knew that her mother was particularly prone to miss her husband during those special days.

Families enacted connecting when they were involved in their daily lives (ID 4, 5, 6, 7, 9). This was for instance the case for the Patterson family, as Brigitta illustrated with a situation she experienced with her young daughters (P16: 1162-1170):

Brigitta: They support me too, they do this deliberately somehow. When they notice that I; well yes, when I maybe; yes, when they get it that I am remembered by something, then they say for example: „You’ve been thinking of granddad, right?“ or something like this. And for them, it is really explicit, and it’s not an issue at all. And that helps me too. //

Uma: That this is so, right?

Brigitta: To talk more, or also to talk easily about it. Because for them, it is no issue at all to talk about it. And this is actually helpful for me, then… //

Uma: // Yes that is. //

Brigitta: to also talk more about it with them.

However, families also purposefully created moments in which they turned to each other. Henry Brown, for instance, used to call his daughter up in the evenings during the early time to tell her that he had not spoken with a single soul the whole day, thereby connecting with her to feel less alone. Those families who saw each other daily or often during the week had more opportunities to share their life with loss simply because they were already together (ID 4, 5, 6, 7, 9), whereas families who did not interact on a daily basis did not necessarily happen to be around each other when a difficult moment arose for one or the other (ID 2, 8, 10).
Family connecting during special moments: Connecting also occurred during special moments in family life, such as the time of the death, when families gathered on festive occasions, and during family group interviews. The death, funeral, and burial were inherent moments of family connection, although to a varying extent.

Convening around the dying-deceased: Participants enacted connecting through convening around the dying-deceased, for example through the death vigil, viewing, the body, organizing the funeral, and making decisions about the burial. The narrative given by the Ford family is a particular strong example of connecting. The family had put an orange hospital bed in the living room, in which Alfie spent his last weeks and died late one evening, with three generations sitting around his bed. End-of-life care for Alfie was a communal endeavour in which three generations of the family, neighbours, and a palliative home care service were involved. It was not only a logistical challenge for the family, but a time of intense community, including many hours in which the family sat together, drank a glass of wine and had family meals. Two days after Alfie’s death, when the undertaker came to collect his body, the Ford family experienced a connecting moment (P17: 812-824):

Sebastian: The undertaker came and we were all in the back [of the house] and the hearse was in front and that was such a // key moment for me, really. //
Kirstin: // Oh I am so thankful to you for that. //
Sebastian: We were in the back, we didn’t want to see how they put him into this box and then //
Kirstin: We went into the bedroom, the women, and you remained in the front //
Sebastian: // No, well not yet. // I was also in the back and suddenly, it was: „They take him away, out of the house“, and it occurred to me that, “No, that is exactly what he always wanted!“. And I went to coffin him and helped to carry him out with his feet first.
Kirstin: That is, well, // I felt deeply impressed. // At first, Sebastian said.. //
Sebastian: // ..as he has always wished it to happen (sniffling). //

The Ford’s narrative is an example of sharing and stood out for the family as a meaningful moment of togetherness. Family participants also helped each other to prepare for and organize the funeral (ID 6, 8, 9, 10). Planning and preparing for the funeral was another family caring practice with which families enacted a supporting and caring availability to each other. Families connected through sitting down and planning the funeral together (ID 9), providing assistance, for example with the writing of the vita and formulation of the death notice (ID 10), or creating meaningful ways to pay last respects (ID 6). Shared decision-making around the burial was a way families enacted connecting (ID 3, 4, 8), as the Ford’s narrative about their decision to keep Alfie’s ashes at home demonstrates (P17: 858-874):
Alice: Well, he never said: „I would like to go in here [urn wall]“. But I said: „Look, I don’t want a burial“. And then he said: „I want to be where you want to“. And I also said, now; when we went to get the urn; Sara came along and then the man there said: „I am terribly sorry, we don’t have any spots left“, he said that they did not have an urn-, (...) not even finished niches in the urn wall ready, but that we could leave him there, that they would store him. And then we said // “No” //

Sebastian: // No, certainly not. //

Alice: Then we took him home, well yes, and he is now downstairs where he used to work.

Sebastian: He will never get into a niche, that’s for sure (laughs)

Kirstin: I don’t think so either. (...) And we took Alfie with us all the time and back home again. And somehow, that has been much better.

From the overall context of the story that families told in the interviews, it became evident that all families connected during this early time following the death as a family. Families, however, differed in the extent of family connecting they experienced during the dying and following the death. The difference occurred in the manner that convening around the death was a very communal enterprise that included spending many hours and days together (ID 2, 5, 8, 9), or was enacted rather individually, with less and shorter communal time (ID 1, 3, 4, 6, 7, 10).

Family gatherings: Family gatherings denoted festive occasions of family togetherness during which family always connected in remembering and honouring the deceased. Remembering during family occasions like Christmas, birthdays, anniversaries, or other festivities was a practice to honour the deceased’s role and legacy in their lives. It happened through sharing memories, relating who the deceased had been as a person, or making a reference to a typical character or manner of the deceased. It included telling a funny story, making a joke contributing what the deceased might have said, calling a memory forth, or lighting a candle. For some families (ID 1, 2, 7, 9, 10), gatherings denoted a moment during which remembering was at forefront, and the deceased’s absences was felt achingly and raw, as Isabelle Patterson and her daughter illustrated with Isabelle’s first birthday party following her husband’s death (P16: 382-388):

Isabelle: He was sitting on the sofa [on his last birthday], in the corner, and everybody who came this time around looked into that corner (cries). You know, [name] did too, she said: “Right, last time, Paul sat in that corner”. The men went – we women were rather in the front. And the // men all went to him. //

Uma: // The men were all in the corner. Yes, yes//

Isabelle: // At the end, all the men were sitting there. //

Uma: // Um // were sitting back there.

Moments in time during which families felt painfully confronted with the profoundness of their loss shifted over time. For example, these families had expected the first times they gathered, for instance on Christmas, with
apprehension, and had found it difficult to live through such meaningful and traditional family moments without their close other present. However, the passing of time created more distance to raw emotions and allowed for more rational insight that helped to accept the fact of the death, and enabled to experience more and more enjoyable family moments. For some, the proverb “time will heal” started to ring true, and they suddenly understood why one would make use of this proverb (ID 4, 7, 9, 10). Families mentioned in interviews that time had indeed passed, and that they had started to live a new normalcy in enjoying each other or in facing present concerns (ID 4, 7, 9, 10).

Family group interviews: Family group interviews also constituted special moments of family connecting since families came together especially to give the researcher a glimpse into their lives with loss. According to families, the interview was often the first time following the death that they actually talked about their loss in such explicit ways together. They described family caring practices of remembering, talking, taking note, and enacting presence percolated throughout interviews in all families. Remembering happened as families spoke about past memories whereas talking and taking note occurred through listening and seeing what each member chose to relate. Families enacted presence through saying something comforting, looking or touching each other to acknowledge the pain and sadness (ID 4, 5, 7, 8, 9).

Table 20: Family caring practices related to loss

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Family disconnecting: While families found manifold ways to connect with each other, they also disconnected, for instance when they made decisions to not talk about their pain, or during moments that were beyond sharing. One way of disconnecting occurred when family members made a decision to conceal their lows in order to not pull their loved one down during a moment of ease. In the following interview excerpt, Keira Fisher and her daughter Chloé explain how they forwent opportunities for comfort even though sharing provided them with relief (P32: 221 / 279-285):
**Chloé:** But I understand that she might feel the same as I do, when she is sad she doesn't want to tell me because I'm not sad at that moment and when I'm sad I don't want to tell her. But I think in time we will just be able to tell each other straight away and not worry. (…..) It's more I guess, if it's happy things, I will speak to Mom about them or if, or if I am 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, she'd rather me speak to her and then we can cry together, which we have done. (…..) I think because I care so much about how she feels and how it's affecting her. I always think, well if she, if she realizes that I'm sad that will add to her sadness. I don't know; it's strange (…)

**Interv:** (to Keira), And how is it; do you realize these moments in which she is sad and does not tell you?

**Keira:** Ehm, sometimes, like yesterday evening maybe, yes. (….). But it is as you've said (to Chloé), that you don't want to sort of burden someone else with your sadness because then the other also gets sad. But most of the time, though, you do feel better afterwards, like yesterday, that was a very valuable moment. But you do have to find this out a bit, that it does not last but can be rather liberating, right, that you can be a bit relieved.

As this exemplar demonstrates, caring for another not only involved connecting, but could also mean disengagement and disconnection in those situations in which family members made a decision to conceal their lows out of concern for the other.

Some moments in daily life were beyond sharing. Such moments arose when family members encountered a song, a place, a saying, an act, a smell, a belonging, or anything really that was inextricably connected to the deceased for them. In contrast to other family members, for widow/ers, with the exception of those who did not miss their spouse (ID 3, 5, 6), such moments were painful, and filled with longing and loneliness. Such moments were instances of existential aloneness that no human presence could prevent, soothe or end for them. During these moments, their life was profoundly about not having a spouse anymore; the closest confidant with whom they had spent decades of married life. For instance, moments of aloneness occurred when widow/ers were alone in their homes (1PM, 2PM, 4FW, 7FW, 8FW, 9FW, 10PM). Edith Mendes found returning home into an empty house one of the hardest things to do, and felt that those moments were here to stay (P27: 73):

> When you get back to the flat and nobody is around. Even when a child comes with me [to their holiday house], but he is not around (cries). And that happens always, right. And what I do then, when I was out grocery shopping and come back, 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“.

Despite everything there was to do in the flat or around the house, their usual pastimes, and business they created, moments crept up during which widow/ers had nothing to do or did not feel up to do anything (1PM, 2PM, 7FW, 8FW, 10PM). Henry Brown had many hours he spent feeling alone in his house; the house itself was the source of emptiness as he had spent so much of his time caring for his wife in it (P8: 138):
What happens sometimes too, you know, when you don’t know what to do and you
don’t have any obligations in that sense, then it comes up more. Or, let’s say, you’re
in bed and you can’t sleep. (…) And these are the moments in which it is (pause)
empty. (…). That is why it is empty. That is why it [the radio] plays; I switch it on in
the morning and in the evenings. After dinner, I switch it off, when the other [TV]
begins to talk. These are such things. Well yes, what happens too is: hard are those
days I don’t have to go somewhere or when the weather is so bad that I think: “No,
there is no use in going outside”. I don’t like it either. On such days, you chew on it
much more. (…) These are such moments, when you rummage through things.

For some widow/ers, special times in the day or week were particularly difficult.
Evenings and Sundays were moments in time during which widow/ers regularly felt
very alone; these were those times in a day and in a week that used to be distinct
couple or family times. Isabelle Patterson, for example, explained (P16: 576 / 632)

You don’t have a purpose, right? On Saturday evening, you think: „Oh, you would
like to make a tea, or would you?“. For you alone, it’s a bit odd, right? (…). And she
[Isabelle’s mother] had the church real close; it’s not far from here too. And she did
not stand Saturday evenings at all, when the church bell rang to welcome Sunday.
And it happened to me; I was in the garden last Saturday, and it hit me; me too.

Particular activities within a day during which the spouses’ absence arose painfully
were also challenging. Alice Ford, for instance, found those moments difficult in
which she had nobody to talk to and during which she started to act as if her
husband were still alive, only to realize he was not (P25: 169):

Well, recently there was a football game on TV, Poland against who I don’t know
anymore. I was in the kitchen and heard: „Oh, they scored a goal“, and I called:
 „Alfie, who scored? Who scored the goal?“ and then I realized that he is not here.
And there are so many things which I (cries, pause). I don’t know. I have to say it
frankly. I hadn’t expected it to be so hard (trembling voice).

By the time of the interview, most widow/ers had recreated situations during which
they felt alright. For example, Henry Brown, about two years following his wife’s
death, felt that he was still suffering, but that he had gained some distance, and that
there was more logic behind his wife’s death (P8: 50 / 68-70).

Henry: I still suffer. That’s; well yesterday, I saw very clearly in front of my eyes
when my wife did not breathe anymore, when I held her, this very moment…. Well,
what I can say is that, for instance, when I drive to my daughter, I drive by the [name
of the clinic where his wife died] (…). Today, I can drive by without problems. But
before, whenever I drove home and I could see it from afar, I had an awful time. That
subsided and today, I can drive by it normally without that I have to think about, or
that tears well up: It is a fact. (…)

Interv: (…) How is it different now compared to the early time?

Henry: There is more logic behind it. Do you understand; it is a fact that you have to
accept and it doesn’t help you anything. You have to pull yourself together and say:
“Yes, I do go there, it will be nice”. (…) That you take this part and enjoy it. Or that
you can laugh out loud once in a while. (…) So I have to admit: Yup, there is
something positive.

The passing of time, therefore, created more and more moments in time without the
deceased that demonstrated to widow/ers that they were, overall, doing fine.


Summary of sub-notion: Families gave manifold examples and described vividly the manner through which they connected to share their loss, as well as how they remained disconnected in their struggle to live with the pain of loss in their individual lives. Connecting-disconnecting unfolded over time during various moments of family community and aloneness. Sharing-not sharing manifested itself as an oscillating family pattern that unfolded in various family moments. Connecting was enacted through convening around the dead, talking about the loss, taking note about how other members in the family were doing, spending time to alleviate aloneness, enacting presence to find solace, and remembering the deceased to honour their place within their family. Disconnecting was either enacted through a conscious decision, or simply occurred as aloneness threw members, in particular widow/ers, into a sea of pain and longing.

6.2.3. Synthesis of the second thematic meaning notion: Sharing-not sharing a world through focusing on the now with loss

The thematic meaning notion of sharing-not sharing captures the way families interpreted and lived with their loss communally or separately. Sharing-not sharing manifested as converging or diverging and concerned families’ interpretation of the loss as painful emptiness, contentment, or relief. In families who converged in their sense of loss, similar features had shaped the individual relationships with the deceased. In contrast, in those families who diverged in their sense of loss, individual members had held a distinct dyadic relationship with the deceased.

Sharing-not sharing further presented as connecting-disconnecting, which unfolded within pre-existing family caring relationships. Families who were involved in their day-to-day lives had more opportunities to share than those whose relationships were looser; that is, who felt less close or who were less involved with each other. However, families’ need to share differed. Those members who did not miss their close other and whose sense of loss was such that it had not painfully disrupted their lives experienced more time during which they were simply doing fine, than did those who were pained by their loss. Family members also made decisions about sharing. Sometimes, sharing simply happened as families reached out to each other to provide, or find comfort upon seeing one member sad or upset. In other moments, they concealed their upset or sadness and refrained from sharing out of concern, and to not burden the other.
Family sharing unfolded over time. The early time around and immediately following the death, and traditional family gatherings were moments during which families always connected. While the interpretation of their loss was enduring, with the passing of time, participants instinctively learnt to live with their loss. The many moments during which families experienced the healing potential of sharing, or individual members their ability to push through difficult moments alone built up a capacity that provided them with a confidence for their future life without the deceased, both as a family and as individuals.

Family sharing disclosed itself as a nuanced, embodied caring practice, which encompassed families’ concerned caring (Fürsorge - solicitude) for each other; that is, their particular ways of being-with in bereavement (Heidegger, 1926/2001). Families enacted authentic moments of being-near (sein-bei). When families connected in a way that expressed their caring commitment, they created comfort and belonging and created a place in their world in which they could be open to each other’s situation (opening-up, moments of connecting). Families also concealed moments of loss and did not craft connecting as openness to each other with every opportunity that presented itself, which denoted missed opportunities of caring for each (closing-down; moments of disconnecting) (Heidegger, 1926/2001).

Not every moment could be shared as a family. Some moments of loss eschewed concerned sharing, or being-with, and denoted moments of existential aloneness. Such moments forced participants to face their own existence as inescapably their own. Moments of disconnected aloneness were non-sharable because they were about the “something” in their existence as human beings that persons have to face alone. This “something”, according to Heidegger, is “das eigenste Seinskönnen” (p. 263), persons’ utmost and own-most ability-to-be self.

In summary, the meaning notion of sharing-not sharing their loss captures families’ interpretations of the loss, which were shared in some families, but not in others. It also portrays families’ way of relating to each other by being-with through concerned caring, while highlighting that some moments are consciously not shared or are inherently non-sharable, which are those moments in which one is thrown back onto one’s very own existence. Sharing-not sharing was therefore constituted by families’ interpretation of the loss, their caring comportment towards each other, and the non-sharability of the inherent moments of existential aloneness in life.
6.3. Continuing or reconstructing family life following the loss (third thematic notion)

Continuing or reconstructing family life following the loss captures families’ situation without the deceased, their specific concerns, ways of involvement, and sense of closeness. It focuses on family life; that is, how families moved forward. The theme evolved from families’ examples of family life, interactive talk-in-action during interviews, and their descriptions of continuity and change in living family. Continuing and reconstructing are two distinct family patterns of transition. In the family pattern of continuing, death did not overthrow the taken-for-granted ways of living family. Rather, it was a conclusion to a long history of increasing distance and emotional disentanglement. Even so, because families shared their world with someone less, some of their practical involvements shifted. Another pattern arose as change and reconstructing. For these families, death was an event that disrupted taken-for-granted ways of living family, and required them to re-figure their doing. Practical involvements changed because of their new situation of and concerns around widowhood and later life, but also because the death meant that their lives had become more intertwined.

Table 21: Sub-themes related to family life

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<th>Main notion</th>
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<td>Sub-notions</td>
<td>Reverberations of deceased’s absence in family life.</td>
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<td>Family matters around widowhood and later life.</td>
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<td></td>
<td>Doing family through involvements in daily life.</td>
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<td></td>
<td>Being family through closeness / belonging.</td>
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Continuing and reconstructing showed up in different areas of family life (Table 21). First, it manifested itself in relation to the reverberations that the deceased’s absence left. Second, it pertained to matters related to living alone and having a widowed parent in later life, respectively. Third, it showed up in families’ concrete involvements in daily life, their doing of family. And lastly, it concerned families’ sense of closeness or belonging, their being of family.

6.3.1. Reverberations of deceased’s absence in family life (first sub-notion)

Continuing versus reconstructing family life were patterns that showed up in the reverberations that the deceased’s absence had on families’ lives. Families’ commotion was constituted by the legacy the deceased had left behind. It revealed itself in the manner in which families had to get by in daily life without the
deceased’s partaking in their family interactions, which had for some families little repercussions, but entailed turmoil and upheaval for others. While for some of these families, the nature of their upset was immediately clear because if evolved around the loss per se, for others the bearings that their close other’s balancing or anchoring presence had on their family life revealed itself only over time as they saw their family interactions become unsettled (ID 1, 4, 7, 8, 9, 10). In contrast, for others, the death ended restrictions of some sort in their family life (ID 2, 3, 5, 6). Because these families had already created a family life somewhat independent of their close other during his or her lifetime, they simply continued with their family life and encountered only minor shifts. Families, in continuing or reconstructing, created a new normalcy in moving forward as a family (Table 22).

Table 22: Examples of participants’ situation of family life following the loss

<table>
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<th>Family pattern: Continuing with family life</th>
<th>Moving to a new normalcy</th>
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<td>Little repercussions</td>
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<tr>
<td>Brown family (ID 02): Learning to live family while close other suffered from Alzheimer; loss of person while still alive.</td>
<td>Coming to terms with a difficult caregiving time.</td>
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<tr>
<td>Fisher family (ID 05): Living family circled around close other; death disburdened family life from constant worrying around debilitating physical and mental illness, ending a strained marriage.</td>
<td>Coming to terms with a strenuous caregiving time.</td>
</tr>
<tr>
<td>Gibson family (ID 03): Living family that circumvented, but included the now deceased; managing without deceased already during his life time.</td>
<td>Simply continuing and enjoying freedom.</td>
</tr>
<tr>
<td>Graham family (ID 06): Living family without depending on, but encompassing the close other while still alive; managing life alone despite being married.</td>
<td>Breaking silences around deceased’s life.</td>
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<tr>
<th>Family pattern: Reconstructing family life</th>
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<td>Turmoil around loss</td>
<td></td>
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<tr>
<td>Ferro family (ID 10): Sudden, shocking void.</td>
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</tr>
<tr>
<td>Patterson family (ID 07): Glaring, paralyzing emptiness, utterly changed and raw world of being a family.</td>
<td>Striving to uphold family life.</td>
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<td>Mendes family (ID 09): Abounding emptiness, painfully felt vacancy in family life.</td>
<td>Filling emptiness with memories and inviting deceased back in.</td>
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<tr>
<th>Unsettled family interactions</th>
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<td>Clarke family (ID 01): Having different views about the amount of support needed by widower; having to deal with ensuing new discord among siblings around extent of involvement.</td>
<td>Working alongside to address concerns around living arrangement and assistance.</td>
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<tr>
<td>Ford family (ID 08): Figuring out imbalance and how to best deal with it; making out, understand, and respect widow’s actions and concerns and what they stand for, generational differences, and different ways to deal with upheaval.</td>
<td>Working together to address concerns around living arrangement and assistance.</td>
</tr>
<tr>
<td>Richard family (ID 04): Having different and fixed ideas and expectations about family member’s roles and actions; having to deal with a long-standing discord among siblings.</td>
<td>Working alongside to address concern around assistance.</td>
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**Unsettling reverberations:** Family upheaval occurred in two ways. First, families encountered turmoil around their loss. For these families, their ways of living family was unsettled from the moment the death occurred, and a painful or shocking void was opened up amidst their family ranks (ID 7, 9, 10). For instance, the Ferro family, who had lost their close other to a sudden, unexpected death, struggled with an utter incomprehensibility of what had happened within their family, as Marlene and her father explained (P30: 281-305):

Marlene: Well, you do have these moments when you think again and again: I still can’t // believe it, somehow. //</p>
Louis: // I think that will never go away completely. //</p>
Marlene: Well, you accept it, you learn to accept it: That’s how it is and that this is basically normal. (…)
Interv: But when you say that you learn to accept it. How do you learn to accept it?
Marlene: Well, how do you learn that (questioning tone)?
Louis: Well, because you know that you can’t do; that it’s beyond your power.
Marlene: That you can’t change it.
Louis: You don’t have any influence on it and that’s why it is one of these things you simply have to accept: “That’s how it is”. Even though it should not be that way, but it is like this anyway. There are many things in life that are like this, but with death it is really extreme. When someone leaves you so unexpectedly, right?
Marlene: Yes, right, because you can’t change it. You can’t go back, can you?

Learning to accept the death as an unchangeable fact helped the Ferro family to find a way to move forward as a family. Also the Patterson family, although feeling their close other’s absence painfully whenever they interacted, attempted to continue their family life as before. Nonetheless, the death of their close other left those families broken and incomplete. They needed to face the painful absence of their loved other, learn to take it as their new reality, and to find and create new connections with the deceased without his or her living presence. As Edith Mendes found (P22: 555): *Yes, we do miss him of course. But it has to continue (cries, short pause). (…) But overall; we do know that he is with us. That we all know. And this helps to bear it*. For these families, therefore, going back to a new normalcy in family life encompassed creating a space to honour and to remember the deceased while upholding their family interactions.

Other families faced upheaval within their family interactions, which became visible for them only over time (ID 1, 4, 8). Families’ upheaval arose because their close other was no longer embodying a particular presence within their family. At the centre of families’ unsettled interactions were their (different) views and ideas around making family life work without the deceased, and each member’s part in it. For example, the Ford family came to realize over time that Alfie’s enduring absence had brought about an imbalance within their family. Alfie used to be the quiet parent
within the family, and his calmness denoted a counterweight to Alice’s temperament, and balanced family life out. The Ford family’s disbalance following Alfie’s death included the legal ramifications for the house ownership, and the best manner to support Alice. The children Sara, Kirstin, and Sebastian tried to spend time with their mother and to help her, yet they also needed to figure out what would indeed be the best thing to do, also for them individually, and workable in the overall context of their lives (P17: 1057-1072):

**Sebastian:** We made again a plan because we thought that would take care of the matter; and Mom would know when someone is coming, that was the issue.

**Alice:** Well, I would say it was not really the work. I // was simply glad if they came right, and //

**Interv:** // That you would not be alone. //

**Sebastian:** // Yes and then // it was indeed so that after everything; I would say after this extreme time during which our employers; during which we all had employers who were very generous; it happened from time to time that we had to cancel something, or that we did not; well, we had to find - I would say that is entirely normal - find out a bit what is actually feasible. In the first emotionality you have this feeling that you plan for the entire year.

**Kirstin:** Or also // to make out a bit. //

**Sebastian:** // To make out // that it does not work out at all, and sometimes, you have to cancel things.

**Kirstin:** Or sometimes you remain stuck at the table and you talk and you go back home // and did not do the work, right. //

**Sebastian:** // You thought you would mow the lawn, right and //

**Kirstin:** And wanting to do both, the social and the work did not work out at all.

Supporting Alice also required the family to find out what their mother’s concerns and actions stood for, and to make decisions about their individual contributions. Alice was caught up in her emotional upset and existential fears, her urgency to make repairs to the house, considerations about moving out into a flat, and managing financially throughout everything. What was difficult for the children was that every discussion around the house and Alice’s living arrangement “veered off onto an emotional track” (Sebastian, P28: 44). Alice, in contrast, felt that her children did not take up some of her pressing concerns, and that they did not understand the challenges she faced in taking care of the house. For example, when Alice complained about the amount of work it took to maintain the house and the garden, her children suggested that she employs a cleaning lady and a gardener. For Alice, these suggestions were unhelpful because she felt they were beyond her financial means. Over the first year, the family was constantly trying to figure out not only what was happening to and in their family, but also how to balance out their family life anew (P17: 1198 - 1214):
Sebastian: And I realize that it spills over to me a bit, when I realize that I have to take over to a certain extent. For a while, I did not take her; and I do feel sorry (to Alice): I think I never told you this, (back to interviewer) like not taken her seriously when she came with all her things. I was thinking: „Now it is the floor, then it is the garden, and then the attic“. This is; you need to learn again to find out those things that really bother her, well, like helping her to balance out. I am not Alfie, but in our own way. For instance, last week, I thought we did a great job.

Alice: Oh yes, and I was so glad to hear for the first time, you (Sebastian) were the one who recently said: // „Mom, I understand you. “ //

Sebastian: // Yes, and I feel sorry about this today, but sometimes, it is like, (to interviewer) can you imagine it? When it comes at you temperamental and you get a list of fifteen things, then you don’t recognize the five central things anymore and you wipe the whole thing away. Well, we had to find ourselves to- (…). It is now that this void comes up in everything, either with the balancing, being here for-. And he asked a question or showed a painting. That is what is missing, and we try to fill it up a bit.

Over time, the family not only came to understand Alice’s concerns and actions better, all four members also came to see some of their different views as an expression of generational differences. What helped the Fords to create a new normalcy in family life was that they respected their different views, acknowledged that they had non-reconcilable differences because of belonging to different generations, and found a way to be with their mother’s outburst and emotions by learning to understand what they stood for.

While the Ford family succeeded in integrating their differences and discords into their family life because they accepted different views and understood their upheaval as a part of how their family worked, for the Clarke family, their ensuing conflict was new and burdensome. Their disruption in family life happened around the siblings’ differing views and capacities around the extent of support and involvement that their father needed, in particular around finding a new place to live for him. Gerard felt left alone by his sister (P2: 486-490 / 721):

Gerard: The whole thing is troublesome. And now, we’ll have to clear out the flat and I know exactly that it will be up to me; my wife does help of course. We basically do everything. Laundry, finances – my wife does – health insurance, physician appointments and all that, and I do the rest.

George: Well yes, she [daughter] just doesn’t do anything like this. (…..)

Gerard: It doesn’t help when she [sister] calls me up and asks how I am doing. I don’t need a helpline. I need someone who gets her hands dirty. I don’t need calls of understanding. This has overshadowed our relationship a bit. It has not been easy.

In contrast, Barbara found that her brother was doing more than necessary, and she felt unable to contribute more given that she went through divorce (P3: 719):

And, I had to say at times; my brother had a different approach with father and has passed on his expectations to me (widower smiles). And I’ve told him: “Let him do this, Dad can do this on his own”. I’ve kind of realized: I have to stand up. But also acknowledge what he does do. I have increasingly done so. I have escaped this all a bit, because I could not, really. (…) He has done so much, incredibly really, and still does do a lot, (to her father) does he not, still?
Bertha Clarke’s death had left her family struggling in rearranging their caring involvements. Thus, for these families, the absence of their close other brought about a need to re-shuffle their interactions and practices to establish a new normalcy in family life. They had lost a member whose presence in family life was appreciated and who had played a vital role in grounding the families’ way of interacting and doing things together. Moving to a new normalcy evolved around finding new ways of anchoring and balancing, which involved re-learning how to interact most meaningfully in doing family, and how to best handle the concerns and discords that arose to families’ attention.

**Little repercussions:** For other families, their family life did not become unraveled following the death because they had created their family life separately from their close other while s/he was still alive (ID 2, 3, 5, 6). Albeit their close other used to be part of family activities, they were less central to family life due to the confining presence that their disabling illness had brought about. Rather, the death ended restrictions in family life, and enabled families to address issues they had not been able to talk about previously. In the Fisher and Brown families, debilitating illness had overshadowed and limited their family lives, and had filled it with suffering. For the Fisher’s, their close other’s debilitating and multiple illnesses had required them to give up a “normal” family life early on. Elizabeth’s death had made the family’s considerations unnecessary after decades of relentless concern. Instead of disrupting their family life, it simply shifted from focusing and circling around their ill member to focusing on the widower Marcus and enjoying their time together. Nonetheless, the death of their close other left families with a need to talk about the strenuous caregiving time. For example, Victoria Brown found a way to talk with her father about the tensions she had experienced seeing the caregiving situation, and the different ways she would have liked it to happen. However, Victoria and her father did not only talk about their differing views and tensions, but also about the haunting memories that their close other’s Alzheimer’s disease had left behind.

While for some families, strenuous caregiving was at the forefront, others had a need to talk about their close other’s difficult life or peculiar character. The Graham family broke some silences around their close other’s past and life-long anxiety, which the deceased had upheld while alive. For these families, the death of their close other had little repercussions because they had already created family interactions that existed independent of the deceased. Nonetheless, the deceased’s difficult legacy that was brought about by illness, silences, or peculiarities reverberated within families in a way that instilled a need for families to talk about it.
**Summary of sub-notion:** All families strived to move forward together in light of their new configuration and situation as a family. What was evident in the data was that the deceased’s absence reverberated in families’ lives in different ways. While for some families, it had little repercussions beyond a need to come to terms with potentially haunting memories of a difficult illness time, or of conflictual and silenced issues of their past family life, other families saw their taken-for-granted family life unravel. These families encountered upheaval in their family interactions because of the painful void or the absence of their close other’s embodied presence that had anchored and balanced family life. For these families, their communal life as a family required conscious attention to make out the magnitude of disruption that their family lives had succumbed to.

6. 3. 2. **Family matters around widowhood and later life** (second sub-notion)

Continuing versus reconstructing family life were patterns that further unfolded in family matters related to widowhood and later life (Table 21, p. 149). Although all families encountered a new, unfamiliar situation of family caring with only one surviving member of the oldest generation within the nucleus of their family, it was for some a situation of reassurance and for others one of concern. Some families felt reassured upon seeing their widowed member’s ability to live alone. In contrast, other families were concerned, at least for part of the time, about their widowed member’s ability to manage alone due to health limitations or feelings of being overwhelmed. Widow/ers felt reassured about their children’s availability, but in some families, widow/ers wished for more practical or reliable partaking of their children in their lives.

**Reassured:** Families of widow/ers who were self-reliant and well able to manage their household without outside help appreciated that they did not have to worry about their widowed member (ID 2, 3, 5, 6, 9, 10), as one daughter, Sophie Mendes explained (P27: 714): “It is of course a good thing, naturally, it relieves a lot”. Even though some of these widow/ers had health issues, such as bronchiectasis, Parkinson’s disease or arthritis (2PM, 5PM, 6PW), and felt a reduced stamina due to their advanced age (5PM, 6PW), they were relatively fit and led active lives, which included physical activities like skiing, playing tennis, cycling, walking, visiting friends and colleagues, taking a day trip or going on a holiday. Family members appreciated enormously that they could be free of added worries, as Emma Gibson, another daughter explained (P11: 83):
She is still so fit and independent and you don’t have to drop by, quasi: „I must go to see my mother“. It is not like that at all. She rather comes here, or she is, because she is so active, I am basically glad that she is still so fit, because, yes, mh.

Alike Emma, who did not worry about her mother because she saw how active and independent she was, Susan and her daughter Charlotte Graham also knew that they had no reason to worry about their (grand-)mother Ida, because she had always looked after herself (P29: 423):

She organized herself a good bit already before. And … (reflects) very self-sufficient. Yes, and basically [she] had always had a certain self-sufficiency, that’s the point. She embodied that, you had that sense with her, that she will manage. Well, we don’t have to worry, we know she is managing.

When death was preceded by strenuous caregiving, the new situation could even be one of less worry, as Victoria Brown maintained (P6: 939): “What is, of course, is: I am much more at ease. I don’t have to think: There will be a phone call and they are both lying on the floor“. Family members, for various reasons, did not worry about their widowed member living alone, even though they did care about their wellbeing and provided practical help when necessary.

Widow/ers in these families felt also reassured upon seeing their self-reliance and their children’s availability. Widowed men in particularly stressed that they could maintain their single household alone, which filled them with confidence, as Marcus Fisher illustrated (P23: 275): „And well, as far as moving on alone is concerned, that is essentially no problem, or no problem I could not overcome“. While managing a household was new for widowed men, it was not for widowed women. Widow’s self-reliance was not a matter of reflection in relation to their practical ability, but in relation to their physical stamina, as Ida Graham explained (P34: 221):

And what I really notice is that I have to pace myself. (…). I’ve figured out that I can’t do more than two things each day, better only one. So that I don’t, that I don’t need two or three days to simply-. Because from time to time I do have quite some pain and that gets at me. And now, maybe 14 days ago I fell so stupidly, and had some problems with that. You don’t see a lot anymore (laughs); I had all colours.

The fact that widows were able to take care of strenuous household work despite their health concerns filled them with a sense of satisfaction. Nonetheless, widow/ers could and did ask their family members for help for the occasional household tasks. In these families, widow/ers felt content with the support they received, and the partaking of their family members in their daily lives. Even though some of the widow/ers (2PM, 3PW, 6PW, 10PM) noted that they did not see their sons often since they were busy working, which served as a justification for their absence, they nonetheless felt that their children’s practical involvement in their life was just fine; they got what they needed, and did not expect more.
Concerned: Families of widow/ers who had needs related to their health limitations (ID 1, 7), or in relation to managing alone in daily life (ID 4, 8) were concerned and worried, whereas the widow/ers themselves felt either very embedded in their family (1PM, 7PW) or wished for more immediate and reliable availability of (parts) of their children (4PW, 8PW). For example, Rosa Richard took care of her household alone, but she felt overwhelmed with everything written, and relied on different family members to manage correspondence, financial matters, and dealings with the authorities or the bank. Rosa turned most often to her daughter. Stella, however, not only felt overwhelmed in those situations in which her mother was emotionally swamped, but also strained by the fact that it was her job within the family (P20: 97):

Or then, like this time around before I came [to visit her] this weekend: “Oh no! These bank statements”. She would like this, and she would like that and I know I have to do it. And yes, well, when she cries a lot, then I don’t have the strength anymore, yes. And Dad used to be here for her in such situations; she is like overwel-, well, it is too much for her and she knows that my brother doesn’t help a bit. Everything falls to me. And in those situations in which I am not well myself, it gets at me. Then I let her cry on the phone and when I have hung up, I cry myself don’t I because I don’t want in front of her. Well, it has happened that I did, when I told her: “You know Mom, it is a lot for me too, I don’t have the strength anymore, at one point it is too much.” She dumps everything on me, well yes, before you dumped everything on him (laughs), now it is on me.

Families thus worried sometimes, although they also saw and commended their widowed member's strength and determination, which was also reassuring to them.

Widow/ers in these families felt either meaningfully embedded in their families, or wished for a more immediate, reliable availability of their children. Isabelle Patterson, whose son continued to live in the same house, and whose daughters lived in the same neighbourhood, appreciated her children’s practical involvement (P39: 65): “We are close, simply close, right? And you drop by quickly to have a look, to see how the other is doing, right?” In contrast, some widow/ers had unmet needs. They felt that the help was not forthcoming in a way that was useful for them or they did not feel cared for in an extent that they hoped or expected. Rosa Richard had experienced that her son had declined her requests for help (P13: 364-372):

Yes, I have a good understanding with him, well I mean we ring; they ring me, I ring them. In that way I can’t; yes of course I do rant sometimes about him and think, yes (laughs) (...) When I do ask at a time that I should have this and that: „We don’t have time, we have.” and then I don’t ask anymore.

Based on such encounters, Rosa felt that she could not rely on her son. Some families, therefore, were concerned about their widowed member’s ability to manage alone, both practically or emotionally, and some of the widow/ers wished for a more immediate availability of their children.
**Summary of sub-notion:** Participants, in moving forward with their family lives, faced new matters that showed up because of widowhood in later life that either meant a reassured continuing, or a concerned reconstituting of family life. A majority of families appreciated the widow/ers’ ability to manage alone, and widow/ers felt reassured by their families’ practical availability. However, *reassurance* was not the prevailing sense of family caring for all participants. Due to health concerns that impacted on widow/ers’ ability to live alone or situations in daily life in which widow/ers felt swamped or emotionally upset and missed their children’s immediate availability, some families were rather *concerned* and worried.

6. 3. 3. **Doing family through involvements in daily life** (third sub-notion)

Continuing versus reconstructing family life were family patterns that pertained to families’ practical involvements in daily life (Table 21, p. 149). Families continued with their habitual ways of doing family in daily life, but some families also created new manners of involvement (Table 23). Most families spoke about their practical involvements as more intense in terms of frequency and the time it needed (ID 1, 4, 7, 8, 9, 10), although it was not as discernible for all families, in particular when their lives were very entangled. These families started to see each other more often to provide support with practical issues and tasks. For some families, however their practical family involvements did not change (ID 3, 5, 6) or became less intense because the need to provide care had ended with the death (ID 2).

**Table 23: Family doing through practical involvements**

<table>
<thead>
<tr>
<th>Shifts in family doing</th>
<th>Family practices</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Continuing with practical involvements</strong></td>
<td>Getting together as a family&lt;br&gt;Visiting&lt;br&gt;Going on long weekends or holidays together</td>
</tr>
<tr>
<td><strong>Intensifying-rekindling practical involvements</strong></td>
<td>Ringing each other&lt;br&gt;Dropping by, visiting, and inviting&lt;br&gt;Looking after grandchildren&lt;br&gt;Spending time to enjoy each other</td>
</tr>
<tr>
<td><strong>Creating new practical involvements</strong> (taking over, changing patterns, initiating)</td>
<td>Helping in new ways&lt;br&gt;Consulting&lt;br&gt;Interacting without detour&lt;br&gt;Meeting in new manners</td>
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</tbody>
</table>
**Continuing with practical involvements:** All families unquestioningly continued with their valued involvements after the death. Such continued family practices included traditional family get-togethers, but also mundane occasions to enjoy each other’s company, such as visiting each other to have lunch or dinner together (ID 1, 3, 7, 8, 9). Families also continued to go on holidays together (ID 7, 8, 9) or met up in the family cottage for a few days (ID 1, 2, 7, 9), just as they had always done. Such established family practices were not changed by a family death.

**Intensifying-rekindling practical involvements:** Families engaged in some established practices more often because they felt it necessary, or needed in their bereavement situation. These caring involvements were primarily aimed at the widow/ers. For instance, families started to ring each other up more often to inquire how the widow/er was doing and / or to tell each other what was happening in their daily lives (ID 1, 2, 4, 7). Family members dropped by, visited, or invited the widow/er more often than before the death (ID 4, 5, 7, 8, 9). Through these intensified phone interactions and face-to-face encounters, families expressed their caring interest in widow/ers’ wellbeing and enacted family community.

Families who had gone through a period of caregiving took up practices that had been interrupted by caregiving. Widows became active again and looked after their younger grandchildren or great-grandchildren, not only to enjoy their company but also to support their children in their family – work arrangements. Families also appreciated that they could now spend time together without having to worry, to simply enjoy each other’s company and to undertake little tours and outings (ID 1, 5, 6, 8). Hence, some family practices were rekindled following the death.

**Creating new practical involvements:** Following the death, families also created new involvements to enact family caring in a way that fitted the new circumstances, but also to establish a new normalcy. These practices were not entirely new; rather, they were modified in the manner in which they took place.

**Helping in new ways:** Families helped each other with various issues and tasks associated with living alone. While helping per se was not a new family practice, the reason for and manner through which families helped was new. For example, in some families, one family member took over from the deceased (ID 1, 4, 7) or helped the widow (ID 8) with financial management, which had not been necessary before the death. Although most widow/ers managed their household alone, family members nonetheless started to help with particular tasks with which they had not
been previously involved, like doing the laundry (ID 1), cleaning the windows (ID 3), mowing the lawn (ID 8), fixing technical equipment (ID 1, 6, 8), shopping for beverages (ID 4), bringing cooked food (ID 4), or giving advice about household management (ID 10). Family members also assisted widow/ers to run errands, like buying new glasses (ID 1) or a printer (ID 8). In two families (ID 3, 6), however, the widow was the person who helped her family members, for instance by running errands or ironing. One widow held caring responsibilities for her adult son with a learning disability, and while he was not living with her, she took care of all practical matters, like, for example, buying, labelling and altering his clothes.

Consulting: Following the death, widow/ers started to involve their children in decision-making, or asked for advice before making a decision in a way they would not have if their spouses were still alive (ID 1, 2, 4, 5, 8). Nonetheless, families felt that this was also an expression of being old, and not necessarily of being widowed per se. For example, Henry Brown asked his children for advice when he wanted to buy a new car, and Alice Ford asked her children for their opinion about her living arrangement in a house that required fixing. Some family members started to take over the role of looking after from their deceased parent, in particular around health issues, and talked with and advised their parents (ID 1, 5, 7).

Interacting without detour: While ringing each other up was an intensified practice for some families, for others, it denoted a new kind of practical involvement because it happened within new dyads. Those husband and daughters who lost their wives and mothers, respectively, suddenly found themselves talking on the phone (ID 2, 5, 10). In those families, the daughters had virtually never talked with their fathers on the phone. Connecting with each other without detour via the deceased was thus a new and gendered family practice.

Meeting in new manners: Families recreated the ways they met and saw each other (ID 1, 2, 3, 8). For example, widow/ers started to drop by unannounced at their family members’ homes or offices. When George Clarke was walking across town in the afternoons, he went to see if his grandson was home, or dropped by at his son’s house. Ona Gibson, when out shopping in the city, always went to see her niece, who worked in a store. Henry Brown also showed up unannounced at his son’s office from time to time to have a coffee with him. Such unannounced, spontaneous visits were a way for widow/ers to stay involved. Families also got together or phoned each other with the purpose to coordinate and organize their support. The Ford family, for example, made a plan and assigned responsibilities to members. Thus, not only the manner, but also the purposes of families’ meetings shifted.
**Summary of sub-notion:** Families moved forward in doing family in light of the specific needs that arose from their distinct situation as a bereaved family. Doing family through concrete involvements *continued* in its established, habitual manner for many families, but it also *increased* for others. Shifts in family involvements occurred in the kind of help families gave to each other in daily life, in their manner of interacting (more directly), and how they consulted and gave advise, also in relation to widow/ers’ health. In those families with an increased practical involvement, individual lives became more entangled and mixed up around supporting their widowed member, as Barbara Clarke explained (P3: 699 / 703 / 707): “My brother and I, we are more in touch. (....) We don’t lead separate lives anymore. We have like dealings with each other because of this responsibility”. For participants, their doing of family arose as practical, caring involvements that potentially forged new alliances and intertwined family members in new ways.

6. 3. 4. **Being family through sense of closeness / belonging** (fourth sub-notion)

Continuing versus reconstructing family life were family meaning patterns expressed in families’ sense of closeness or belonging (Table 21, p. 149). Families felt a strengthened closeness within dyads and took away new insights about their family belonging, whereas others experienced an unchanged degree of closeness.

**Strengthened sense of closeness / belonging:** The strengthening of families’ sense of being a family revealed itself in two ways. First, in moving forward as a family, dyads within families felt that they had grown closer together (ID 2, 4, 8, 10). Members within a family did not collectively feel closer, rather, they had grown closer with some, but not necessarily all members in their family. Sara Ford gave a vivid description of the way she came about to feel closer with her sister Kirstin through caring for their widowed mother (P37: 192 / 196):

> The closeness with Kirstin came about because my mother had (....) reacted very strongly and Kirstin looked after her a lot. She lives close to her and can drop by quickly. And I also did a lot with her and somehow we were able to, to look at the difficult things that come up in such situations, and put it into a perspective. And since we do this, we are much better. (....) And then we talk about this, that Kirstin does take part and I don’t, and what this is like when she does take part and it is never enough. And then we get into this good place without having to change anything. Well, it is just doing so much good, without that we have to rant about Alice nor that we have to unite against her, but it is more like: “Aha, exactly, I do certain things but I simply have to be aware that once this is done, the next thing will follow and then--; it will not stop and when I am willing to do this then it is okay”. And I say: “I don’t do this because basically, it is about something else and I choose to rather do something with her”. And that just does us good.
Closeness arose for family dyads because they started to turn to each other in their new family situation, for instance, through talking about the challenges, or by being available to each other, as Rosa Richard explained about her relationships with Maria, her sister-in-law (P19: 209):

Yes, she is simply a person to turn to for me, right. Just yesterday she came by again and brought me some soup that her husband had made. And (...) she rings me up at least once a week and says: „You can tell me if I can help you with something“. Right, she is such a good person. I can’t stress that enough.

Maria and Rosa’s moving closer arose from the backdrop of a long history of sharing daily life, as expressed by their habit of doing each other’s hair once a week over 50 years. Living through caregiving and bereavement together has made their already committed relationship even more important and intense. An increased sense of closeness arose for family dyads through the practical involvements they had with each other because of their new family situation.

Second, families also gained from their experience of the death and bereavement an insight about their sense of belonging, as Louis Ferro explained: (P35: 120 / 250): “Well of course, you did see our connection, that [it] was real, right (...) What I discovered was that we don’t have any problems as a family, because we are simply in contact, and each one can say what he wants”. While the Ferro family learnt that their family ties did indeed work, the Ford family gave an example of the confidence that a family can take away from their shared experience of witnessing death and living through bereavement: (P17: 1596-1610).

Sebastian: And what I appreciate extremely, well, I knew it before but it was confirmed once more. And that is the beauty about Alfie’s death, you know, that we function as a clan. We did come extremely close during that time of end of life care, and even now with the worries around mother, and laughing with mother, that //
Alice: // I believe // that is why he was so calm // because he- //
Sebastian: // Yes, but also now // that is why I am so calm too, now that he is gone. You know, this knowledge that no matter what happens, my sisters and alike, they are simply, they show up and that has something extremely reassuring. (...) That gives you real confidence.
Kirstin: Yes it does.

The Ford siblings felt that although they were not closely involved in their daily lives, they were left with an insight that was revelatory and confirmatory about their sense of being a family. While the Ford family gave an example of a positive, strengthened sense of belonging that brought about a confidence and new, immediate sense of closeness, the Richard family, and in particular Stella, became disenchanted as she realized that her family could not even pull it together in such a difficult moment as a family death, as she explained together with her mother Rosa (P13: 221 – 229):
Stella: Well what I was tremendously disturbed by was, ehm, when he died, afterwards, our family ties. I have a brother and occasionally, it was like (clashes fists). He did, [name of brother] did not accept anything from me, nothing at all and I got into a rage, simply because he said so and so and such and such, and then I said: „No, I would like to have this a bit differently”, also with the death notice and with everything else, really.

Rosa: Or with the minister // that we- //

Stella: // He simply- //

Rosa: When we had the meeting.

Stella: The little sister had nothing to say; that is how it happened. That was very negative for me.

Stella felt as distant and at odds with her brother as she used to, and her hopes that the death of their father would bring about some agreement evaporated already in the early days following the death. Families’ insight about their sense of belonging was therefore not always positive.

**Unchanged sense of closeness:** Families whose sense of closeness remained unchanged through the death had always been a closely knitted family who interacted on a daily or weekly basis (ID 1, 7, 9). For them, no change was discernible. Other families continued in their rather loose, spontaneous and more sporadic way of interacting (ID 3, 5, 6) because the death did not constitute a moment in their family lives that brought about turmoil or upheaval. However, because families’ sense of closeness unfolded within dyads, it was not always the same for each family member. In the Graham family, for example Charlotte felt that through the shared experience of losing her grandfather, she moved close to her grandmother and her cousin, while her mother felt that things remained unchanged.

**Summary of sub-notion:** In moving forward as a family, families’ sense of closeness or belonging was an essential unifying element and expression of their long-standing caring commitment. Families’ perception of being a family was an enduring idea that had unfolded over decades. The data revealed, however, that the experience of witnessing a family death could bring families closer together, or had the potential to provide them with new or confirming insights about the nature of their family. While dyads within some families felt strengthened in their closeness and / or belonging through turning to each other in their bereavement situation and caring for their widowed family member, other families found that their sense of closeness remained unchanged.
6. 3. 5. Synthesis of the third thematic meaning notion: Sharing a world through moving forward as a family

The elucidated thematic notion of *continuing or reconstructing family life following the loss* illustrates the different bearings that the death of a close other unfolded in families’ lives. Continuing and reconstructing arose as two distinct family patterns that depict what happens in families’ collective lives following a family death, and in particular a death of a member of the oldest generation that also ends an intimate partnership of a couple and the twosome unit of parenthood within families. Although these two family patterns are not mutually exclusive, nor pure in their manifestations in family participants, they give shape to the twofold variations that existed for families as they moved forward with their collective lives.

Obtained data showed that for some families, their life-world became a changed one as the abounding absence of their close other stripped away their inherently understood and meaningful way to be and act as a family. Families’ everyday familiar world withdrew or collapsed into total alienation when the close other’s absence was such that it had taken away their presumed and smooth being and doing of family. The deceased’s absence took away families’ absorbed way of living family. It released angst, a term used by Heidegger (1926/2001) to describe how an openness to the world is created that leaves families without a graspable possibility to be in it. This radical moment of undetermined openness to be and do family created an opportunity for families to reconstruct their family life in new, more authentic, that is, their own way. In reconstructing, a new way of living family (the doing of) was created by participants, and a new, albeit situated truth about their family (the being of) was revealed. The withdrawing of the world became manifest in families as turmoil and unsettled family interactions, an initial inability to make sense of member’s actions and comportments, a perplexity and at times an almost paralyzing-being-lost in what to do with and in this new family situation, and a struggle to grasp what was at stake for the family.

However, the close other’s absence in families’ lived world did not take away everyday familiarity and being-at-home as a family when participants had faced the deceased’s absence already during his or her lifetime. These families experienced little disturbance and only minor changes. The manner that family life unfolded following the death for some participants in this study suggests that families’ life-worlds do not only collapse following a death, but for whatever reason that can, and does transform a close other’s presence as family member into an absence, such as illness or alienation, as some families in this study had experienced.
Families’ changed situation – that of a family with one person less – brought new matters to the forefront, and shifted families’ attention. Families found familiarity in keeping going with those things that had and still worked for them in the context of their relational whole, like the various ways in which families gathered together and looked after each other. Families also moved back into their absorbed and transparent way of relating in their family world by acting together over time, which created a new normalcy, and a new presumed situation as a family. This arose in this study as the doing of family through practical involvements. Families also remained put in anxious unfamiliarity to actualize their own-most potential to be family and to realize some truths about themselves. These new, albeit inherently provisional and situated truth revealed the kind of family they had become, and surfaced as the being of family through a sense of belonging and closeness.

In summary, the meaning notion of continuing or reconstructing family life captures families’ moving forward towards a new or continued everyday familiarity. Moving forward pertained to the unique concerns of later life, the concrete family involvements, and families’ sense of belonging. The close other’s absence brought about by death was for some alike a withdrawing of their meaningfully grasped and seemingly certain family world into openness and uncertainty, creating a potentiality to actualize their distinctively own ways of living and becoming family, and to realize some truths. Such insights enabled them to move forward in meaningful relations and concerned caring as a family in later life.

6.4. A world shared – a world apart: Families’ bereavement experience

In conclusion, this chapter detailed the interpretive findings of the living with loss study, which unfolded around the death, loss, and family life and were formulated into three interrelated thematic meaning notions. These thematic notions explicated distinct patterns that arose across families, including the family pattern of weaving the death into the family narrative, an oscillating family pattern of sharing-not sharing life with loss, and two distinct family patterns concerning family life, that of continuing, and that of reconstructing family life. This chapter elucidated families’ understandings and actions through which they made sense of and related to their lived world of loss.
Families' loss experience arose as a world shared, and a world apart. The shared family world involves families’ communal quest to give meaning to the death to encompass it into their collective past, their connecting in daily life with loss, and their doing and being of family in later life. A world apart entails the unique ramifications the death unfolded for each family generation, the divergences in interpretation and disconnections in daily life. Living with loss is thus a world shared by those who live family, but a world apart in which members live with their unique experience alone.
7. Discussion

What do bereaved families’ descriptions and narratives tell us?

This hermeneutic-phenomenological study is one of a few that investigates families’ experience after a close other has died. It is only a beginning to answer the call of many scholars for a more relational approach to bereavement (Bosticco and Thompson, 2005; Hayslip and Page, 2013; Rosenblatt, 2013; Thirsk and Moules, 2013). This interpretive study provides a unique and in-depth illustration of families’ lived world without their close other with whom they had shared decades of family life. An interpretive approach within phenomenology was well suited to uncover families’ meanings, relational patterns, practices, and concerns since it attends to both the unique and shared perspectives and voices, and is concerned with the situated, idiosyncratic life-worlds of families (Chesla, 1995; Smith et al., 2009). The findings, formulated into three thematic notions bring forth the communal meanings and practices across families, while also highlighting distinct and diverse family patterns. As such, the study’s findings provide an answer to the research question.

Gleaned interpretations portray the manifold ways that families in later life come to terms with a family death through mutual meaning-making, live with the loss together and separately, and transition into their new situation as a family with a widowed member living alone. Family participants looked back to their close other’s death to *weave the death into their family narrative*. Findings captured within this first thematic notion emphasize families’ need to grasp the significance of the death, and to assign it with meanings they can live with within their specific frame of reference of their family. Insights related to how families make meaning suggest that families want to understand the death as a good death, as a unique and existential moment in family life, and a turn in the multigenerational nature of their family. While theorizing about meaning-making following a death abounds in the bereavement literature (see for instance Attig, 2001; Attig, 2004; Gillies and Neimeyer, 2006; Neimeyer, 2001b), empirical description of the meanings families give to a loss of a close other, and how meaning-making unfolds as a family practice that is embedded in the social word, the world of family relationships, has not been addressed beyond one single study undertaken more than 15 years ago (Nadeau, 1998).

Second, families focused on the now by *sharing-not sharing their loss*. This thematic notion attends to how the experience of loss and grief unfolded between members of a family, thereby adding a relational perspective to the mainly individualistic body
of bereavement knowledge. While some families’ interpretation of loss was univocal, other families held a multiplicity of interpretations capturing a wide range of feelings: contentment about a good conclusion to a difficult time, relief about an end to suffering and strenuous caregiving, a painful emptiness that includes missing the loved person, or a sense of regained freedom. Families connected with each other to learn about each other’s individual situation with loss through revealing, and provided or found comfort through convening around the deceased, talking about the loss, taking note of actions, spending time, enacting presence, and remembering together. At the same time, family members disconnected and concealed their feelings, and lived through difficult moments alone.

The relational family pattern of sharing-not sharing identified in this study has not been previously described with bereaved families. The only programme of research that has been undertaken with bereaved families embarked from normative ideas of family functioning, emphasizing that openness, closeness, and absence of conflict is best for individuals’ grief outcomes (Kissane et al., 1996a; Kissane et al., 1997; Kissane et al., 1996b; Kissane et al., 2006). Such findings marginalize the experience of those families who are not close, do not share, or face discord for a variety of reason, and delegates it in the realm of unhealthy family behaviour that warrants professional interventions. Furthermore, they value one way of family interactions over others. Critical voices of such a perspective have become louder over the last decade, and have emphasized the complex, contextualized and ever-shifting nature of family interaction, in which paradoxical ways of relating, and the co-existence of several voices creates a symphony of family health (see for instance Baxter, 2006; Hartrick Doane and Varcoe, 2005a; Hartrick Doane and Varcoe, 2005b; Parse, 2009). The findings of a couple of very recent qualitative studies do indeed suggest that couples negotiate closeness-distance, and connecting-disconnecting following the loss of a close other to find their own way to live with the painful ramifications of their loss (Barner and Rosenblatt, 2008; Hooghe et al., 2012; Rober and Rosenblatt, 2013; Rosenblatt and Barner, 2006). The findings of this study describe for the first time the ways that families – in contrast to couples - converge and diverge in their interpretations of the loss, and connect and disconnect in their lives with loss. Based on this qualitative study, it is posited that families live with their loss in an oscillating and coexisting way that includes closeness and distance, connection and separation, concordance and difference.

Third, participants moved forward in continuing or reconstructing their lives together. Findings subsumed under this thematic notion shed light on how family caring
unfolds in bereavement, extending current knowledge about family caring in later life. It emphasizes how families’ way of being and doing may be transformed. Some families faced upset, new concerns, increased their involvements, and took away insights about their way of being family, whereas others faced little change. While for some families, the taken-for-granted ways of being and doing family was forever altered with the death, other families did not feel shaken in their shared family world.

This is the first study to actually shed light on the ways that families in later life enact their family community without their close other. Theoretical propositions to date, rooted in developmental life-cycle and systemic perspectives, have posited that a death brings about a disequilibrium, requiring families to realign roles and functions according to the life-cycle stage they find themselves in (see for instance Jeffreys, 2014; Walsh, 2014; Walsh and McGoldrick, 2004a, 2013). The findings of this qualitative inquiry not only question the proposition that families face disruptions in their family life – some did, others did not – but illuminates the manner in which families figure out their communal lives in light of the particular concerns related to later life. In their family lives without the close other, all families continued some of their practical ways of doing things, intensified some, rekindled others interrupted by caregiving, and created new family caring practices.

The study’s findings reveal that living with loss entails community and aloneness, a world shared, and a world apart. It suggests that families live with their loss of a close other together as they integrate shared meanings into their family narrative, enact community through convergence and connection, and move together to continue or re-create their family life without the deceased. Death and loss, albeit to a varying extent and for different lengths of time, brought families together in their quest to face their bereavement situation as a community of committed and involved persons. In the process, participants in this study enacted family. Families’ practices uncovered in this study illustrate the concrete ways in which participants “do” family in later life bereavement; that is, how they practiced family meaning-making of the death, family sharing of loss, and family community in daily life after the loss. Findings further propose that members of families live with their loss apart from each other. A family death holds distinct implications for each generation and individual who has lost a living human presence with whom s/he had been in a dyadic relationship as spouse, child, in-law, or grandchild. Life with loss not only occurred in diverging ways for individuals of the same family, it involved disconnection during moments in which members do not want to reveal or cannot
share with others. Therefore, death and loss happens to “a family”, but affects its members and generations in unique ways.

In this chapter, families’ concrete life-worlds are illuminated in light of the larger societal and cultural context, and the study’s strength and limitations are highlighted. The study findings are discussed in relation to the different bodies of knowledge at which intersection they are located, such as bereavement, family science, and nursing. Even though the study has been undertaken from a nursing perspective with the aim to inform nursing practice with bereaved families, it holds relevance for a variety of disciplines that are concerned with families, and for various health professionals who practice with individuals and families after a close other has died.

7.1. Family participants in context

Participants in this study were ten traditional families of widow/ers who were on average 80 years old and continued to live in the community after the death of their spouse. While generalizability is not an aim of interpretive research (Creswell, 2013; Smith et al., 2009), it is important to understand study participants in context. To transfer the findings to other family groups, attention needs to be given to how family participants were constituted by their specific situation. Who took part and who did not; that is, which families, and which members, is also of concern.

7.1.1. The situated context of family participants: Some key issues

Nine of the ten family participants lost their close other following a period of debilitating illness late in life, which is reflective of demographic trends that more people live well into old age, with a majority dying following a time of progressive illness of two to three years duration (Swiss Statistics, 2013c; von Wartburg and Näf, 2012). A majority of family participants provided care to their close other at home, from a few months to several years. In Switzerland, family caregiving occurs frequently in later life, and it is usually the spouse, or then a child who takes on the primary responsibility for care (Perrig-Chiello and Höpflinger, 2012). This was also the case in this study, in which spouses acted as the primary caregivers. In so doing, they relied on the help of professional home nursing services. All families were able to look after their close other at home until a few days or a week before the death. Moreover, half of the families witnessed their close other’s death at
home, which is more than has been reported in one Swiss study, in which 23% of persons were found to die at home (Fischer et al., 2004).

**Gender, age, and ethnicity:** Most participants in this study were women, in particular among children (86%) and grandchildren (100%). As women in the family are usually the ones to provide care and support to their older members, the high percentage of female participants among family members should not be surprising (Imhof et al., 2012; Kesselring et al., 2001; Perrig-Chiello et al., 2010). With 60% women, gender distribution among widowed older persons corresponded with that of the local population of the same age (City of Winterthur, 2013). Given the inclusion criteria for age, participating older spouses became widowed at a later time in their lives than the average Swiss women or men (Swiss Statistics, 2009). The gap between the mean age of becoming widowed among women and men, however, was wider among participating widow/ers than in the general population.

Family participants were a culturally and ethnically homogenous group. Only one widow and one deceased had moved to Switzerland from another Middle or South European country when they were young adults. All participants were white. Among foreign-born Swiss inhabitants, only 7% are older than 65 years (Swiss Statistics, 2008). Given the low percentage of older, foreign-born persons, it is not surprising that family participants were mainly of Swiss nationality or decent.

**Household structure and living arrangements:** Alike a majority of multi-generational Swiss families, participants lived in separate, small households in close proximity to each other (Imhof et al., 2011a; Perrig-Chiello and Höpflinger, 2012; Swiss Statistics, 2005). In this study, almost all widow/ers continued to live in the same flat, house, or neighbourhood within the first two years following the loss because they were still able to manage on their own, with little help from their families. Most older persons beyond the age of 80 years old do indeed live alone in Switzerland, and it is likely that the majority of those who have lost their partner subsequently live alone (Imhof et al., 2011a; Imhof et al., 2012; Swiss Statistics, 2005). Only the oldest widower (88y) moved into a residential home about one year after his wife had died, reflecting the fact that a move into long term care occurs most often very late in life (Swiss Statistics, 2014). As such, participants’ living arrangements were typical of the Swiss household structure of later life families.
7. 1. 2. Who took part and who did not: Considerations about participating and non-participating families and members

Widow/ers most often invited an adult child to co-partake in the study, but grandchildren and in-laws were also invited. Widow/ers were free to ask whoever was close to them; however, family for them meant their offspring or a close member of the same generation. This suggests that traditional family ties are important for widow/ers, and continue to hold meaning into old age. Some families in this study were very close and interacted on a daily basis, particularly when they lived nearby, whereas others were seeing or ringing each other once a week or less regularly and in wider time intervals. As the data shows, family participants lived with conflicts, distant relationships, and difficult situations, which coexisted with happy moments, close ties, a history of mastering difficult times together and remaining committed to each other despite conflicts, and making arrangements that accommodate members in their family community.

Some members chose to not take part, because of a lack of time, or because they did not want to talk about their experience. Most often, those family members who were already most closely involved with the widow/er in daily life participated. In contrast, those who were one step further away, or disliked talking about their emotions, chose to not take part. Some family members only volunteered after the researcher had already met with other members of the family. This suggests that members’ comfort level to talk with the researcher about their loss differed. It is also likely that only those members within families took part whose relationship was such that sharing and talking was an established part of their interactions.

Older persons with non-traditional family ties, without “family”, or whose family situation included estranged relationships or non-kin members were unlikely to have taken part in the study for a variety of reason. They might not have been invited by recruiting personnel for study participation in the first place. If invited, reasons that led older persons to decline participation involved a lack of members’ willingness to talk about the experience together or to an outside person, hesitation to spend the little time resources they had with each other with participation in the study, or reluctance to ask a close other for another favour. The fact that those families with more constrained family resources or estranged relationships could not be included in this study may mean that some aspects of families’ loss experience were not captured in the findings. Moreover, findings may overemphasize the mutuality in meaning-making, the nature and extent of family sharing practices, and families’ sense of belonging and doing together. Participants in this study were only those
families who remained committed and involved with each other following the death. Although some members were more distant than others, they were comfortable, or, at the very least, it was possible for them to talk about the death with each other and an outside person. It is important to keep in mind that a prerequisite for participation was that at least two members would take part in a minimum of one family group interview. This might have, unintentionally, played out as an exclusion criterion.

7.1.3. Concluding remarks about families' lived contexts

Family participants belonged to the same culture, but represented different socio-economic backgrounds. They were multigenerational and nuclear families, and lived in heterosexual relationships. With the exception of one family, families lost their close other after a period of illness and family care. Their family composition, provision of family care, and living arrangements are reflective of a majority of the Swiss society of these generations in an urban setting. Participants differed in their sense of closeness, daily involvements, and past history of family lives, including their interaction patterns. Even though estranged, culturally diverse and non-traditional families have not been reached with this study, gleaned family features suggest that a blend of different Swiss families whose oldest generation is 75 years or older has been included. Considerations around family members' gendered and heteronormative representations, cultural issues, and life-cycle should be taken into account when transferring the findings to other families and contexts.

7.2. Study limitations and strengths

Within interpretive research, some methodological issues warrant closer attention, since they determine the interpretive potential and scientific merit of a study (Cho and Trent, 2006; de Witt and Ploeg, 2006; Kearney, 2001; Nelson, 2008; Whittemore et al., 2001). The strengths and limitations of this study pertain to the study sample, data gathered, questions around voice and representation, and research strategies employed.

7.2.1. Rich data: How many participants? What kind of data?

In qualitative research, the size, quality, and type of data generated in interaction with research participants are important determinants of a study's interpretive
potential and credibility (Benner, 1994b; Creswell, 2013; Morse, 2000; Smith et al., 2009). In this study, relevant methodological considerations include the size and richness of the data, but also the sources used.

**Sample size:** In this study, ten families with two to four members were deemed to be an adequate sample size to answer the research question. A sample size of ten widow/ers, along with 20 family members falls in the range, or even exceeds the few recommendations made in relation to phenomenological research (Creswell, 2013; Mason, 2010; Morse, 2000; Munhall, 2007; Parse, 2001; Smith et al., 2009). Moreover, included families showed some similarities that increased the homogeneity of the sample, such as prior caregiving, an expected death, family composition and widow/ers’ ability to manage life alone or with some help.

**Completeness and redundancy of data:** Besides number of participants and homogeneity of a sample, the completeness and richness of each case, and the redundancy across cases are important determinants of sample size (Benner, 1994b; Smith et al., 2009). In this study, efforts were undertaken to achieve completeness and richness by the use of multiple interviews. Most participants took part in at least two interviews, and interview material of each family included several hours of taped dialogue. Data gleaned from each family was considered to be rich because it included multiple perspectives, and was gathered at several time-points. Elicited descriptions (reflective data) and examples (narrative data) were relevant to the research question, and there were relatively few interview excerpts with less usable content. Data collection with each family stopped when the researcher had reached a sense of completeness of data with those who agreed to take part within a family. This was the case when a family’s and individual’s story was exhausted for the point in time during which data collection unfolded. This became evident when no new question arose during the analysis of each interview, and when participants felt that they had told everything they had to say.

In this study, similar thematic issues started to come up after the fifth family was included. Families’ experiences began to show commonalities, although differences and nuances continued to exist. For instance, meanings around the loss started to show distinct patterns, and patterns of family relating also started to become visible. Variations in experiences continued to show up in subsequent families, but no new thematic idea came forth. In addition to such methodological criteria, practical issues around available time and resources also co-shaped decisions about sample size.
Use of multiple data sources: This study relies solely on interview data, and no observational data were gathered. It has been suggested that observation is a fitting manner for data collection, also in interpretive phenomenology, since it allows us to see family caring practices; that is, families’ involvement and engagement with their world in action (Benner, 1994b; Chesla, 2011; Paley, 2014; Walshe et al., 2011). In addition, the use of more than one source of data is thought to increase the richness and depth of a study (Benner, 1994b; Smith et al., 2009). The main reason that observation was not used was the difficulty of carrying it out given the phenomenon under study. If families would have been recruited during caregiving or end-of-life care, they could have been observed in their homes and during the death duties and funeral rites. However, this would have posed ethical issues of its own. Thus, as an alternative, concrete narratives of everyday actions were sought during the interviews to learn about families’ situation, meanings, and concerns as they come to the fore through their actions. Moreover, family group interviews held an observational element, as family members embodied their relationships through speaking about their experiences, with many non-verbal clues passing between them that could be observed by the interviewer, who then captured her observations in field-notes. Thus, family group interviews can be posited as family relationships in-action, and it is likely that some of families’ enacted interactions were similar to how they ordinarily talk to and relate with each other (Benner, 1994b; Bjornholt and Farstad, 2014; Taylor and de Vocht, 2011).

The use of multiple interviews, and a combination of family group and individual interviews allowed us to glean families’ shared perspective at the same time as the voices of each family member could be heard. This enabled the researcher to attend to different points of view and to learn from several members at the same time what their experience of living family following a loss was like. Individual interviews were useful since they allowed for further exploration of an individual’s situation, and to follow-up on issues that came to the fore during group interviews. Moreover, family members revealed their own perceptions about each other’s situation. The methodological literature suggests that family members might be more willing to reveal their very private views and experiences in individual interviews (see for example Åstedt-Kurki et al., 2001; Eggenberger and Nelms, 2007b; Taylor and de Vocht, 2011). This was also the case in this study. Even though the researcher did not learn anything substantially new during individual interviews that had not already been talked about, or at least been hinted at during family group interviews, she was able to explore it more in-depth and to clarify it further. Hence, the inclusion of
several members of a family, with multiple interviews consisting of group and individual sessions denotes a strength of this study (Bjørnholt and Farstad, 2014). A multiplicity of voices, representations, and perspectives could be included in the analysis, which enabled the researcher to discern shared views and nuanced differences within each family, and across each family generation. This added complexity takes into account the very fluid nature of family, and the fact that there is virtually no distinct composition that is family to all those involved.

In summary, a sample size of ten families, and 37 interviews lasting a total of 50 hours generated a considerable amount of textual data. While the inclusion of more families might have added nuances and variety to the findings, this data volume is likely to have achieved completeness and redundancy of the data in relation to the research question. Common meanings, family patterns and caring practices could be discerned and illustrated in-depth and breath. The use of observation would have added another lens on families’ experience; however, the conduct of several family group and individual interviews was well suited to learn about families shared and individual perspectives. The study’s findings are thus well grounded, and provide a unique, and much needed perspective on families’ bereavement experience.

7.2.2. The power of direct speech: Capturing participants’ voices in a different language

The use of two languages, (Swiss) German and English, posed some unique methodological challenges for this research project. Because Swiss German is a spoken language only, Standard German is used for any form of written communication in Switzerland. It is also used as one of the official, publicly spoken languages (for instance in schools, on TV and radio). The researcher, who is fluent in both languages, collected the data in German, but analysed it in English. Thus, participants expressed their experiences and narrated their stories in Swiss German, and recorded interviews were transcribed in Standard German. In contrast, all field-notes, reflections, interpretations, and research log entries were formulated in English. This allowed the two co-researchers, who acted as the primary researcher’s thesis supervisors and could not read the original transcripts, to follow data gathering and analysis processes closely. They were thereby enabled to partake in interpretive efforts and to be as close to the data as possible given the language restrictions. A third co-researcher, who acted as a local advisor and who is fluent in both languages, read parts of the transcripts, co-participated in reflective
sessions during data gathering, and provided occasional methodological advise during the analysis of the data. Because interpretive ideas emerged and were refined in English, the need to translate findings could be averted. However, extensive quotes were translated into English by the primary researcher to permit further independent review and discussion.

Criteria for cross-sectional language research, in which the researcher and participants do not speak the same language, propose that rationales for language selection be given, translator credentials and roles be described, and specific methods be applied to ensure valid data collection (Croot et al., 2011; Squires, 2009). However, little methodological guidance exists in the qualitative research literature about studies in which participants and researchers share the same culture and language, but in which findings are reported and translated in another language (Chen and Boore, 2009; Santos et al., 2015; van Nes et al., 2010). Since English is the dominant language in research communities, reporting qualitative research in a different language than it was undertaken is a frequent practice. In this study, the research team’s language and research competencies ensured that the culturally embedded meanings conveyed through language were captured in translations and interpretations. Nonetheless, despite the bilingualism of two researchers, and efforts to transmit original spoken word as close as possible to the original meaning, some of its powerful message might have been lost in direct quotations, albeit not in the thematic notions, family patterns, and practices itself. The use of English as the language for reflection and analysis precluded the need for translations beyond original data, such as quotes (van Nes et al., 2010). Even though no professional translator was used, every effort was undertaken to remain close to participants’ original expressions and their meanings conveyed in language throughout translations (Santos et al., 2015).

7.2.3. The issue of representation: Whose voices are being heard?

The study represents the voices of ten distinct families. Their detailed direct accounts create an opportunity for nurses and other professionals to learn about families’ experiences from their point of view, and from within their world as uniquely lived by them. The in-depth illustration of family experiences of living with loss is a strength of this study. However, caution is needed since this study provides only a snapshot into families' lives during a relatively short period of time, which is not based on all family members. A consensus exists that the family experience can be
obtained through one member only (Cody, 2000b; Ganong, 2011; Gilliss, 1991); however, multiple perspectives allow for a more nuanced understanding and comprehensive representation of a families’ polyphony of voices (Hartrick, 1995). Even though data was gathered from participating family members about their perceptions about other non-participating family members to learn about sameness and differences, as well as about family interactions in bereavement, the findings are clearly based on the direct accounts of those who participated within families.

The findings of this study are representations of families who found a way to speak about their loss. Families who have a history of difficult relationships, mutual resentments, or rules against talking openly might have felt unable to take part in the study (Black and Santanello, 2012; Nadeau, 1998). The fact that families with estranged or conflicted relationships, family secrets, a strong need for privacy, or inability to talk about the deceased and the death were not reached is a major limitation of this study. It is likely that study findings do not depict the lived world of these families. As a consequence, findings do not represent the full scope of, and variance in families’ mutual meaning-making (or potential absence thereof), sharing-not sharing, and transitions in family life, and may have failed to capture other essential aspects of families’ loss experience. The transferability of the findings is thus limited to those families who live relationships that enable them to face the loss as a community of people who care for each other, and do not necessarily reflect the experience of families who do not have a common ground from which they can live with the loss of a close other. The fact that most family participants had cared for their close other during their chronic illness and end-of-life might have strengthened their relationships and created an ability to respect differences, make compromises, or find a consensus in how to work together (Schulz et al., 2001; Schulz et al., 1997; Stajduhar et al., 2010c). These capacities may have given them a shared background from which they felt comfortable to take part in the study.

No family assessment tool was used to quantitatively describe family characteristics. Measures of family functioning rely on normative ideas about family composition, roles, responsibilities, and functions in relation to a particular developmental or life-cycle phase (Kissane and Lichtenthal, 2008; Walsh and McGoldrick, 2013). For this study, such standardized ideas about what families should do or not do, or normative ideas about what constitutes a “healthy” and “well-functioning” family were seen as limiting the clinical understanding of (diverse) families. Many nurses and other health professionals have critiqued the utility of functionalistic views of families, and have pointed out that they might disable nurses from providing
meaningful and capacity-building care to families that strengthen own priorities and ways of living family health (Cody, 1995b; Hartrick Doane and Varcoe, 2005a; Parse, 2009; Wright and Leahey, 2013). For this reason, no descriptions of families in terms of standard measures of functioning were used. Readers are required to approach families’ stories of loss from an open stance, and to learn about their situation by listening to their unique expressions, needs, priorities, and manners to live with their loss in their specific context.

7.2.4. The co-constitutive nature of interpretive inquiry: Are claims justified?

The interpretive endeavour that constitutes this study became possible because the researcher and participants engaged with each other based on a shared background understanding, yet from their distinct culturally and historically situated position (Heidegger, 1926/2001; Plager, 1994). The co-participative nature of interpretive research poses unique challenges. While it is acknowledged that it is a matter of impossibility to become fully aware of one’s own situation, assumptions, values and beliefs, researchers are required to not shy away from every effort to do so (Finlay, 2002a, b; Geanellos, 1998a). The aim is not to eliminate the researcher’s imprints, but to make them as visible as possible so that the reader can make an informed judgement about the findings’ trustworthiness.

A systematic approach was taken throughout the study process to rise to the awareness the manifold ways in which the researcher’s own situated context, thinking, and values co-shaped this study. At the outset of the study, the researcher engaged in a thorough reflective undertaking to explicate her fore-understandings. In so doing, the researcher wrote about her own situation and history as a nurse and family member, elucidated her own values, beliefs and assumptions, and explicated her theoretical ideas about bereavement and family. As her own fore-understandings were spelled out on paper and became the subject of her reflective attention, she was able to discern limiting and enabling ideas. This process continued throughout data collection and analysis. The researcher turned to reflections about her own presence in the study following each encounter with families or before moving on to a new phase in the study. Moreover, whenever an encounter, a story, an analytical idea disquieted her, she took the time to hone in on the matter.

When brought to the fore, the new insights about the researcher’s frame of reference and assumptions created, in addition to the methodological frame of the
study, a basis for decisions. Decisions that needed to be made included how many interviews with whom and in which constellation should be undertaken, how many families were needed to obtain as complete and rich a data set as feasible given the time resources, how to go about the analysis process to achieve as full an understanding as possible, and when the interpretive process was completed. Through this endeavour, the researcher not only brought to the fore her own presence in the study, but gained ever new understandings of the subject matter under study (Gadamer, 1975/1989; Geanellos, 1998a).

Taking part in the research may also have co-constituted families' experiences. The researcher’s presence with families during several interview encounters provided families with an opportunity for meaning-making of the death, sharing their loss experience, and reflecting on their family lives in a manner that they may not have received otherwise.

Gleaned interpretations were not brought back to families. Consulting with participants about the “accuracy” of interpretation from their perspective is seen as a way to enhance the credibility of findings (Creswell, 2013; Sandelowski, 1993; Speziale and Carpenter, 2007). However, in hermeneutics, interpretation arises in dialogue with text, which the interpreter approaches from his or her situated context (Gadamer, 1975/1989). There is no right, objective understanding, but temporary, provisional one (Spichiger and Prakke, 2003; Taylor and de Vocht, 2011). It has been suggested that the best way to increase credibility of the findings is prolonged engagement with participants and data (Benner, 1994b; Speziale and Carpenter, 2007). The conduct of multiple interviews in this study enabled the researcher to engage in hermeneutic conversations with participants; that is, bring interpretive insights from previous encounters back to families for further clarification, reflection, and talk about its unique meanings and relevance from the participants’ perspectives (van Manen, 1990). While this is not the same as member checking, it allowed the researcher to engage in interpretive conversations with participants on an ongoing basis that enabled her to penetrate the meanings of the text more fully.

Even though a significant effort has been made to make explicit the researcher’s person and footprints in the study, not all ways in which the researcher co-shaped the study could be brought to light. Humans can never fully understand and reflect on their own way of being and going about their life-projects, and much remains a mystery (Heidegger, 1926/2001). This also holds true for interpretive researchers (Finlay, 2002b; van Manen, 1990). The researcher’ position in the world enabled some interpretations over others, and disabled some understandings of families. As
a consequence, the study’s findings, in line with the philosophical underpinnings, created contextualized, partial understandings that exist in and shift from moment to moment (Heidegger, 1926/2001; Taylor and de Vocht, 2011). The aim of such contextualized, in-depth understanding is to inform action that enhances the good in clinical practice (Benner, 1994b; Spichiger and Prakke, 2003; van Manen, 1990).

7.3. Family practices in bereavement: Seeking meaning, enacting caring

An attention to family practices in this study arose from the philosophical tenet that human beings understand their world and themselves because they meaningfully act in it (Heidegger, 1926/2001). As such, families’ life-worlds can be disclosed through the study of their embodied actions. Human beings create meaning as they act in relation to something; a world in which each Being co-participates (Bachtin, 2011; Heidegger, 1926/2001; Soboleva, 2010). Within an existential-ontological frame of reference, in which this study is situated, human beings disclose; that is, gain understanding about their Being through acting and being concerned with their practical and relational world; it is an embodied being-in and being-with (Bachtin, 2011; Heidegger, 1926/2001). As Kesselring and colleagues (2009) expressed, “practices connect us to others. Through practices we share with others, we understand who we and who our fellow contemporaries are” (p. 6).

The identification of practices that participants engaged in to make meaning or care for each other evolved from their narratives, as well as from observations of family interactions during interviews (Benner, 1994b). Observation of real-life family interactions and actions would have provided a more immediate access to families’ practices than observing families during a research interview (Benner, 1994b; Chesla, 2011; Plager, 1994). Nonetheless, family group interviews engaged family members around their experience of the death and life with loss in a way that also revealed their concerns and caring actions towards each other (Benner, 1994b).

7.3.1. Families’ meaning-making practices

Families enacted meaning-making to create shared meanings of the death. Soboleva (2010), in interpreting Bakthin’s philosophy of the act (2011), maintained that “meaning or sense are not a given, but are produced in the creative process of
dialogue\(^6\) (p. 27). Families in this study co-created meanings in dialogue with each other, and in the space that was opened up through their participation in the research. The dialogic nature of the interviews explicitly encouraged participants’ meaning-making efforts. Such dialogic co-construction of meanings was defined as a family practice. Families’ meaning-making practices arose as storytelling, comparing-contrasting, and generational situating.

**Family storytelling:** Talking, and telling stories is one way of doing family (Langellier and Peterson, 2006). In this study, mutual storytelling served as the dialogic medium to understand what the death meant for each family. Storytelling arose as the most important family practice through which families not only negotiated communal meanings of the death but also created a family story about the death. According to Langellier and Peterson (2006), storytelling “is a product of family interaction, a way of making sense of experience, a means to encode familial images and abstractions in stories, and part of an ongoing struggle to create and maintain a coherent system of meanings through narrative” (p. 99). They maintain that families perform stories, and stories are told for a particular audience to “reveal the family in operation as family” (p. 100). Study participants performed their stories for the researcher, and in this process, they also lived and created a particular narrative of their experience of the death. Walter (1996) proposed that today’s families often run out of opportunities to talk about the death and the deceased; something that he posited as essential to the process of grief. He gives several reasons why families lack the opportunity to talk, including the unravelling of cultural or religious rituals, differences in members’ loss experiences, absence of a tradition of talking across generations, the separation of home and work, and the physical separation among family members. Families’ participation in the research created a facilitated space, which enabled them to engage in narrative meaning-making through storytelling. The interview denoted one particular locale in which families performed their story of death and loss. With the practice of storytelling, families created meanings of the death that were inscribed into their family narrative in a particular way. Albeit widely discussed (see for instance Baddeley and Singer, 2009; Berger and Weiss, 2009; Bosticco and Thompson, 2005; Gilbert, 2002; Walter, 1996), only one family study has previously identified the importance of the family practice of storytelling to shared meaning-making of a death (Nadeau, 1998).

\(^6\) Translated by the researcher from the original statement: „…dass Bedeutung oder Sinn keine Gegebenheiten sind, sondern erst im kreativen Prozess des Dialogs erzeugt werden“
Comparing-contrasting and generational situating: Two other meaning-making practices were evident in families’ talking about the death. One way families practiced meaning-making of the death was through comparing-contrasting, which has been previously found in one study (Nadeau, 1998, 2001b). Comparing in this study served to point out the vulnerability that arose for family members in their lives, in contrast to Nadeau’s (1998) study, in which the purpose of comparing was about seeing the current death as more positive or negative than previous experiences based on age, cause and suddenness of the death. A reason for this difference might be that the current study included families who were quite alike in terms of age and kind of death, whereas in Nadeau’s study, some families had lost members of a younger age, and of various family memberships. Participants also created analogies, and contrasted death with birth, and dying or grieving with labour (Nadeau, 1998). These other significant family events served as a reference point to better grasp the current situation. For participants in this study, such analogies helped them to put into word what was difficult to express otherwise. During the interview, comparing-contrasting was practiced to explain what the death meant; that is, how it was alike or different from previous family experiences. This study is thus only the second to identify comparing as an important family meaning-making practice following a death. Albeit the concrete purposes that meaning-making served were somewhat different in the two studies, both describe how family meaning-making was practiced in light of families’ context, their narrative, as previous family occurrences served as the backdrop from which meanings were created through the family practice of comparing-contrasting.

Another meaning-making practice identified in this study was termed generational situating. Generational situating arose as a practice of discernment in relation to the changes that occurred in the multigenerational set-up of family as well as the generational differences. As families were talking about the changes to their multigenerational family, they also talked about the differences in meaning for each generation. Generational situating was a meaning-making practice that has not been previously described. It may at best bear some resemblance to the notion of living legacy described by Black and Santanello (2012). For families in their study, the deceased father’s legacy included particular values and worldviews that continued to shape their own lives and actions. Some families in this present study also made comments about how they saw their close other’s looks or skills live on in the next generation. However, generational situating was not used in relation to legacy, but to put into words that the witness to their family, and the beholder of
memories and values had forever gone, and to grasp the implications this absence held for the generativity of their family. What is common to the idea of living legacy and the practice of generational situating is that families behold what the deceased left them, for instance his or her stories, or typical ways of doing things, but how this unfolded was very different in each study. Generational situating was about locating the death within the family, and served to create a space for the different meanings and existential implications across generation.

7.3.2. Families’ caring practices

In this study, caring practices included families’ everyday actions, rituals, habits, and newly created ways to live family in the wake of loss. Some of participants’ caring practices were centred on their lives with loss while other caring practices were oriented towards continuing their family life in a later life context. These two kind of caring practices bear some resemblance to the dual process model of coping with bereavement put forth by Stroebe and Schut (1999; 2010). Some of the practices that families engaged in were rather “loss-oriented”, which in the dual process model “refers to the concentration on, and dealing with, processing some aspect of the loss experience itself” (Stroebe and Schut, 1999, p. 212). Other practices that arose in this study were more “restoration-oriented”, which, in the dual process model, pertains to secondary stressors; that is “what needs to be dealt with, and how it is dealt with” (Stroebe and Schut, 1999, p. 214). The oscillating process in the model suggests that both kinds of coping happen at the same time, with moving to the fore and the back according to the primary or secondary stressor of loss that needs to be dealt with. Alike this oscillating coping process, families in this study enacted caring practices all-at-once. For instance, “spending time” could both serve to alleviate aloneness, and was thus done by families as a way to care for each other in the wake of loss, but spending time was also a habitual way of enjoying family company that unfolded in spite or irrespective of the current loss situation.

Thus, the findings about caring practices suggests that, similar to individual coping, family caring practices serve different purposes. However, family practices are not equal to individual nor to family coping. Caring practices pertain to how families interact and act (Kesselring et al., 2009; Plager, 2009), rather than to how an individual processes stress. Coping is limited to mental representations of stress and responding to this stress, a conceptualization that resides in a positivistic worldview of cause and effect (Stroebe and Schut, 1999). In contrast, practices are...
embodied relations to things and persons who matter to us; they are embedded in a practical and relational world; they are about enacting the good in human relationships (Kesselring et al., 2009; Plager, 1994). As such, the identified caring practices in this study express families’ connecting and community.

**Convening and remembering:** Through caring practices, such as convening around the dying and remembering, families enacted public and created private mourning rituals to connect with the deceased in new ways. Family rituals are quintessential practices of healing and remembering (Gudmundsdottir and Chesla, 2006; Hedtke and Winslade, 2004; Imber-Black, 2004; Vale-Taylor, 2009).

According to Imber-Black (2004), families’ ritual lives include particular traditions, holiday celebrations, and life-course rituals, but also rituals of daily life, and provide “the path for needed mourning, healing, and commemoration” (p. 343). Participants’ narratives disclosed how they came together around their loved one in his or her last hours, organized the funeral, made decisions about the burial, and found in the grave a place that held comfort or was rather meaningless. For some families, these early days and weeks were a time of cherishing family connections. In addition to public mourning rituals, they created their own rituals of saying good-bye that were important sources of healing. Walsh and McGoldrick (2004b) maintained that being in “direct contact to the dying member” (p. 9), and families’ communal engagement in mourning rituals help families to acknowledge the reality of the loss, accept it as a fact, and find comfort through sharing. However, public mourning ceremonies may not hold much meaning for families, or simply not take long enough to serve as a source for healing (Imber-Black, 2004). Gudmundsdottir and Chesla (2006), in their study with parents after a sudden death of a child, found that parents created their own, private rituals long after the conclusion of public mourning rituals. Parents kept a token of their child, created memorials, and found manifold ways to connect with their dead child. In this current study, not all families found in the practice of the culturally embedded mourning rituals a source of comfort, and they also differed in the extent that such rituals allowed them to enact family togetherness. Similarly, for families in Black and colleagues’ study (2012; 2014), after-death rituals could be a source of comfort, or of confusion, particularly so when different ideas about how to practice these rituals existed within families, or when their family beliefs were such that these rituals did not hold much importance.

Families also practiced remembering to invite their close other back into their lives. Remembering conversations helped to create a place for their loved one in their
family despite their absence (Hedtke and Winslade, 2004), and to create a lasting place of love (Attig, 2000, 2001). Whenever families came together, they shared memories, told stories about past experiences with the deceased, and talked about the deceased’s life and character to co-shape his or her legacy for their family, and the next generation. In so doing, they honoured their close other’s rightful presence in absence in their shared lives and attempted to keep them close. The positive role that continued bonds with the deceased play for those left behind has increasingly been recognized (Field, 2006; Klass et al., 1996), although the proposition that one needs to move on and invest in new relationships continues to be seen as an important task in grieving (Walsh and McGoldrick, 2013). “Reinvestment” might be a contemporary conceptualization of Freud’s (2006) idea that survivors need to withdraw energy from the deceased and refocus on the living; an idea that has been keenly critiqued as falling short of the complexity of life’s relationships. Findings reveal the manner in which families practice rituals of honouring the deceased’s role in family life through remembering conversations, and sheds light on the after-death practices through which they bid farewell and created places to remember. Families’ communal remembering and remaining connected with the deceased in new ways suggests that families continue to see their close others as part of their family web.

**Talking, taking note, and enacting presence:** The family caring practices of enacting presence, taking note, and talking helped families to enact community. These caring practices are manifestations of intentionally lived family sharing. Enacting presence arose as bearing witness to each other’s pain of loss and occurred when family members turned towards each other to face their vulnerability (Bunkers, 2014; Cody, 2001a, c; Mitchell and Bunkers, 2003; Naef, 2006). Taking note was essentially a practice of interpretation, as family members observed each other’s actions, behaviours, and verbal expressions, and took them to be a sign of the pain of loss or of their well-doing. It was a rather passive and silent practice, and a way through which family members learned about each other’s situation. Talking was a practice used to learn about each other’s situation proactively, but it was also a way of being alongside each other when the loss itself became the focus of family interactions (Hooghe, 2012). Talking with others about grief, in particular with families and friends, has been found to be a frequent practice in bereavement (Jakoby, 2014). In this study, family caring practices that were enacted around the loss sought to foster comfort, growth, and the good within family relationships (Kesselring et al., 2009). Emotional support has been shown to be helpful for grieving individuals and families (Greeff and Human, 1994; Greeff et al., 2011; Ha et
al., 2006), however, the concrete manner in which families practiced such emotional support within their daily lives has eluded scholarly attention to date.

**Gathering, helping, consulting, meeting and interacting in new ways:** The practice of family life after a close other has died aimed to address families' new concerns with a widowed older member living alone. Family traditions and habits of gathering denoted continued family practices, served to celebrate festive occasions, and to nurture mutigenerational and dyadic relationships. However, some daily practices of doing family changed, in particular because the widowed member of their family had reached later life. Some of these practices shifted naturally, whereas others were purposefully changed to accommodate family members' new needs. It has been previously found that widowed older persons rely more on their children for support than do their still married age counterparts six months following the loss, and that children receive less help from their widowed parents than they do from their still married parents (Ha et al., 2006). Such intergenerational support unfolds in light of previous patterns of support flow, and denotes a practice continued yet altered by a significant family event like a loss (Ha et al., 2006; Utz et al., 2004). This was also evident in this study with family practices that continued, yet were enacted differently or more intensely than before the death.

### 7. 3. 3. Concluding remarks about family practices

Families in this study engaged in practices to make meaning of the death, and in practices to care for each other. Meaning-making practices served to better understand and create shared meanings of the death whereas caring practices pertained to families' shared life with loss as well as how to best continue family life. Family practices include activities, habits, rituals, and routines; that is, established and any new ways of doing things with the aim of enacting family (Imber-Black, 2004; Kesselring et al., 2009; Plager, 2009). According to Plager (2009), “making and sustaining a family and the life of that family falls under the rubric of practice” (p. 197). Because practices reveal what matters to people, they are an essential route for understanding families' life-world.
7.4. Family meanings of the death: Narrative constructions

This study demonstrates that the loss of a close other leaves families with a need to understand the death in the context of their past family lives. In a communal quest, families in this study derived the significance that the death held for the multigenerational nature of their family and assigned particular meanings to the loss itself. Searching for meaning is inherent to human existence; it is a primordial way of being-in-the-world (Attig, 2001; Frankl, 1977; Heidegger, 1926/2001). When the taken-for-granted way in which we live for the most part of our lives becomes undone, we seek to grasp the utterly unfamiliar by seeking not only to understand it but to create our own ways to make it part of our world that is home to our existence (Heidegger, 1926/2001). Constructing meaning, in fact, is essential to family health and becoming (Parse, 2009). Shared family meanings nurture community and commitment (Berger and Weiss, 2009). Collective meaning-making “through family transactions and cultural and spiritual resources” helps families to glean a “coherent perspective on the death and ramifications of loss”, which encourages “continuity with their belief system and life course” (Walsh and McGoldrick, 2013, p. 21). In contrast, when families fail to reach an agreed-on collective meaning, they may tend to disintegrate (Berger and Weiss, 2009). However, families not only co-shape meanings in joyful and sorrowful moments, they “revere the intentions” of different members in “acknowledging with regard the meaning that family members give to situations” (Parse, 2009, p. 307). Thus, while meanings are shared, they may also differ within families (Parse, 2007, 2009). Families in this study did indeed co-shape meanings all at once in their unique family ways as they created common and distinct meanings of their situation. Those family meanings related to the death itself were the same across family participants, while families differed in their meanings given to their individual sense of loss.

7.4.1. The family meaning of the death as a good death

How death happened to families mattered. Participants talked about the circumstances of the death to create a particular meaning of the death as a good death. Seeing the death as a good death created peace with families’ experience of witnessing end-of-life and dying, no matter the exact circumstances. Evidence from quantitative studies with individuals about the impact of the circumstances of the death on bereavement outcome, such as whether death was expected or sudden, preceded by pre-loss communication among couples, or whether the place of
death was as wished, is inconclusive (Carr, 2008; Carr et al., 2000; Hauksdottir et al., 2010; Hsieh et al., 2007; Metzger and Gray, 2008; Miyabayashi and Yasuda, 2007; Stroebe et al., 2007; van der Houwen et al., 2010; Wolff and Wortman, 2006).

In one qualitative study with bereaved family carers of cancer patients, specific circumstances somewhat facilitated the grief process from carers’ point of view (Dumont et al., 2008). This seems to be particularly the case when carers could be present, felt prepared, experienced the death as beautiful, and were able to smoothly move through the organization of practical tasks immediately following the death (Chan and Chan, 2011; Dumont et al., 2008; Lee et al., 2013; Lee and Carr, 2007). Their past ability to do everything possible was found to be important for family carers to make peace with how end-of-life care had happened to them, and instilled them with a sense of accomplishment (Dumont et al., 2008; Koop and Strang, 2003). Seeing an end to suffering provided relief for family carers, although images of suffering or bad memories of the illness time and caregiving could also haunt them (Akiyama et al., 2010; Dumont et al., 2008; Koop and Strang, 2003). For families, it has been shown that making sense of the death occurred in relation to the duration of the illness, the suffering members perceived to occur, the place of death, and family members’ presence (Black et al., 2014), the deceased’s (un)readiness to die and whether the nature of death was seen as fitting to the person (Nadeau, 1998). The insights from these qualitative studies are similar to the findings in this study, in which feeling prepared, fulfilling wishes, witnessing a peaceful death, and facing the loss late in life following a period of suffering in illness were those assertions around which families made meaning of the death as a good death. These assertions of a good death arose from families’ own worldview, beliefs, and traditions, and were imbued with western cultural and social values of autonomy, control, and choice (Black and Santanello, 2012; Carr, 2003; Chan and Chan, 2011; Machin, 1998; Steinhauser et al., 2000; Walter, 2003). Family participants valued when they had time to prepare and had been able to fulfil wishes, which reflects cultural values of choice and control. The absence of pain and suffering was also important for a “good death” (Ellershaw and Ward, 2003; van Gennip et al., 2013), but when agony occurred, it fostered upset for those left behind (Curtis, 2003; Jones and Willis, 2003).

Individual and family studies to date univocally suggest that families do make meaning based on their perception of the circumstances of end-of-life and death. However, not only the circumstances per se, but how persons derive meanings from the particular context of their family seems to hold important ramification for the
individual bereavement experience (Gilbar and Ben-Zur, 2002). This was also evident in this study. Families experienced a strong need, and were willing to engage in quiet lengthy negotiations and dialogue to walk away from their experience of end-of-life and dying with positive meanings of the death. Alike families in this study, Rober and Rosenblatt (2013), in analysing a literary narrative, found that in the first family conversation about the death, families constructed a story about the loss. In so doing, information about the circumstances of the death was disclosed or framed in a way that created a meaningful story, which enabled the family to come away from their experience of a family death with a public, shared story (Rober and Rosenblatt, 2013). Rober and Rosenblatt (2013) proposed that such a story of the death is “a story they will have to publicly believe in and live with for years. It is the story they will be trapped in together, even if they do not believe all of it” (p. 184). Through family stories, family meanings, identities, and realities are negotiated, and a grand family narrative is written and rewritten (Koenig Kellas and Trees, 2013). Participating families’ efforts centred on creating a communal, meaningful story of a good end to a long life. All ten families, no matter the exact circumstances of the death, created a meaning of the death as a good death, which was important for their family wellbeing.

7.4.2. The family meaning of the death as a distinct and existential situation

For some families, the death of such a close other, like a spouse or (grand-) parent, brought about an unfamiliar, new terrain for some members, leaving them vulnerable and bewildered. The loss of their close other took on the meaning of a turning point in members’ lives that utterly changed their perceptions of daily life and threw them into the unknown. Attig (2004) maintained that “bereavement undermines what we have learned about how to be and act in the world” (p. 350), requiring persons to re-learn their daily lives. Individual members felt indeed exposed in their daily lives because some of the familiarity in their way of feeling towards and acting in the world had been taken away, and they experienced an increased vulnerability. At the same time, as Attig (1996, 2004) suggested, much still worked for them in their lives, and grounded them in the familiarity of their own personal lives. The meaning of the death as vulnerability or turning point, in which everything seems different than before, was similar for families to that of previous events that had taken away some of life’s familiarity and assuredness, such as becoming a parent, seeing the children leave home, or the parents’ divorce, which was also a way that multigenerational families in the family study by Nadeau (1998)
made sense of the death. The death took on the meaning of a special family time, a time in their family that was outside of the average, usual way of living family.

7. 4. 3. Family meanings in relation to life and multigenerationality

For participants, the passing of a family member in later life was an inherent meaning of family (Parse, 2009). It brought home to them that families do indeed change, also through death. Therefore, families in this study took the shifting nature of their generational make-up to be an expression of the natural course of family life (Chambers et al., 2009; Connidis, 2010), which has not been previously found in empirical investigations. One reason might be that this study seems to be the only study attending to families’ experience of loss in later life, whereas other studies included families of all ages (Davis et al., 2012; Mayer et al., 2013; Nadeau, 1998).

Families in this study also derived existential meanings from their close other’s death. Several studies have in fact found that those family members who are left behind gain a new awareness of their own finitude, which may bring about changes in the ways they set priorities (Black and Santanello, 2012; Dumont et al., 2008). In Nadeau’s (1998) family study, “lessons learnt” included; “set priorities, how to live life, and put relationships first” (p. 221). The lesson “don’t take others for granted” and “live in the moment”, however, were mostly made by those families who had lost a young member, or who were faced with a sudden death. This might be an explanation for the absence of these insights in the current study.

What has not been previously described is the way meanings differed across generations, which was something that family participants emphasized. For instance, for members of the oldest generation, their own closeness to death was predominant. The loss of a spouse took away some of the apprehension that they had previously felt when thinking about their own death. In contrast, grandchildren’s insight was more like a lesson, a lesson about death. The loss of their grandparent made death more real to them. Adult children’s insights were closest in meaning to those found by Nadeau (1998), and they started to ponder their own way of life, priority setting, and plans for later life. Thus, families in this study assigned particular meaning to the death in relation to their families’ multigenerational nature, but also gained existential insights about the meaning of life.
7. 4. 4. Different family meanings assigned to the loss

The meaning ascribed to the loss differed between families. Many families experienced the death as a relief and/or felt gratitude for the way death happened. Families, however, were also sad and painfully missed their close other’s loving, anchoring, or connecting presence. This was particularly the case for those families for whom the deceased had embodied a home and a place to turn to where understanding and help was guaranteed. The panoply of experiences present in participating families reflects the diversity of human experiences of loss (Carr, 2008; Dumont et al., 2008; Naef et al., 2013; Neimeyer, 2006b, 2014; Ott et al., 2007; Wolff and Wortman, 2006). The rigidity espoused by normative view about a right way to mourn the loss of a close other, including that grief needs to be part of what one feels, or who should or should not grieve in which way, has long been questioned (Bennett and Bennet, 2000; Doka, 2008; Harris, 2009-2010; Moules, 1998). Moreover, in most situations, the loss experience entails not just one feeling, but encompasses many different, sometimes even conflicting emotions (Harris, 2009-2010; Hockey et al., 2001; Holtslander et al., 2011). In this study, families’ sense of loss was very often marked by the coexistence of sadness and relief, pain and gratitude, missing and appreciating new opportunities that arose for their collective lives. Research has shown that bereavement is complex, and involves many different features (Naef et al., 2013). The findings around families’ sense of loss do indeed emphasize the variety of meanings that families assign to the loss, questioning the position that grief is inherent to bereavement.

7. 4. 5. Concluding remarks about family meanings and meaning-making

In this study, families created meanings in relation to the death and to their sense of loss. Meanings of the death were shared across all participants, in contrast to families’ interpretation of their loss, which differed. According to Patterson and Garwick (1994), “family meanings are the interpretations, images, and views that have been collectively constructed by family members as they interact with each other; as they share time, space, and life experiences; and as they talk with each other and dialogue about their experiences” (p. 287). This study demonstrates that when faced with a death, families rewrite their narrative in a way that helps them to find meaning and peace with their experience of death (Attig, 1996, 2004).

Families in this study made meaning both as a group of two to three members, as well as on their own. Some families told their story of loss together, and one main
thread of meaning was evident. In contrast, other family members wove together at least two different strands of meaning that complemented, and at times contradicted each other. The manner in which families create both family and individual meanings of difficult situations in interaction has been previously investigated (Koenig Kellas, 2005; Koenig Kellas and Trees, 2006, 2013; Trees and Koenig Kellas, 2009). Koenig Kellas and Trees (2006) found that the extent of which meanings of a difficult family event were shared was constituted by families’ degree of engagement, perspective- and turn-taking, which could be seen as features of a dialogic exchange. In families who created family meanings, all members were actively engaged in a story-telling process, multiple perspectives co-existed and were both integrated and represented in the stories “to create an emergent meaning comprised of multiple interpretations” (Koenig Kellas and Trees, 2006, p. 62). In contrast, when individual-level sense making occurred in the family context, members were still engaged in a story-telling process, but it was less interactive, multiple perspectives were rarely integrated into a common view, and interpretations focused on the impact on the individual, rather than on the family. Such a coexistence of different levels of meaning-making was also found in the salient study on family meaning-making of death (Nadeau, 1998), in which meaning-making unfolded on the level of couple, dyad, individual and whole family groups. Families constructed and rehearsed meanings while they were engaged in ordinary family conversations. Such “family speak” resulted in a “weaving together of individual threads of meaning “(Nadeau, 1998, p. 148), and unfolded through family members agreeing or disagreeing with, interrupting, or echoing each other, making references to and questioning another family member’s statement of meaning, or finishing each other’s sentences. Such an interactive talking about the death was also found in this study. Families engaged in quite lengthy dialogues about the death and negotiated differences in perceptions through agreeing, complementing, filling in the details, or by adding their differing, individual perspectives. It is important to note that the study interview situation was a specific locale for the creation of family meanings that may be different from the opportunities that families have in their lives. However, it is posited here that meaning-making may not be different from other situations in which families seize or receive an opportunity to dialogue about their shared and individual experience of death and loss, as it may occur in interactions with friends, extended family, or health professionals.

In this study, the meanings gleaned became part of the families’ narrative; they co-constructed families’ identity (Kiser et al., 2010; Koenig Kellas and Trees, 2013).
their family stress framework, Patterson and Garwick (1994) maintained that families create meanings in relation to the family event itself, their identity as a family, and their view of the world. Families in this study did indeed create meanings in relation to the death and loss, as expressed in the family meanings of the death as a good death, a death that is followed by an unfamiliar feel in life and leaves the family particularly vulnerable, and a death that holds unique implications for each family member. Another level of family meaning pertains to how family identity changes in the wake of the stressful event (Patterson and Garwick, 1994). Family identity is close in meaning to the notion of family narrative discerned in this study. Identity, expresses as a narrative construct, can be seen as a depository or co-constructed background understanding of shared assumptions, values, stories, traditions, rituals, and meaningful secrets (Koenig Kellas and Trees, 2006). As such, meanings arise from and constitute a families’ narrative of a defining family moment like the death of a close other. A family death is alike a chapter in the family narrative that needs to be written through the communal meaning-making process by families (Walter, 1996). Families in this study were able to imbue the death with meaning, and to weave it into their family narrative. A third level of meaning arising from stressful situations pertains to families’ worldview; that is, how they understand life and family in general (Patterson and Garwick, 1994). This rather abstract aspect of meaning constructs refers to how families’ world inherently makes sense or needs to be re-constructed (Attig, 2001, 2004; Black et al., 2014; Neimeyer, 2001b). Family beliefs and worldviews have indeed found to be important for family meaning-making in one study (Black et al., 2014). The importance of meaning-making in “re-learning the world” (Attig, 2001) or “re-constructing a personal world of meaning” (Neimeyer, 2006a) following such a loss has evolved as a major concept in the bereavement literature over the last decade (Gillies and Neimeyer, 2006; Hibberd, 2013; Kunkel et al., 2014; Neimeyer, 2001a; Neimeyer et al., 2002). While attention lies mainly on individual meaning-making, Neimeyer and colleagues (2014) pointed to the need to understand how meanings in life are co-created within a broader social context. For study participants, their values and beliefs were not questioned in such a fundamental way that it required of families to re-create their family worldviews. Rather, it denoted the background from which they made sense of the death. The present study thus attended to the very ways that families interactively integrated co-existing meanings into a shared family narrative. It sheds light on the ways that a shared history, identity and beliefs acted as the backdrop from which families created their distinct meanings of the death.
7. 5. **Family relations in living with loss: The coexistence of community-aloneness**

Families in this study faced the death of their close other in light of their previous family caring relationships, both with the deceased, and with each other. Their previous relational patterns created the context from which family members’ interpretation of loss was the same or different, and from which families lived with their loss together or rather alone. Sharing-not sharing surfaced as a family way of human-to-human relating in bereavement. Relational family patterns are manifold, but one essential way of being-with others is through recognizing another as in need of human community, bearing witness to each other’s unfolding lives, including difficult moments such as the experience of a profound loss (Levinas, 1998; Naef, 2006). Human relating is being-with others (Heidegger, 1926/2001). Those who see themselves as family live such commitments, which arise from choices made given the situation a person is born into (Cody, 2001a; Hartrick and Lindsey, 1995; Heidegger, 1926/2001; Parse, 2009). This study sheds light on how families live with loss through sharing their interpretations, and by enacting family connecting. Families’ descriptions, however, also illuminate how not-sharing arises from divergences in interpretations and needs, and manifests as a question of choice.

7. 5. 1. **Families’ relational pattern of connecting-disconnecting**

“Family sharing” as a theoretical idea has been put forward as an essential characteristic of grieving families (Jeffreys, 2014; Walsh, 2014; Walsh and McGoldrick, 2004b, 2013). However, empirical descriptions of how family sharing unfolds in bereavement are rare. The family study by Nadeau (1998) identified stimulators and inhibitors to family sharing, defined as “talking about the death” (p. 86), which bears some resemblance to the description of the family situations in this study in which families enacted sharing. In both studies, families who interacted frequently had more opportunities to share, and interviews were one locale during which sharing, or talking about the death, respectively, occurred. Tolerance for difference was evident in all family participants in the current study, and it may well be that those families who had rules against sharing, or felt cut off from each other (Nadeau, 1998) were not represented in this study. Protectionism, an inhibitor to sharing in Nadeau’s study, was also found in this study as family members made decisions not to reveal their pain of loss out of concern for the other. Family rituals, both immediately following the death as well as traditional family gatherings were
moments in which families in this study connected with each other around their loss, whereas in Nadeau’s study, family sharing was related to death rituals only. Overall, while the content to which sharing or talking refers is different between studies, findings suggest that some aspects of loss unfold at the family level and are shared, whereas other issues play out on the intrapersonal level, and are therefore not shared.

In other situations than bereavement, for instance when living the end-of-life of one member, two qualitative studies have identified that sharing-not sharing coexisted for families (Carlander et al., 2011; Taylor, 2012, 2014). For instance, connecting-disconnecting constituted the main pattern of the couple relationship in a study about intimacy and sexuality in the face of a life-limiting illness (Taylor, 2012, 2014). In a study with families living close to death at home, “being me and being us in a family” evolved as the patterns that constituted families’ “striving for the optimal way of living close to death” (Carlander et al., 2011). The concrete ways that family sharing (stimulators, connecting, we-ness) and not-sharing (inhibitors, disconnecting, me-ness) unfolded across these studies was quite different. Nonetheless, family sharing-not sharing seems to be a distinct pattern of family relating at the end-of life and in bereavement. Hence, this current study adds empirical evidence to nursing knowledge about family health, suggesting that families deal with profoundly challenging situations of illness, dying, and loss together and apart as each member needs to find his or her own way (Butt and Chesla, 2007; Carlander et al., 2011; Eggenberger and Nelms, 2007a; Taylor, 2014).

What is common to a majority of writings about grieving families is the assumption that members need to talk about their emotions in order to come to terms with and resolve grief (Gilbert, 1996; Kissane and Lichtenthal, 2008; Walsh, 2014; Walsh and McGoldrick, 2004b, 2013). Within the theoretical bereavement literature, sharing, defined as talking or expressing feelings in other ways, is seen as central to the family mourning process, and vital for family adaptation to loss (Walsh, 2014; Walsh and McGoldrick, 2004b, 2013). For instance, Walsh and McGoldrick’s definition of the family adaptational task of “sharing the experience of loss” posits that a lack of family communication might not only threaten the shared mourning process, but aggravate individuals’ pain or bring about a sense of alienation from the family. Some studies have indeed found that open communication and expressions decrease grief intensity within the first year of bereavement (Kissane et al., 1996a; Kissane et al., 1996b; Traylor et al., 2003). Kissane and colleagues (1996a; 2008;
2006) have put forth two broad categories of family functioning in bereavement, suggesting that those families who tend to feel close, share their distress, and have no conflict or only conflicts they can accommodate experience no adverse outcomes on the individual level and adapt well as a family to their new situation. In contrast, they found that families who have fractured or chaotic relationships and did not speak with each other, felt estranged, had some conflict, or did not share emotions faced more adverse psychosocial morbidity. According to their typology, family sharing, defined by closeness, expressiveness and absence of conflict, enables families to grieve openly and adapt well, whereas those families who did or tended to not share, faced difficulty in their bereavement.

Contrary to these assertions that sharing is essential for healthy and “well-functioning” families, research has also suggested that not-sharing, or not-talking and not expressing emotions is vital to families’ well-being following the loss of a close other (Hooghe, 2012; Hooghe et al., 2011; Rober and Rosenblatt, 2013). In fact, one study found that people often lack the opportunity to, or refrain from talking about their grief with others for a variety of reasons, for instance because other persons to confide in are unavailable (29%) or do not ask about grief (33%) (Jakoby, 2014). Other reasons for not talking about grief included not wanting to burden the other (43%), assuming it was not the right moment (25%), not daring to talk (21%) or finding it inappropriate (19%). Research with couples has revealed that not talking about a painful experience that often cannot be adequately captured with words is as useful a family strategy to live with loss as is talking (Hooghe et al., 2011, 2012). Hooghe and colleagues (2012; 2011) proposed that both confronting and avoiding the loss is needed to regulate grief, as families negotiate the closeness they can bear to the pain of loss, and the distance they need to live with their close other’s absence. Using examples of couples, they demonstrated that family members steer clear from sharing through talking at the same time as they create other ways to connect, without focusing on the loss per se. Couples faced or turned away from the unbearability and unspeakability of their child’s loss by negotiating closeness and distance to the pain both as individuals, as well as a couple. The way families navigated sharing-not sharing in this study is somewhat different from the way that couples in Hooghe and colleagues’ (2011, 2012) investigation negotiated closeness and distance. In their study, explicit talking about their child or sense of loss only exacerbated their pain and there was no comfort to their individual situation that they could give to each other. This was not the case for families in this study. One reason for this divergence may lie in the difference of loss (child vs.
older member) and the fact that the current study did not include couples. For participants, sharing through talking and enacting presence was a source of comfort, and a way to enact family caring and community. Through family sharing practices, families felt comforted and their isolation eased.

However, sharing was only possible to a certain extent for family participants, as some situations remained non-sharable. The unsharability of one’s situation of loss was an expression of existential aloneness and suffering (Stroebe et al., 2005). According to Wilkinson (2005), the unsharability of suffering, “may well be one of its most essential attributes; it may be precisely as a result of suffering being locked in the realms of personal experience (...) that confounds representation and defies our capacity to provide an outward formal expression of the contents of our experience” (p. 16). However, family members also withheld from sharing their situations of pain because they chose to conceal their vulnerability, or were afraid that they pull the other into the pain in a moment of ease. According to Walsh and McGoldrick (2004b), families may block talking to each other to protect the other and oneself, particularly when family members feel overwhelmed and frightened by the intensity of emotions present. While this may have been at work for family participants too, those family members who did take part in the study withheld from sharing not because of fear, but rather out of concern and affection for the other, or because they felt utterly unable to. When they did connect with each other around their loss, they experienced it as comforting, positive, and helpful, albeit at times also as painful. In this study, not-sharing, expressed as disconnecting, did not arise as a risk for dysfunction or for a disrupted grieving process as cautioned by Walsh and McGoldrick (2004b, 2013), but rather as a way to skilfully respect members’ unique ways, expressions, and capacities in their individual experience of loss. This study adds evidence to the evolving claim that not-sharing is as inherent to families dealing with a situation of loss as is sharing. During bereavement, sharing-not sharing within family relationships can be posited as a constant tension between what to reveal, and what to conceal. When grief is seen as a relational dialogical process, there is a “constant tension in relationships between the two contradictory needs: the need for disclosure (openness) and the need for secrecy (closedness)” (Hooghe et al., 2011, p. 912).

This study adds empirical support to a small body of scholarship that has started to question the overemphasis on “open family communication” as central to family adaptation, pointing to the importance of the specific contexts of families, and the ambivalences and tensions inherent in relational living with loss (Baxter, 2004,
Drawing on the idea of “polyphony” and “dialogism” put forth by the Russian thinker Mikhail Bakthin (1984), Baxter and colleagues have posited that family is an interplay of multiple, contradicting forces engaged in an unfolding, ever-changing dialogue (Baxter, 2004, 2006; Baxter and Montgomery, 1996). Polyphony refers to the coexistence of different, unmerged voices that are engaged in a dialogical relationship (Baxter, 2006; Hartrick, 1995). Dialogism stands in contrast to the “monologization” of the human experience; that is the reduction of human diversity into “determinate, closed, totalizing concepts” that Bakthin found to imbue and restrain most of our social and cultural lives (Baxter and Montgomery, 1996, p. 24). He maintained that all social processes arise from such “a contradiction-ridden, tension-filled unity of two embattled tendencies”; the centripetal and centrifugal forces (cited in Baxter and Montgomery, 1996, p. 25). The centripetal force refers to the tendency for unity, whereas the centrifugal force relates to a propensity towards difference (Bakthin, 1984; Baxter and Montgomery, 1996). Family can thus be seen as a polyphony of voices in which the opposing voices of family members coexist in a tendency to come together and to move apart (Hartrick, 1995). In applying Bakthin’s view to family communication, Baxter (2006) proposed that “the dialogic move is one of recognizing that family life is a both / and experience – families gain their meanings from the give-and-take interplay of multiple, competing themes or perspectives. Communicative life in families can be viewed as a dialectic in which different, often opposing, voices interpenetrate...”. In the relational dialects theory that draws heavily on Bakthin’s work, Baxter (2004, 2006) maintained that there are at least three major contradictions that underlie all family interactions: First, there is the contradiction between independence and separation with interdependence and connectedness; second, the tension between stability, routine, and predictability with change, novelty, and surprise; and third, the opposition between openness and disclosure with discretion and privacy.

In a similar vein within nursing, Parse (2009) has been quite explicit about the paradoxical patterns of relating through which families, from moment to moment shift their interactions and become as a family. In her theoretical account of human-to-human relating, revealing-concealing, connecting-disconnecting, and enabling-limiting are inherent relational patterns that are lived by families (Parse, 1998; Parse, 2013). Moreover, one of the essential ways that families live their health (i.e. human becoming) is through shifting patterns. Shifting patterns pertains to how “family patterning is revealed and at once concealed in the ebb and flow of
togetherness-aloneness”, which is expressed in a coexisting communion-solitude (Parse, 2009, p. 308). For Parse, being together is “witnessing with diverse fervour”, and being alone is “moving away from in a recognizable cadence” (p. 307). Such being together is expressed through families’ bearing witness to each other in face-to-face encounters, through silent immersion in thinking about the other, or with a lingering presence as family members remember and behold (Parse, 2009). For Parse, such relational family patterns not only coexist in a paradoxical symphony, but are ever-changing, arising from choices in intimacies that families make as their relationships unfold in their specific situations.

Propositions about the paradoxical and ever-shifting nature of family relational patterns (Parse, 1998; Parse, 2009, 2013) are similar to the dialectical ways in which family live in the dialogical flux of family interaction (Baxter, 2004). In fact, these scholars, from different vantage points, have emphasized that human beings become in interaction with others in a coexisting, contradictory and paradoxical process, as Baxter and Montgomery (1996) maintained: “The self is constructed out of two contradictory necessities – the need to connect with another (the centripetal force) and the simultaneous need to separate from the other (centrifugal forces)” (p. 25). Family community, the moving or being together to share denote the centripetal forces, and solitude, the moving away and being alone in not-sharing, are the centrifugal forces at work. The relational pattern of family sharing-not sharing can be posited as an expression of centripetal and centrifugal forces that are at play in families’ lives with loss, and of the inherent contradiction that exist in the very nature of family interactions. Sharing for families in this study was about revealing, connecting, and enabling change - the moving together; and not-sharing was about concealing and disconnecting - the moving away and living with the loss individually.

In summary, this study not only supports findings of a few previous studies that emphasize the importance of sharing-not sharing for families at the end-of-life, they can also be aligned with a more polyphonic, dialogical conceptualization of family in which members relate with each other through the tendency to move together and apart. Thus, to emphasize that sharing, such as open communication or closeness, is needed to live with the loss of a close other, falls short of understanding families’ complex experience of loss, in fact, it denotes a shortcoming if it is assumed that sharing is the best way for families to face the pain of loss (Hooghe, 2012; Hooghe et al., 2011). This study sheds light on the ways that sharing-not sharing unfolds for families in their lived experience of loss, and demonstrates how connecting and disconnecting serve an important function within families.
Theoretical assertions about grieving families suggest that members quite often differ in their grief experience (Bowlby-West, 1983; Gilbert, 1996; Walsh and McGoldrick, 2004b). Walsh and McGoldrick (2004b), for instance, point out that a family might hold “a range of feelings depending on the unique meaning of the relationship and its loss for each member” (p. 11). This proposition was in fact confirmed in this study with the relational pattern of convergence and divergence. Family participants’ interpretations of loss were shared or not shared within families. Convergences or divergences in the loss interpretation were not only based on a family’s history, but depended on the significance that the dyadic relationship with the deceased had for each member. For widow/ers, it is well established that the relational quality of their marriages provides the background from which the interpretation of loss as painful absence or relief arises (Carr, 2004; Carr, 2008; Carr and Boerner, 2009; Carr et al., 2000; Dumont et al., 2008; Pruchno et al., 2009; Wolff and Wortman, 2006). This study suggests that previous characteristics of the relationship also constitute the sense of loss of other family members, and give rise to sameness or differences within a family’s experience of loss.

In contrast to research with individual family members, little research exists that investigates how sameness or difference in loss unfolds within families. The study by Black and colleagues (2011; 2012) is the only one to suggest that families may be united or separated in their experience of grief, albeit how reactions were the same or different for family members was not a main focus of their analysis. Rather, an important finding in their study was that families held ideas about each other’s appropriate way to grieve. Walter (2000) has pointed out that families denote an important locale of “policing grief” through their family norms and dynamics. Culturally embedded norms and beliefs about a right or good way to grieve co-shape families’ experiences of grief, and they also constitute an individual’s possibility to express and live his or her grief (or absence thereof) in unique ways (Black et al., 2014; Moules et al., 2004; Walter, 2000). Although a few family members in this study took issue with expressions of absence or presence of another member’s grief in this study, most participating family members respected each other’s unique situations and understood their member’s sense of loss as an expression of the relationships they had had with the deceased and of the kind of person as which they knew them. Some even stressed the importance of respect for each other in their individual efforts to live with the situation. This finding is somewhat contradictory to some writings in grief that posits that family members
may indeed have fixed ideas about who should and should not grieve in which way; an occurrence that has been termed as disenfranchised grief (Doka, 2008). One reason for the absence of such beliefs or expectations about each other’s way to grieve may be that families who took part in this study were families who had learnt over the course of their multigenerational family life to respect differences. In fact, multigenerational relationships thrive best when differences are acknowledged and accepted (Chambers et al., 2009; Conidis, 2010; Silverstein and Giarrusso, 2010). However, it is important to note that those families who live disrespect in relationships might not have been represented in this study. Moreover, many propositions about grieving families are based on couples or families with younger children. While couples may indeed find it difficult to see and respect each other’s unique ways to grieve, and find their couple relationships become undone when they do not find a way to share their life with loss (Barner and Rosenblatt, 2008; Hagemeister and Rosenblatt, 1997; Rosenblatt and Barner, 2006; Umberson, 1995), this might not be the case for multigenerational families in later life. Lastly, another interpretation may be that understandings about grieving families to date have failed to acknowledge the complexities of families’ life with loss. Family members are embedded in multiple and overlapping relational webs of connections, which are way more ambiguous and paradoxical than commonly assumed (Baxter, 2004; Hartrick, 1995; Hartrick and Lindsey, 1995; Moules, 2009; Parse, 2009).

7. 6. Family transition patterns in later life: The bearings of the deceased’s absence on family concerns, involvements, and belonging

Throughout their lives, families see themselves confronted with many unfamiliar and challenging situations that constitute the very essence of family life (Chambers et al., 2009; Parse, 2009; Wright and Leahey, 2013). As they experience the comings and goings of persons that join or leave the family, or are confronted with new, unfamiliar situations, families affirm or recreate their collective lives (Attig, 1996; Parse, 2009). In light of a new situation, established patterns of being and doing family may continue to work and hold meaning, or require a profound reorientation (Attig, 2004). Following the death of their close other, families in this study did indeed face such a new family situation. The vacancy left by the deceased, together with the particular health context of the widowed older family member co-constituted families’ challenges in their lives to come. Many participants recreated their
involvements, their doing; and felt differently about their family, their being and belonging. However, the extent to which their situation of bereavement required them to figure out their concerns and involvements anew, and the degree of change they experienced in their belonging together differed considerably.

7.6.1. Families’ new contexts: Concerns, involvements, and closeness

For participants, the deceased’s absence in family life unfolded in the specific context of later life. All families had a widowed member who was around 80 years of age and who lived alone with a responsibility for a household or house and garden. A couple of widow/ers in the study felt as fit and healthy as ever, but most lived with some health limitations, such as musculoskeletal pain or a chronic condition, and felt that their advanced age had put a lid on their energy. This new situation of the widowed person – living alone in a time in their lives in which they expected to lose rather than to gain energy, to face more rather than fewer health problems, and to rely more on others rather than less – constituted families’ concerns.

Family concerns in later life: Family participants focused on the well-being of their widowed member. Similarly, a previous study with several members of the same family following the death of a husband / father in later life also reported that adult children’s new role centred on the concern for their mother, and where and how she would live out her life (Black et al., 2011). In focusing on their widowed member, some family participants appreciated that their widowed member was self-reliant and did not depend on help, whereas other families worried, either about their widowed member living alone with persistent health limitations or emotional turmoil related to the loss. It seems that family interactions and support, defined as attending to each other’s needs, vary considerably among families following the death of a close other, also due to the specific health situation (Wiegand, 2012). Previous caring patterns also matter in how families’ concerns for their older widowed members unfold (Bennett et al., 2010). Findings from the longitudinal Changing Lives of Older Couples (CLOC) study indicate that previous family features, such as social support or intergenerational ambivalence, investigated from the perspective of the widowed member, were the two most important predictors of support from children (Ha et al., 2006, Ha, 2008), and level of ambivalence following the loss (Ha & Ingersoll-Dayton, 2008), respectively. In the CLOC study, widow/ers received more support from their social network than their married age-counterparts, but did not differ in their availability of a close confidante six months following the
loss, in contrast to 18 months after the death, at which married older persons had significantly more often a close confidante to rely on than widowed older persons had (Ha, 2008; Ha and Ingersoll-Dayton, 2008). These findings suggest that families tend to rally around their close other early on, giving concrete emotional and practical support and taking on the role of a confidante, in contrast to later on, at which point family support and the availability of a confidante seems to have somewhat worn off (Ha, 2008; Ha et al., 2006; Ha and Ingersoll-Dayton, 2008).

While it is not possible to, nor the aim of this study to make claims about the extent of change in family support over time following a family death, participants reported spending more time together and to have more practical dealings with each other in the months following the death than they did later on, when their communal lives became established in a new way. The findings about families’ concerns and their mutual involvements thus illuminate how the doing of families unfolds in later life bereavement, and is constituted by the unique circumstances in later life, such as health limitations, issues around independence, and living situation.

**Family belonging and closeness:** For some families, facing a family death had a transforming effect for their sense of being a family or their degree of closeness. The insights that families took away were both positive and negative, although positive, reaffirming insights about their family prevailed for participants. The transforming ramifications that a shared experience of a family death can unfold on families’ sense of closeness and belonging has been previously found. For instance, on study reported that families felt strengthened in their family “we”, and experienced a desire for closeness following a family death (Black et al., 2011; Black and Santanello, 2012). In another study, couples experienced greater closeness following the death of a parent, not only because they shared feelings and talked about the person who had died, but because they shared an awareness that they had gone through something very difficult and painful together that enabled them to experience mutual support, reliance, and understanding (Rosenblatt and Barner, 2006). Similarly, an increased sense of closeness in this study arose for families from their ability to share life in different and new ways as a result from walking alongside and sharing a concern for each other and about the widowed member. A sense of belonging also surfaced for participants from their shared experience of the death, which instilled them with an assuredness and confidence in their future. Inner-family strength; that is, working together and relying on each other has indeed found to be an important factor of family resilience following a loss (Greeff and Human, 1994; Greeff et al., 2011).
However, not all family participants or members experienced greater closeness, or took away insights about their sense of being a family. In particular those families who already felt very close before the death, and continued to feel and act in close interaction following the loss did not feel that anything had changed beyond the painful absence they were struggling with. Moreover, those families who felt that the death did not reverberate much in their family life also did not see any changes in their sense of being a family. These families felt not as affected by the death in their sense of being and belonging, and the death did not mean that they experienced a new strength or growth as a family. It has been previously reported that some families or couples even experience greater distance, or families found themselves increasingly falling apart, in particularly so when they held mutual resentments that they could not resolve (Black and Santanello, 2012; Rosenblatt and Barner, 2006).

7.6.2. Family patterns of transition in bereavement

A family death denotes a time of transition in families’ (developmental) lives (Kralik et al., 2006; Meleis et al., 2000). Family participants, in light of their unique family situations, varied in their experience of continuity versus change in their family lives following the loss. Some families did experience a time of transition as they re-created their family doing. They had to re-learn what members’ actions stood for, or face upset arising from different expectations, for instance about the support that should be forthcoming from family members. For others, the familiar feel in daily family life had evaporated with the death. Whenever these families got together, everything felt different, and their transition entailed recreating meaningful ways of being a family. Yet some families felt their interactions and involvements were still the same as before the loss, and they did not experience a period of change or adjustment in their family life. This study thus revealed different patterns concerning the nature and extent of families’ transition.

**Transition concerning family interactions (the doing of family):** A disruption of established family interactions that required families to renegotiate their interactions occurred for those three family participants whose widowed member faced limitations, required some sort of support, and whose family members struggled to meet these need. Families’ transition included an ongoing process of figuring out what was at stake for their family life, and to continually and repeatedly negotiate what worked in the overall context of their lives (Connidis and McMullin, 2002). For these families, the implications of their disruption in family life was closest in
meaning to the systemic view that a death “disrupts the family equilibrium and established patterns of interaction” (p.12), and requires families to “realign relationships and redistribute role functions to compensate for the loss and restabilize family life” (Walsh and McGoldrick, 2004b, p. 25) (see also Detmer and Lamberti, 1991; Hayslip and Page, 2013; Kissane, 2014; Shapiro, 2001; Walsh, 2014).

It has indeed been reported that the death of a family member can bring about a dramatic shift in parent-child and sibling relations, including conflicts, in particular when caring commitments are called for and siblings fail to reach some form of mutual consensus about how to give support (Bedford and Avioli, 2012; Connidis, 2010; de Vries, 2012; Ingersoll-Dayton et al., 2003a; Ingersoll-Dayton et al., 2003b). At the same time, it has been noted that parent-child relations exhibit remarkable stability and continuity when one parent becomes widowed (Sechrist et al., 2012). The concept of ambivalence within parent-child relationships in later life might thus be useful to explain these contradictions and understand what happens for bereaved families in later life when faced with a new situation and concerns that disrupt their habitual way of interacting (Luescher and Pillemer, 1998). Ambivalence refers to the contradictions and paradox that exist in relationships; to “simultaneously held opposing feelings or emotions that are due in part to countervailing expectations about how individuals should act” (Connidis and McMullin, 2002, p. 558). Life transitions, such as a family death, may increase tensions and the need to negotiate ambiguous and contradictory feelings and needs (Baxter, 2007; Ha and Ingersoll-Dayton, 2008; Luescher and Pillemer, 1998; Willson et al., 2003; Willson et al., 2006). Such ambivalences within family relationships became evident in this study. The way that competing ideas, in particular between a widowed parent and an adult child, or among siblings reverberated in family participants’ lives required that they did negotiate their ambivalences in one way or another to make their family lives viable. Siblings in a few families had to negotiate how they provided support, which included conflict for some, and time investments for other. Some widowed persons in this study expressed some ambiguous feelings towards their children’s availability for concrete help, while also feeling concerned about not wanting to bother or burden their children too much. Such ambiguous feelings have previously been reported by Talbott (1990), who found that about half of mothers in later life felt neglected or unappreciated, were dissatisfied with the amount of help they received, and also felt apprehensive about both bothering and burdening their children. In contrast, support from family members has also been
found to be particularly appreciated and helpful for widow/ers, with adult children taking on a central role in helping their widowed parents (Ha, 2008, 2010; Ha and Carr, 2005; Kanacki et al., 1996; Pinquart, 2003). Such appreciation was also found in the current study, with widowed persons emphasizing how well embedded they felt within their families. For participants, their new intergenerational family situation included to either figuring out anew, or to accept the fact that a child or sibling did not act in the expected or hoped for manner. It is important to note, however, that family negotiations about the kind and amount of support occurred for some families, yet not for all. In this study, intergenerational challenges were limited to those families whose widowed member was in need of some form of emotional or practical help.

Transition concerning the absence (the being of family): Another way that the death reverberated in families’ lives concerned the absence of the close other. Those families who experienced a unified, painful emptiness and profoundly missed their close other felt, at least at the beginning, paralyzed by the vastness of loss, and tried to keep going as before. Their experience was similar to Attig’s (2004) proposition that some ways of acting in the world cease to be meaningful, whereas others still work and sustain those bereaved. Over time, these families recreated ways to meaningfully be family through their beloved, shared activities in different, new ways. For instance, in one family, through the process of dropping by again and again at their mother’s house, the daughters got used to the fact that only she was there, and appreciated that their own children could stay and make more noise, which had not been possible before. In another family, members whose close other had died suddenly needed to find a way to connect directly with each other in order to keep going as a family. In those families, widow/ers were self-reliant and well, or the family was so close that helping their parent was simply part of their daily life, and did not arise as a new or specific family concern.

Transition as continuity: Lastly, for four families, their taken-for-granted way of living family was not questioned with the death; rather, what changed was that they felt enabled to speak about the family time leading up to the death, and the deceased’s life in different ways. One possible explanation for families’ uninterrupted continuation in life may reside in the fact that death happened following a long illness time during which the close other withdrew slowly but steadily from family life, and during which families already organized themselves
Participants’ descriptions did indeed reveal that their close other’s mental illness, or a difficult marriage, had placed some sort of restriction on their family lives, so much so that they had created family interactions that existed independent of the deceased. The continuity in family life, arising from a good conclusion to challenging and long times together prevailed for these families. Their sense of relief and/or gratitude is similar to reports from research with family carers, which demonstrated that a death may come as a relief, rather than bring about grief when the work of caregiving or family relations (i.e. marriages) were particularly challenging (Pruchno et al., 2009; Schulz et al., 2001; Schulz et al., 1997; Stajduhar et al., 2010c). In addition, these families appreciated a moment in their family life during which they did not need to worry about their oldest member, and felt assured about their well-being. Widow/ers cherished their self-reliance despite their advanced age and health limitations. They not only felt disburdened from the restrictions of caregiving, their family members also tended to worry less than before the death.

7.6.3. Concluding remarks about family being and doing in later life bereavement

This study proposes that the being and doing of family matters not only during caregiving and end-of-life, but in bereavement (Brazil et al., 2003; Schulz et al., 2001; Schulz et al., 2008; Stajduhar et al., 2010c). In later life bereavement, older family members’ expected or actual increase in need for support in daily living, together with family members’ worries about their well-being and struggle to provide meaningful help, constitute their concerns (Chambers et al., 2009; Connidis, 2010; Sechrist et al., 2012). Families also experience different patterns of transition that ranged from considerable change to stability. Only one study was identified that described a range of possible family trajectories after a death. In families following the withdrawal of life support due to an unexpected sudden illness or injury, Wiegand (2012) identified different types of family management styles, which differed in terms of their “management behaviours”; that is, according to their ability to understand the death in the wider context of their family worldview, to interact and communicate with each other, and in their efforts to attend to each other’s needs. Families’ styles also varied according to the “perceived consequences”, such as health effects on surviving members, the ensuing emotions, families’ ability to move on, and the weakening or strengthening ramifications on their family ties. These “management behaviours” and “perceived consequences” bear some resemblance
to the findings in this study that capture how families continued to be and do family in a variety of ways. While Wiegand (2012) typified different family styles based on pre-existing theoretical ideas about how families manage when faced with a health crisis, this study brings forth patterns of family transitions that capture the variety of ways in which families continue their lives after a family death. The coexistence of both change and continuity somewhat questions the widespread assumptions that families’ taken-for-granted life-world (Attig, 1996, 2004), or the equilibrium of their system is disrupted (Gilbert, 2007; Jeffreys, 2014; Walsh, 2014; Walsh and McGoldrick, 2004b, 2013), suggesting that for some families, collective life and their sense of closeness simply continues unchanged. The qualitative nature of the study and the number of family participants belies the possibility to draw explanatory conclusions, or to describe the commonality and variance in family patterns of transition in more depth, respectively. However, it can be posited that the nature and extent of transition and change that occurred in bereaved families arose from their specific context and unique family configurations. In her family conceptualization, Parse (2009) contended that ever changing, unfolding possibilities are essential to family becoming, which arise “with the comings and goings of those persons named a family by individuals” (Parse, 2009, p. 308). With such comings and goings, “an infinite number of options are available to coshape the transfiguring of family” (p. 308). Such transfiguring moments enable families to initiate anew and persistently go on. For some of the participating families, the unfamiliar predominated, and they created new ways of being and doing family, whereas for other participants, the familiar pervaded.

To date, the concrete ways that families care for, and support each other through doing; the acting towards and for each other during particularly vulnerable family times, such as end-of-life and bereavement has received scarce attention within family research. This study is one of the first family bereavement studies to illustrate the manner in which family caring is enacted through the mutual flow of concern, partaking, and concrete help among persons who see themselves as family.
8. Recommendations and conclusions

How does what we have learnt from bereaved families inform theory, practice, policy, and research?

The interpretive potential of this study is constituted by its methodological grounding in hermeneutic phenomenology. The aim of interpretive inquiry is “to respectfully understand the lifeworld, critically evaluating what is oppressive, ignorant, or troublesome from the perspective of the participants and identifying sources of innovation and liberation within everyday practices” (Benner, 1994, p. 123). The benefit of phenomenological research is that it provides practitioners with “tactful thoughtfulness: situational perceptiveness, discernment, and depthful understanding” (van Manen, 1990, p. 156). This study’s interpretive power and scientific merit thus lies in its capacity to enlighten nurses and other health professionals in their understanding of the unique situations of bereaved families, and to enact the good and ethical in their clinical practice (Benner, 1994b; van Manen, 1990). Families’ voices, as represented and interpreted in this study, have the potential to challenge the constraints in clinical practice and to question health care structures that neglect families’ relational experiences. Furthermore, the in-depth findings about families’ experience of loss give rise to a range of possible ways that nurses and other health professionals may be helpful for families following the loss of a close other late in life.

In this concluding chapter, key insights about bereaved families are highlighted, and theoretical contributions are delineated. Implications for health policy, along with recommendations for care delivery are outlined. In so doing, it is demonstrated that family-centred care structures and processes, along with relationship-focused family interventions may be beneficial for bereaved families, although not all families may need clinical attention. Recommendations for clinical practice with bereaved families to facilitate meaning-making, strengthen relationships, and support family transitions and caring are elucidated, and concrete modalities are suggested for nursing practice. While this interpretive study sheds light on families’ meanings, patterns and practices during bereavement, much remains unknown. Thus, future research is needed to increase understanding of diverse families and the specific family processes in bereavement, as well as to discern needs for care and to evaluate specific nursing interventions for bereaved families. A synthesis of the study’s interpretive approach and reflections on the core findings conclude this chapter.
8.1. What the study reveals about bereaved families

Four key insights about bereaved families can be gained from this study. First, living with loss arose as an inherent family capacity. Second, when bereaved, (family) relationships denote a resource. Third, storytelling lies at the heart of families’ meaning-making and enables them to integrate the death into their shared past. Fourth, living family in bereavement is an ever-shifting interplay of multiple, contradicting forces and voices engaged in a mutual, dialogical process.

8.1.1. Living with loss: An inherent family capacity

Families have an inherent capacity to live through new and unfamiliar situations that arise from critical experiences, such as a family death, and they do so in their unique and diverse ways. This study revealed that families who lost a close other late in life are well able, over time and in making an additional effort, to make meaning of and create peace with how death unfolded, to live with the emotions through sharing them while also understanding and respecting differences and their non-sharability, and to work out new or continued ways of being and doing family in light of their new situation. The study findings illustrate the common and diverse ways that families rise up to the challenges of loss, and demonstrate that families hold considerable capacities in moving forward as a family. Therefore, the manner in which families in this study lived with the loss of their close other denotes an inherently healthy process of living family. Families’ challenges, tensions, disagreements and connections are an expression of the range of experiences inherent to human life and relationship. As such, this study adds to a growing body of knowledge that stresses person’s resilience in living with loss and extends it to the family level (Bonanno et al., 2004; Neimeyer, 2014; Rumbold and Aoun, 2014; Stroebe et al., 2007; Walsh, 2014).

Families’ lived world as disclosed in this study defies pathologizing attempts and expert interventions that are based on judgements about normal and abnormal, healthy and unhealthy ways to function as a family or to live with grief (Aoun et al., 2012; Harris, 2009-2010; Moules, 1998; Moules et al., 2004). Nurses and health professionals should therefore refrain from making value judgements based on deeply engrained ideas about how families should or should not cope with a loss, or what families ought or ought not do and feel. Labelling families’ responses to loss as healthy, functional, or appropriate for the type of loss, or the life phase holds no meaning for families and does not capture their lived world of loss. Also, care based
on predetermined ideas about desired outcomes, such as how grief should be overcome, or how families should cope with the loss in a particular way, is uncalled for (Cody, 1995b; Moules, 1998). Findings question the widespread bereavement support models that are built on the assumptions that grieving people have a problem with experiencing grief for which they need psychological or psychiatric interventions (Aoun et al., 2012; Rumbold and Aoun, 2014). Rather, health professionals should engage in health promoting practices to seek a family’s multiple and coexisting perspectives and actions, and co-participate with families to identify their capacities, adversities, and potential needs in bereavement (Aoun et al., 2012; Hartrick Doane and Varcoe, 2005a). In so doing, they should skilfully assess families’ vulnerabilities and possible risks for abiding suffering that may limit their health, well-being, and ability to live daily life and family in for them meaningful and supportive ways (Agnew et al., 2010; Relf et al., 2010).

8.1.2. Family relationships: A resource in bereavement

Families are committed and relate with each other to face their new situation of bereavement in later life. In this study, participants’ relationships were concrete sources of comfort, care, love, security, and practical help and emotional support. Families drew on their past shared history, relational connections, established routines, and sense of community to live with the close other’s physical absence in their lived world of family. Within their family connections resided the strength and aptitude to find meaning, live with the loss, and (re-) create their family being and doing. For families in later life, bereavement may include discords or upset in relationships about how to best do family, which may pose new adversities with which they struggle. However, the death of a close other may also disburden relationships from strenuous caregiving and constant worry. This study revealed that families live with their loss, to a large extent, by drawing on their relational past.

As a consequence, practitioners should appreciate the importance of family and other relational connections when encountering bereaved older persons, and acknowledge that the absence of such connections may be as constitutive of older persons’ family experience in bereavement as is the availability of family (Hartrick Doane and Varcoe, 2005b). This study builds a strong case for practitioners in any setting to actively involve family members, and to open up a space in which families can appreciate their relational capacities, and work out how to be most helpful to each other (Bell, 2011; Hartrick Doane and Varcoe, 2005a). Clinical work should
recognize family and community resources, facilitate family processes and strengthen capacities. If family members are non-existent, absent or unavailable, practitioners should be aware that bereaved older persons still experience family, even if their experience may be one of feeling isolated and alone, and elicit older persons’ relational experiences, what family means for them, and how their family situation constitutes their lives and potential need for lay or professional support (Cody, 2000b; Hartrick Doane and Varcoe, 2005b; Rumbold and Aoun, 2014).

8. 1. 3. Family storytelling: At the heart of the matter

When facing a life-changing event, such as a close other’s death, families make sense of their lives, re-shape their purposes, and construct their identities through talking and storytelling (Attig, 2001; Baddeley and Singer, 2009; Neimeyer, 2001a; Sedney et al., 1994; Walter, 1996). Storytelling aids healing and family relating (Kiser et al., 2010); it is a way of knowing and reflecting to construct meaning, and to connect disjointed events or experiences and different perspectives into an intelligible whole (Taylor, 1997). Bereaved families engage in extensive storytelling to negotiate differences, to share or withhold information, as well as to complement or affirm each other’s individual perceptions and meanings, which allows them to come away with distinct family meanings and a shared story of the death, and create peace with how they managed end-of-life, the dying, and the aftermath (Nadeau, 1998; Rober et al., 2012). This study reveals the manner in which families used stories to create family meanings of the death, which they interactively weaved together to form a coherent family narrative. Storytelling lies at the heart of families’ meaning-making endeavour, and co-creates their lived reality, the fabric of their family life (Kiser et al., 2010; Moules and Amundson, 1997; Moules and Streitberger, 1997; Nadeau, 2001a). Families story their lives, and how they tell their stories matters because stories carry within them how people feel and act (Gilbert, 2002; Hedtke and Winslade, 2004; Kiser et al., 2010).

To encourage meaning-making and families’ interactive weaving of their family narrative, nurses should invite and listen to families’ stories. Remembering conversations and storytelling create a unique opportunity to shape and re-shape meanings in relation with others; an opportunity that nurses and other health professionals should seize (Hedtke, 2014; Kiser et al., 2010; Moules and Streitberger, 1997; Taylor, 1997). As Hedtke and Winslade (2004) explained, “helping people reach acceptance gives way to helping them construct meanings
which will sustain them through the transitions that death demands” (p. 43).

Narrative approaches to medical and social care seem to be well suited to co-create opportunities for families’ meaning-making, and may help to re-story their lives in a way that creates peace with past suffering (Hedtke, 2014; Moules and Streitberger, 1997; Nadeau, 2008; Parry and Doan, 1994; White and Epston, 1990).

8. 1. 4. Living family: The interplay of multiple, contradicting voices engaged in a dialogical process

In bereavement, family is a multidimensional, ever-shifting interplay of different voices and contradicting forces that move together and apart in their shared and individual efforts to live with the loss of their close other. The findings support family models that emphasize the complex, multivocal, contradictory, relational, contextual, and continuously shifting nature of family health that arises through family values, priorities, situations, relational patterns, and ways of being and doing family (Baxter, 2004, 2006; Baxter and Montgomery, 1996; Hartrick Doane and Varcoe, 2005a; Parse, 2009), but question some of the family bereavement tasks of adaptation (Walsh and McGoldrick, 2004a). This should not be surprising, since this study departed from a critique, not only of normative, stage-like conceptualizations of grief, but of distinct ideas about families as a group of people who hold distinct roles and functions specific to a certain stage in their lives. Theoretical ideas of adaptation, in fact, operate on the assumption that families have to work through some communal tasks in order to get used to their new situation without the deceased (Attig, 1996). Thus, the conceptualization of family tasks arises from the idea that families denote a distinct configuration of people who need to function in a certain way to achieve maximal health and well-being. The premises that families’ way of doing things to minimize conflict, emotional tension, and family estrangement equips families best for bereavement might fall short from helping nurses and other health professional to understand diverse family processes in bereavement. The study’s findings demonstrate that such task-oriented ideas, albeit potentially useful in certain situation, fail to capture the complexity, paradoxical nature, and oscillating ways that families make meaning, live with loss, and move forward as a family. In contrast, more relational, contextualized and dynamic understandings of family health are more suitable to capture families’ complex and multi-layered experiences following a family death. Although the family conceptualizations used are not specific to bereavement they can accommodate empirical knowledge about family bereavement, for instance as generated by this study, to inform nursing practice
The findings of this study can be seen as a useful, empirically-based addition to existing theoretical ideas about family bereavement. They question some of the mainstream theoretical propositions about family bereavement, and posit them as limiting understanding and action in clinical practice, and as unhelpful for families’ struggle to create a meaningful family life.

8.2. What the study means for today’s health care system

Three implications can be derived from this study for the delivery of care in today’s health system. First, family members of an ill and dying person should be explicitly recognized as recipients of care in their own right. Second, attending to family processes in bereavement has the potential to achieve positive health outcomes for families. Lastly, relational approaches to practice are required to empower bereaved families.

8.2.1. The need to recognize families and family carers as recipients of care

Family members denote an important source of support in later life, and take on the brunt of emotional and practical support that would otherwise fall to formal health and social care agencies (Andersson et al., 2003; Buckner and Yeandle, 2011; Grande et al., 2009; Greaves et al., 2002). Increasingly, today’s health care system delegates care to families without providing adequate services and resources (Hudson, 2013; Hudson and Payne, 2011; Stajduhar et al., 2010a). In Switzerland, recent changes made to how services are funded implicitly rationalize services, and shift the financial burden and responsibility from acute care to communities and families (Madörin, 2014; Schubert et al., 2013). Because health services are usually geared towards the ill and dying person, they end with his or her death.

This study points out that it is necessary to create structures and processes of care that recognize and include family members across the continuum of care (Help the Hospices, 2009; National Institute for Clinical Excellence, 2004; Registered Nurses Association of Ontario, 2006a, b). Families in this study played an active role in the care of their ill and dying member at home, and continued to look after each other in their changed circumstances of bereavement. Some widow/ers who were carers themselves before the death of their spouse became those cared for by their
offspring thereafter. Hence, family caring shifted in how it unfolded; that is, within which dyads, in its level of intensity, and in relation to its central concerns and challenges. The need to support family carers does therefore not necessarily end with the death of the ill member. If close others were to be explicitly recognized as recipients of care, service delivery could continue based on families' needs, rather than end with the occurrence of a death, as it was the case for families in this study. Minimizing family members' unique risks and vulnerability for suffering in bereavement is part of health professionals’ duty of care (Aranda and Milne, 2000; Relf et al., 2010). Thus, the explicit recognition of family members and family groups as recipients of nursing care throughout the continuum of care is called for, and including family members into delivery of care should become a routine part of nurses' work in any setting.

8. 2. 2. The need to attend to family processes in addition to outcomes

In later life and during bereavement, attending to family processes may act as a preventive and therapeutic strategy to promote family and individual health, increase quality of care, and improve effective service delivery (Ayers et al., 2004; Gustafsson et al., 2013; Victorian Order of Nurses, 2012; Wimpenny et al., 2007). When family relating and caring is supported, older widowed persons are more embedded in their family network that enables them to remain in their own homes. Families may also be better able to provide care and rise up to the challenges of supporting each other without or with less adverse consequences for their own health and well-being (Borland et al., 2014; Mahrer-Imhof and Bruylands, 2014). This study makes a case for the centrality of family processes to families' well-being in bereavement; such as the processes of making meaning, of entering, staying, and re-engaging in relationships, and of being and doing together in a community of committed persons. Thus, facilitating families' healthy processes may promote positive family outcomes.

In today's outcome driven health care system, the importance of the processes itself; that is, the paths for healing, the unique and diverse ways to live with loss, and specific needs of real-life families are easily overlooked and relegated to be of lesser importance (Cody, 2001b; Schubert et al., 2013). However, a focus on bereavement outcomes alone fails to capture what matters to families. For families in this study, the absence or presence of grief or conflict, or their exact level of functioning held less relevance. Rather, what was of concerns for them was how
they could find meaning, live together and separately with the loss, and transition into their new family situation. The interconnectedness of family processes and outcomes should therefore be recognized, and attention should be given to how families live with loss, and not only to predetermined outcomes of family health or functioning when assessing effectiveness of bereavement care.

8. 2. 3. The need for a relational approach to empower families

Findings point to a need for a relational approach to work with families to negotiate and create an optimal situation for bereaved families. In the current discourse of cost-efficiency, those providing care and treatment (i.e. professionals and lay carers) and those receiving care (i.e. individuals and families) disappear behind standardization, streamlining of processes for maximum output, and objectively measurable outcomes to which efficiency figures can be attached (Madörin, 2014). The long-standing evidence that care services are essentially relationship work that is socially negotiated, occurs in particular situations and places, emphasizes meanings and human engagement, and become therapeutic and healing because it is enacted in human practices of care, is increasingly disregarded even though it has been consistently found to be essential for quality care (Dosser and Kennedy, 2012; Lowson et al., 2013; Malone, 2003).

In this study, living with loss unfolded within relationships among family members, but also with others around them. For instance, the manner in which “being-in-relation” with the researcher facilitated families’ meaning-making and sharing, and negotiating caring despite the fact that the intent of the encounter was not a therapeutic one, suggests that relationship work is fundamental to clinical practice that aims to help families in bereavement. In clinical practice, nurses should create opportunities for individuals and families to build their capacity in living with their unique challenges and suffering (Currier et al., 2008a; Hartrick Doane and Varcoe, 2005a; Moules, 2009; Moules et al., 2007; Thirsk and Moules, 2013). Through being present in a human-to-human relationship based on a specific expertise about the nurse-family process, nurses potentially co-create family health, nurture healing, alleviate suffering, instil hope, and strengthen family practices (Bournes and Naef, 2006; Hartrick Doane and Varcoe, 2005a; Naef, 2006; Parse, 1998; Watson, 2003). Nurses’ presence with bereaved families has not only the intention to be health-promoting, but has also the potential to be therapeutic in that it reconciles differences or invites family groups or individuals to respect the limitations present in
other family members or their specific family situation, thereby co-creating new family practices (Thirsk and Moules, 2012, 2013; Wright and Bell, 2009; Wright and Leahey, 2013). For instance, through brief therapeutic conversations, nurses can strengthen family capacities and relationships and soften suffering (Bell, 2011, 2013; Chesla, 2010; Hartrick Doane and Varcoe, 2005a; Svavarsdottir et al., 2012; Wright and Bell, 2009; Wright and Leahey, 2013). Thus, the importance of working relationally with bereaved families cannot be emphasized enough.

As a consequence, nurses and health professionals should be able and be enabled to attend to relational family processes in later life and bereavement through care structures and processes that value process and relationships, and which recognize relationship work as an important determinant of quality of care. It is vital that whenever nurses meet families, they engage in a relational practice that includes, first, getting and staying in sync; second, taking a stance of respectful inquiry through asking questions, listening and attending, and identifying needs and concerns; and third, offering therapeutic conversations during which families take the lead and nurses refrain from wanting to change or move families on in a particular way (Hartrick Doane and Varcoe, 2005a; Hartrick Doane and Varcoe, 2005b; Parse, 1998; Thirsk and Moules, 2013; Wright and Leahey, 1999). Nursing education and professional practice development initiatives should explicitly empower nurses to provide family-centred, health-promoting care and specific family nursing interventions in bereavement (Registered Nurses Association of Ontario, 2006b; Victorian Order of Nurses, 2012). A culture that values families and relationships, and which recognizes and seeks to acknowledge vulnerability and soften suffering is needed (Wright and Bell, 2009). In such a culture, therapeutic work can be fostered, and continuity of care that starts in end-of-life care and continues into bereavement ensured (Johanna Briggs Institute, 2006). Findings question the predominant focus on efficiency and cost-effectiveness of care that constrain health professionals’ moral agency and rationalize resources urgently needed for individualized, person and family centred care in any setting.

8. 3. An agenda for action I: Care and services for bereaved families

Different health professionals, such as nurses, social workers, family physicians or chaplains, among others may ensure continuity of services from end-of-life into bereavement, offer needed care when they encounter bereaved families, and
provide or create access to specific bereavement services (Arthur et al., 2011; Ayers et al., 2004; Field et al., 2007; Hashim et al., 2013; Kissane and Dumont, 2014; Neimeyer, 2012; Victorian Order of Nurses, 2012). This study suggests that practitioners may act as a catalyst for family meaning-making, discerning and respecting shared and diverging experiences, and for finding a way to live family in their new constellation and with their new concerns. While it has been demonstrated that a majority of bereaved families do not need psycho- or family therapy (Kissane and Dumont, 2014; Kissane et al., 2006), it has been found that families benefit from health-promoting, family-centred care and family nursing interventions when they experience health challenges (Chesla, 2010; Hartmann et al., 2010; Östlund and Persson, 2014; Svavarsdottir et al., 2012). Creating access to and providing family-centred services during bereavement has been explicitly recommended for cancer care settings by the UK National Institute for Clinical Excellence (NICE, 2004). The NICE guidance advises the use of a three-component bereavement support model, and suggests that all bereaved family members should receive information about bereavement, available services, and how to access them (level one). Family members who feel a need to review and talk about their loss experience should in addition receive a formal opportunity to do so, either through community and volunteer services or from health professionals (level two). Lastly, level three involves the provision of specialist interventions that meet the particular needs of vulnerable groups (level three). In this study, it became indeed evident that families or individual members who lost a close other late in life due to a variety of causes are well able to live with the loss in the context of their family and community (level one of NICE model), but have nonetheless a need to talk about past experiences of caregiving and end-of-life care, the death, and the many challenges, difficult moments, and new issues they face in bereavement. Is so doing, they may appreciate the presence of a health professional (level two of NICE model). The study findings indicate that specialist family nursing interventions should be available to bereaved families (level three of NICE model), although they may only be called for in certain situations.

8. 3. 1. Creating family-centred practices in end-of-life and in bereavement

During end-of-life care, nurses’ presence may soothe families’ strains and uncertainty, and reassure the family that they are not alone (Borland et al., 2014; Griffiths et al., 2013). Participants repeatedly emphasized how important and calming nurses’ concrete care, information-giving and talking about the dying itself,
and their availability during the last days of their close other’s life was. When participating families talked during interviews directly about how nurses and other health professionals could, or had been helpful to them, it was through respectfully listening to them and their needs, concerns, and questions, and by attentively acting based on what was important to individuals or whole family groups. What was also appreciated by families were the moments created by nurses (and the researcher during the study) that had allowed them to come together and talk about their painful and challenging family situation, during which a nurse not only created the space, but also facilitated the actual process of talking about, for instance, dying, and commending their family way of doing things.

During end-of-life care in acute, long-term, or home care, nurses and other health professionals should be aware that the circumstances of the death, such as family members’ feelings of preparedness and their wish to be present, as well as the peacefulness of the death matter for families, facilitate their meaning-making efforts, and positively influences their loss experience (Stroebe et al., 2007; van Gennip et al., 2013). This study revealed that when families had an opportunity to co-participate and contribute in their preferred manner to end-of-life care, it was easier for them to make peace with the manner death happened to their close other and their family. Nurses in any setting in which people die should therefore attend to families’ need to talk about their preferences and wishes with each other and / or the health care team, and provide appropriate symptom management to prevent unnecessary agony.

Nurses and other health professionals should also assess whether families have a need for follow-up care early on after the death, and create access for families to ask questions or talk about the end-of-life and the dying itself (Agnew et al., 2010; Lebus et al., 2014; Payne and Relf, 1994; Relf et al., 2010; Wimpenny et al., 2007). For some participants, questions about the nature of the death lingered, and they lacked the opportunity to turn to health professionals who had been caring for their ill member at the time of the death. Routinely offering a family conference following the death could be helpful for families, and facilitate their meaning-making process (Lebus et al., 2014). Rituals invited by an institution, for instance an annual remembrance service for all families of persons who had died in a nursing home, or symbolic caring gestures, were also described as meaningful and comforting by participants (Field et al., 2004; Reid et al., 2006b).

After a family death, nurses and other practitioners should be aware of the importance of family relationships and practices to people’s bereavement
experience whenever they encounter an individual in any care setting. Some recently bereaved widowers in this study required primary or acute care within the first year following the death because they faced an unstable health situation. Their need for care was constituted not only by their health issues, but their sense of loss and available family connections and support. Health professionals should therefore be aware that a recent loss has multiple ramifications for older persons’ family and health situation, and offer care to bereaved family members whenever they encounter them.

Primary care also holds a unique role in bereavement support. Most bereaved older persons in this study had regular appointments with their family physician for reasons other than their bereavement situation. Such points of contact with the health care system denote an opportunity to identify individual and family needs and concerns, to provide primary family bereavement care, or make referrals to specialist services (Agnew et al., 2010; Birtwistle et al., 2002; Lyttle 2001; Payne et al., 2002; White and Ferszt, 2009). Health professionals who have been involved with families before are best posited to do so (Birtwistle et al., 2002; Field et al., 2007; Jansma et al., 2005; Lyttle 2005; Milberg et al., 2011; Reid et al., 2006a). Thus, family physicians and community nurses are likely to act as gatekeepers (Harris and Kendrick, 1998; Hashim et al., 2013; Lemkau et al., 2000; Nagraj and Barclay, 2011). However, their manner of and ability to provide bereavement care varies depending on their educational preparedness and knowledge about grief and best practice in bereavement support (Breen, 2012; Breen et al., 2014; Ghesquiere et al., 2013; O’Connor and Lee-Steere, 2006; Payne et al., 2002). Thus, it is important that they work with other health professionals to ensure that family-centred bereavement care is available to those in need (Cruse Bereavement Care, 2013; National Institute for Clinical Excellence, 2004).

8.3.2. Creating services to bereaved families: Family nursing interventions

While family-centred caring practices and primary bereavement care are a necessary part of any professional nursing practice (IFNA Family Nursing Practice Committee, 2014; Victorian Order of Nurses, 2012), working therapeutically with bereaved families tends to lie in the realm of advanced practice competencies (Bell, 2013). Levels of education and clinical expertise nurses have when working with bereaved families determine the kind of services they can offer. Family nursing interventions require clinical expertise and competencies in working with families in
vulnerable situations. Individual nurses should know their capacities and limits, and exercise clinical judgement to determine when a referral for psycho- or family therapy, or other specialist services is needed.

To date, specialist interventions are most often recommended for those within “dysfunctional”, at risk families (Del Gaudio et al., 2012; Kissane and Lichtenthal, 2008; Masterson et al., 2013) or with “complicated grief” (Aranda and Milne, 2000; Ghesquiere et al., 2011; Schut and Stroebe, 2005; Schut et al., 2001; Stroebe et al., 2007), although the definition of the latter remains a matter of debate (Harris, 2009-2010; Neimeyer, 2005-2006; Shah and Meeks, 2012). Accordingly, needs assessment is most often based on risk for, and criteria of family functioning, or presence of “complicated” grief reactions that are considered outside the cultural and clinical norm (Agnew et al., 2010; Harris, 2009-2010; Kissane and Lichtenthal, 2008; Kissane et al., 2006; Masterson et al., 2013). While the normative discourse underlying such needs assessment may be problematic in itself, some discriminatory criteria are necessary when screening for risks. Thus, it has been argued that how family members respond to and cope with loss are as important to bereavement assessment as are risk factors aimed at predicting “unhealthy” outcomes (Brocklehurst et al., 2014; Machin and Spall, 2004; Relf et al., 2010). The findings of the current study give rise to an alternative, complementary frame to discern families for specialist interventions that falls within the scope of advanced (family) nursing practice. They address recent insights that a more selective approach is needed when offering bereavement services (Currier et al., 2008b; Schut and Stroebe, 2005), and answers the call for more health-promoting approaches to bereavement care (Aoun et al., 2012; Aoun et al., 2014).

**Who is most likely to benefit from family nursing interventions?** Families’ descriptions and narratives about their lived situation, and observations made during the interviews brought to the fore that some families may benefit from health-promoting family nursing interventions. This study implies that those families who do not engage in shared meaning-making and cannot incorporate the death into their family narrative, whose inability to share, or differences in their sense of loss instils suffering, or who face a profound upheaval in how to best be and do family, may have the greatest need for family nursing interventions. Family nursing interventions to facilitate meaning-making, strengthen families’ relational capacities, and to soften suffering may be most useful in the following situations:
**When families have a strong need to make meaning:** Family caregiving, end-of-life, and circumstances of the death can leave members exhausted or haunted by difficult and painful memories. They may feel a need to talk about the meanings and ramifications of their past experiences on their present lives and relationships. Different perspectives and needs during caregiving, end-of-life, and the dying may also mean that families want to and can now talk about the manner in which they lived through this special family time.

**When not-sharing and differences in experiences leave family members alienated and alone:** Family members who feel not understood, or find themselves isolated in their experience from others in the family, but would value more connection, may need someone who listens to their feelings, concerns, and perspectives that they cannot or do not want to share with their family. They may also need someone with whom they can talk about how to best relate with their close others (Hooghe, 2012).

**When families and/or individuals suffer:** Families or individual members who suffer because they miss the deceased or feel disconnected from their close others may need someone to be alongside and present to soften suffering (Moules, 2009; Moules and Streitberger, 1997; Wright and Bell, 2009).

**When families struggle with how to make family caring and their involvements work:** Families who find their caring involvements upset and need to figure out how to best support their widowed member, negotiate expectations, and create workable ways for everybody involved may need someone who facilitates discussion about needs, concerns, expectations, possibilities and limitations. They may also need concrete information and advice about available support services.

**When families would like to plan ahead:** Families who would like to plan and prepare for what lies ahead, for instance for future living arrangements, preferences for end-of-life, and family caring arrangements, may need someone to facilitate discussions or to assist in creating a concrete plan of action.

In contrast, family nursing interventions may be uncalled for when families feel content with how end-of-life and family caring unfolded, and at peace with how death happened. When there is little disruption in family life, and when a sense of continuity and familiarity in their lived world pervades, families may not need a nursing presence in their family. Lastly, when families have no reason to worry since their widowed member is self-reliant and lives with only minor health challenges, which s/he can manage to her/his satisfaction and does not feel limited in daily life in interrupting manners, nursing counselling and support may not be required.
How should family nursing interventions be delivered?: It is essential that bereavement care is embedded in the context in which people live (Rumbold and Aoun, 2014). Given the fact that most families in this study have not been involved with specialist palliative care or hospice services, but relied on the care provided by their family physician, general home nursing, and hospitals, does indeed suggest that family interventions should be located in the community to ensure accessibility and acceptability. Nursing bereavement interventions that are part of care programmes offered at the end-of-life in persons’ home, such as general or palliative home care, may thus be well suited to offer services that families otherwise have no access to, and ensure continuity of care (Agnew et al., 2010; Field et al., 2004; Lyttle 2001; Reid et al., 2006a, b). Home visiting programmes and nurse-led family services in the community that offer advanced family nursing interventions to individual members and family groups denote a further unique opportunity to work with bereaved families and to support families through concrete counselling and support (Bell, 2008; Family Nursing Network, 2014; Mahrer-Imhof et al., 2014; Moules et al., 2007; Naef et al., 2008; Thirsk and Moules, 2013). In Switzerland, one such nurse-led family counselling program for families of older persons has been recently established, and denotes a concrete site for establishing family nursing interventions for the bereaved in the future (Mahrer-Imhof et al., 2014, see also http://project.zhaw.ch/de/gesundheit/famber.html).

Based on the study’s findings, it is not possible to draw any conclusions about the timing of family interventions. It is probable that families’ needs and potential to benefit vary depending on their unique situations, and fluctuate over time in a non-generalizable or predictable manner. While family interventions offered by palliative and home care services might be more accessible during the early time, home visiting programmes and family services delivered in the community and primary care might be better suited to reach families later on in their bereavement situation (Rumbold and Aoun, 2014). Thus, it is not only important that families do have ongoing access to family interventions, but that family interventions are offered in a way that fits families’ particular situation at the specific moment in time they seek it (Hudson and Payne, 2011; Thirsk and Moules, 2012). Given the findings of this study that demonstrate how families share and interactively live with loss and move forward together in bereavement, nursing interventions with family groups, rather than individual family members, seems be well founded, although individual interventions may also be called for (Clark et al., 2011; Hartmann et al., 2010; Martire et al., 2004).
The relational nature of families’ experience of loss does suggest that relationship-focused family interventions are most suited to address families’ concerns. Such relationship-focused family interventions aim to strengthen families’ relational capacities and to build skills in communicating, working with differences, and creating viable solutions to the concrete problems that families face when confronted with health challenges (Chesla, 2010; Mahrer-Imhof and Bruylands, 2014; Martire et al., 2004). Reviews of family interventions for patients with a chronic illness have consistently demonstrated that relationship-focused interventions have a stronger effect on outcomes such as depression, anxiety, and burden than do psycho-educational interventions alone (Chesla, 2010; Hartmann et al., 2010; Hopkinson et al., 2012; Martire et al., 2004; Shields et al., 2006; Weihs et al., 2002). When illness is part of families’ concern, a need for information and for skills to manage symptoms and therapy exists – a need that is usually addressed with psycho-educational interventions (Weihs et al., 2002). After the ill member has died, families’ needs differ from that of a chronic illness situation. The study findings demonstrate that the paradoxical and oscillating patterns of family relating are at the core of families’ bereavement experience. Since the loss of a close other denotes essentially a change in relationships on many levels, for instance in relation to the deceased and among those who are left behind, using relationship-focused interventions with bereaved families seems to be most promising.

8. 4. An agenda for action II: Clinical practice with bereaved families

Based on the study findings, it seems essential for nurses and other practitioners who offer primary and specialist bereavement care to create a space for families to first, narrate their experience of death and loss to make meaning; second, to share or become aware under which circumstances and manners they would like to share with their family; and third, to discern or negotiate the way they would like to be caringly involved with each other and face the challenges that arose from their situation as a family without the close other. Through such a collaborative, mutual engagement, family patterns, adversities and capacities may be recognized and helpful family actions taken. For instance, Parse (1998), in her practice methodology, proposed that nurses co-participate with families to illuminate meanings, synchronize rhythmical relational patterns, and to mobilize transcendence; that is, bear witness to the changing way to live family health as families set priorities, make decisions, and create their unique possibilities to move
beyond (Cody, 1995b, 2000b). In bereavement, illuminating meaning may pertain to
families’ quest to make and find meaning in the way death had happened,
synchronizing rhythm may mean that nurses help families to share and see that not-
sharing may be an important and valid side of their experience of family
togetherness, and mobilizing transcendence may be about collaboratively creating
doable ways to live family in light of later life with a widowed member living alone.
The findings of this study reveal that bereaved families may want nurses and other
health professionals to walk alongside them in looking back, focusing on the now,
and moving forward as a family. Three sets of recommendations for working with
bereaved families can be derived from the study findings, pertaining to each of the
three main experiential themes identified.

8. 4. 1. Facilitating family meaning-making

First, in looking back, families in this study experienced a need to make sense of
how end-of-life and death has happened to them. Because families use stories and
storytelling to make sense of the death, providing an opportunity for families to
create a meaningful story of the death, and to re-weave their family narrative to
encompass this particular death and loss is important for working with families
(Gilbert, 2002; Hedtke and Winslade, 2004; Morrison, 2007; Moules and Amundson,
1997; Nadeau, 2008; Neimeyer, 2001a; Sedney et al., 1994). For instance, Sedney
and colleagues (1994) proposed that family therapist use the stories that families tell
about a death as a therapeutic medium, since stories not only provide emotional
relief, but help to make an experience meaningful and brings people together. In a
similar vein, Hedtke and Winslade (2004) maintained that conversations help
bereaved family members to “re-member”; that is, re-construct family membership of
their loved one in absence. Storytelling opens up a dialogical space for families
(Rober et al., 2012), acts as a vehicle to reconstruct meaning (Hooghe et al., 2011),
and invites healing (Hedtke, 2014; Hedtke and Winslade, 2004; Moules et al., 2007).
Nurses, whenever they encounter families following a loss, should be aware of the
central role of their stories, and storytelling for understanding the death as
meaningful and good. Moreover, they should also approach bereaved families
realizing that the death of a close other may denote an existential, extraordinary
family moment that increase their vulnerability, and ripples out in various ways
among generations, leaving the family forever changed. Thus, nurses should attend
to families’ narratives, and create time and a safe surrounding in their practice to
invite families’ stories of loss.
8. 4. 2. Strengthening family relationships

In focusing on the now, families not only hold a unified or diverse sense of loss in daily life, they also find comfort through sharing, yet do not or cannot share everything. It is important that nurses and other health professionals are aware that the interpretation and ramifications of the loss may be quite unique for each family member, and even differ greatly within, and across families. Long-standing assumptions about and findings from research aimed to discern who may suffer most in a family following what kind of loss (i.e. based on relationship, cause, or age) may be in the way of meaningfully working with families and individual members, as are beliefs about a right way to grieve (Doka, 2008; Harris, 2009-2010; Moules et al., 2004). Grief may or may not be part of what families experience, and they may or may not share their sense of loss. Nurses should therefore listen to what the loss means for each person belonging together as a family. The use of circular questioning to invite families to speak about how members experience the loss the same way or differently might be a useful approach to not only better understand the differences present, but also to facilitate families’ awareness of such differences (Dumont and Kissane, 2009; Kissane and Dumont, 2014; Kissane and Hooghe, 2011; Nadeau, 2008; Wright and Leahey, 2013). An in-depth understanding of the meanings of the loss from each person’s perspective and of the sameness and difference present in families is an important foundation for discerning individual and families’ needs for nursing interventions, and to assess a potential need for referral to specialist interventions, such as psycho- or family therapy, when grief and suffering within families is debilitating for their daily and shared lives.

Nurses can strengthen family relationships through creating a space for families to share sameness and respect difference, and to reach out to each other to provide comfort. However, it is important that nurses recognize and appreciate that there are moments that cannot, or feelings and thoughts that persons choose to not share. This study questions the often unreflected clinical premise that close ties and open sharing is the most helpful family strategy to live with loss. As a consequence, nurses should explore with individuals and family groups how not-sharing, expressed as not talking, or living moments of pain alone, may be helpful, and under which circumstances sharing (talking, enacting presence) may be comforting. Hooghe (2012), for instance, propose that “exploring and acknowledging the tensions and hesitations of all family members in therapy gives them a chance to better understand the process of talking and not talking in their family” (p. 323).
Thus, it is essential that nurses realize that not-sharing is just as valuable a way to live with loss than is sharing. Remaining silent and separate as well as talking and connecting holds its unique risks and benefits. According to Hooghe (2012), “talking about talking” with families may increase their tolerance for differences in their experience and way of living with loss. It may allow nurses and other health professionals to explore the ways that families and dyads may want to connect with each other in their experience of loss while also seeing other ways to enact caring for each other. When nurses attend to families’ capacities to share, and thematise their adversities or choices to not share, they can potentially strengthen family relationships through increasing family members’ mutual understanding and respect. Moreover, they also create a space for individuals to express feelings and thoughts they may have nobody to talk about, but feel a need to voice. Nurses’ presence might also open up a space for family sharing in a facilitated, safe environment. Coming together as a family with a nurse may enable members to share in a way they have not have a previous opportunity to do: Learning about each other, receiving and providing comfort, seeing sameness and differences, and respecting unique was of living with loss.

8. 4. 3. Providing support for family transition and caring

In moving forward, families contend with the best way to do and be family in later life. Nurses, due to the nature of their spatiotemporal structure of their work (Peter and Liaschenko, 2004), are ideally situated to provide support, in particular to those families who face upheaval in figuring out and negotiating their concerns, caring involvements, and supportive practices. Nurses should also be aware that families differ considerably in the extent of change they experience following a loss. When nurses encounter a family, or an individual whose family has lost someone, they should inquire about the family’s experience of change and transition, and invite family members to talk about their needs, expectations, capacities and limitations. They should do this from awareness that some families experience stability, whereas others face considerable upheaval. The study suggests that nursing counselling around how to best allocate and organize family support and caring might in fact only be required by those families whose widowed members are in need of practical and emotional support. Some widow/ers in this study experienced hospitalizations within the first year following the death, which was an expression of their unstable health or exhaustion from caregiving, and further increased their need for family support, at least temporarily. What was of concern for families, however,
was often not so much the support itself, but the process of figuring out and having different expectations or capacities for support, which created discord for some. Nurses should create opportunities for family members to talk about their new situation as a family, their unique needs and capacities, thereby facilitating family negotiations and appreciation for individuals' abilities to contribute and each member's limitations. Taking a stance of non-partiality and without a pre-set agenda for change or solutions, nurses may invite those present to talk about their situation, hopes, fears, and concerns for the future, and how they envision their lives as a family (Cody, 2000b; Kissane and Dumont, 2014; Wright and Leahey, 2013).

8. 5. An agenda for action III: Researching what this study leaves unanswered

Nursing research with bereaved families is scarce. With a few notable exceptions, bereavement research has been conducted with individuals. This present interpretive inquiry denotes a beginning explication of families' loss experiences and adds a family perspective to bereavement in later life. However, it also leaves many questions unanswered. A further exploration of family health and responses in bereavement in general, and for the additional study of family meaning-making, sharing - not sharing, families’ concerns and patterns of transition in particular is needed to more fully capture family variances and diversity. Moreover, based on the study’s findings, the need for nursing care should be identified, and family nursing interventions for bereaved families developed and evaluated.

8. 5. 1. Further research to understand diversity in bereaved families

It would further the understanding of bereaved families if a similar study would include several members of estranged families in individual interviews. This might extend current understandings of family meaning-making, sharing – not sharing, and family transition patterns and caring practices from the perspective of families for whom not-sharing is a prevalent relational pattern, and may thus not want to take part in a family group interview.

As this study denotes a beginning exploration, the diversity and variance of families' lived world should be taken into account in future family bereavement studies. To date, most family carer research stems from palliative or cancer care settings, and
little insights exists about the everyday bereavement experience of families who live with other life-limiting illnesses. Thus, the perspective of community-dwelling families with people dying of other causes than cancer, and who have not received specialist palliative or cancer care services is called for (Aoun et al., 2012; Rumbold and Aoun, 2014). Research with families of different cultural and ethnic origin, non-traditional families, and families in different life situations is needed to extend understanding of families’ loss experience. The family experience from the perspective of individuals who may not hold traditional family ties should also be captured (Hartrick Doane and Varcoe, 2005a). Insights about family health and relationships can be gleaned based on the perspective of one person alone, or the individual perspective of several members of a family, which is somewhat different from the current study that focused on the family unit (Åstedt-Kurki et al., 2001; Bell et al., 2000; Cody, 2000b; Feetham, 1991; Gilliss and Davis, 1992; Sullivan and Fawcett, 1991). Other qualitative approaches than hermeneutics, such as ethnography or narrative analysis, would shift the focus of analysis, and potentially unearth different and complementary aspects of the loss experience, such as family cultural patterns and rituals, or discursive practices, respectively (Creswell, 2013; Madden, 2010; Wertz et al., 2011). Quantitative research that investigates, for example, constitutive factors of meaning-making or determinants of family well-being and transition pathways in living with loss and moving forward as a family would also be a valuable extension of the yet small body of empirical knowledge about family bereavement. More longitudinal inquiries would also help to better understand how families’ experiences and practices unfold over time.

8.5.2. Future phenomena for the study of family bereavement

To increase the empirical knowledge base for health professionals about family bereavement, each of the identified family patterns warrants further inquiry. While family meaning-making and family storytelling have been previously investigated (Black and Santanello, 2012; Black et al., 2014; Davis et al., 2012; Koenig Kellas and Trees, 2006; Nadeau, 1998; Rober and Rosenblatt, 2013; Rober et al., 2012; Trees and Koenig Kellas, 2009), how connecting-disconnecting unfolds in bereavement has only been the focus of a few studies with bereaved couples (Barner and Rosenblatt, 2008; Hooghe et al., 2011, 2012; Rosenblatt and Barner, 2006). The manner in which families live with the loss as a community of committed and involved people in being together and apart arose as one of the most essential and new insights from this study, and necessitates further inquiry. Losing a close
other is inherently about changing relationships, with the living and the death (Ayers et al., 2004; Shapiro, 2001). How relationships unfold both in helpful, comforting, and strengthening as well as unsupportive, encumbering, and unnerving ways requires empirical investigation with particular attention to the simultaneous and paradoxical, yet complementary manner in which persons negotiate their relationships following a loss of a close other. Lastly, how families fare in bereavement, in particular what concerns, upsets, and commits them, as well as the extent of change they experience beyond the close other’s irrevocable absence calls for further inquiry. Even though a couple of studies have looked at the psychological outcome of family members (see for instance Kissane et al., 1996a; Kissane et al., 1997; Kissane et al., 1996b; Traylor et al., 2003) and the experience or effect of social support for widow/ers (see for instance Ha, 2008, 2010; Ha et al., 2006; Kanacki et al., 1996; Kaunonen et al., 1999), family caring; that is, how families look after each other in light of the new challenges that they face has not been the focus of research to date; a gap that has been previously pointed out (Schulz et al., 2008). Family caregiving following the loss of a close other, rather than merely before, should therefore be studied, especially so since most families will experience the loss of a member of their oldest generation later in life when they already face other losses and are likely to experience times of vulnerable health. How families interact together in their daily lives to handle an individual’s health challenge, symptoms, limitations, and therapeutic processes, the concrete family practices that denote families habits and capacities, or represent rather adversities and challenges, are also of interest (Kesselring et al., 2009).

8. 5. 3. Research to increase insights into bereaved families’ need for care

Future research with bereaved families should help to clarify families’ need for nursing care and bereavement support offered by a variety of different health professionals. This study demonstrated that not all families, or members of a family, may feel a need for nursing or other health and social care, albeit they appreciated the attentiveness and opportunities they received as a family to reflect and talk about their situation. Moreover, little research-based knowledge exists about which families in which situations and circumstances experience an additional burden and suffer more because they lack professional attention and support (Breen et al., 2014). The only family typology as a basis for intervention that has been developed through research in oncology palliative care relies on the normative concepts of family functioning (Kissane and Hooghe, 2011; Kissane and Lichtenthal, 2008;
Kissane et al., 2006). Because of the complexity, paradoxical and multidimensional nature of families’ experience of loss, identifying those most in need for care might be a difficult endeavour. Professionals’ perspectives may differ from families’ view about their needs, and family members’ concerns and needs may also diverge. Future research should explicitly clarify families and individual members’ perspectives about their need for health and social care in bereavement. It should also determine how the needs of families may be assessed, and who is most likely to benefit from family nursing interventions.

8. 5. 4. Research to develop and evaluate family nursing interventions

Lastly, research is needed to develop and test family interventions in bereavement. Based on the study findings, outcome measures should be able to capture the oscillating, paradoxical family patterns of relating and pay attention to not privilege one indicator of family relating over others, such as closeness, affection, or emotional disclosure (Stroebe et al., 2005). Level and extent of meaning-making, and families’ capacities to master their new caring situation may denote further useful outcome measures. A call for more research that examines clinical practice with families, in particular the process of nurse-family relational practices, rather than investigating phenomenon of family health alone, such as grief, has been put forth (Bell, 2011; Thirsk and Moules, 2013). Hence, intervention research should also attend to the relational processes and caring practices inherent in the intervention processes to render visible the mechanisms through which particular outcomes can be achieved (Bell, 2011; Kesselring et al., 2009).

8. 6. Concluding remarks

This hermeneutic-phenomenological inquiry posits that humanly lived meanings and actions arise from a situated, historically and culturally constructed context that serve as a common ground for the researcher and participants to co-create insights about the phenomenon of concern to the study (Benner, 1994b; Leonard, 1994; Plager, 1994). The cultural tradition, social world, values and beliefs, ideas and expectations, and inherent assumptions are seen as the entry point into interpretive inquiry that unfolds as a spiralling, hermeneutic movement (Gadamer, 1975/1989; Spichiger and Prakke, 2003). Thus, this inquiry departed from the researcher’s position in the world as a nurse researcher and family member, who came to the
study with her past experiences and assumptions, and specific questions for inquiry. The nursing practice context in Switzerland set up the possibility for access to some families, but not to others. Families who committed their time and energy to the study allowed the researcher a glimpse into their lives and truth, and helped her to move to a new horizon of understanding that formed the study findings. The study’s findings need to be understood as situated since they arose from the particular contexts in which these families lived, and through purposive research-participant encounters that aimed to shed light on families’ experiences of loss in later life.

The data for this study are families’ entrusted stories and descriptions that were both enabled and limited by the researcher’s presence in the family situation. These encounters were not only shaped by methodological considerations and the researcher’s comportment, but by families’ preferences, their comfort, and need to remain safe as feeling and acting individuals and families; practical issues, such as time and resources of those involved in the study; and questions of voice and representation arising from members’ decision to take part in the study or to remain absent. Family group interviews set up a natural context for dialogues in which ordinary talk and interaction patterns could unfold alike families’ everyday communications, which added transactional textual data, but also concrete observations to families’ reflections and stories (Benner, 1994b). Such family group interviews enabled families to enrich and expand stories and reflections by countering, contrasting, or reaffirming the individual voices of family members, whereas solo interviews added explicitly individual perspectives to the data. The researcher acted as the interpreter of gathered family stories and descriptions of their loss experience, and understandings arose through a spiralling movement among the initial research questions and emerging lines of inquiry, continually evolving and shifting fore-understandings, recorded and lived memories of interactions as experienced by the researcher, and textual data. This interpretive engagement happened through writing and reflecting about families’ situation, concerns, meanings, and embodied actions, and the researcher’s footprints in the evolving understandings. A prolonged engagement with families enabled the researcher an in-depth glance into families’ lived world, and to partake in their lives through several dialogic conversations. Through this interactive process, participants left their imprints on the researcher.

Through this study, I came to appreciate the complex and ambiguous processes at play for families when facing the loss of a close other, and learnt that family relating is at the core of human existence, whether through its supportive and nurturing
interconnectedness or alienating and haunting absence. I took away anew and in
deeper ways an insight into the power of families' stories, the transformative effect
when different and potentially contradicting perspectives are valued, and the healing
potential of dialoguing and listening. In interaction with participants, I also came to
better understand the vulnerabilities, challenges, and potentialities that are inherent
to existential situations, in the face of the luring losses that life incorporates at every
breath. Families' enduring commitments and perseverance in the face of suffering
and loss, and their creative and manifold ways they (re-)created their daily family
lives allowed me to understand the powerful and nurturing place that family relations
can embody. Most importantly, I learnt about the subtle and artful ways in which
family members navigate connecting and revealing; the moving together, and
disconnecting and concealing, the moving apart. My own learning from this
interpretive endeavour and engagement with bereaved families deepened my
understanding of family relations and how people live with a family death in later life,
and transformed my own way of seeing and doing as a wife, mother, daughter,
sister, friend, as well as a nurse and researcher.


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Appendix A: Published literature review

Review

Characteristics of the bereavement experience of older persons after spousal loss: An integrative review

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ABSTRACT

Background: Spousal loss can be a dramatic life event for older persons, and a difficult experience that affects everyday life. Research shows that bereavement influences health and well-being in old age and involves changes in social networks. However, the nature of the bereavement experience for older widows/widowers remains unclear.

Objectives: To determine key characteristics of the bereavement experience of older widowed persons.

Design: An integrative review of the literature was performed using the framework developed by Whittmore and Knaff (2005).

Data sources: Research studies investigating aspects of the bereavement experiences of widowed older (≥65) persons (n=38) were included. The electronic databases Medline, CINAHL, PsychInfo, Sociological Abstracts, and Cochrane Library and relevant journals were searched up to February 2011.

Review methods: The health sciences literature was searched systematically and iteratively to determine relevant studies. Data analysis and synthesis of primary sources of qualitative and quantitative research studies occurred through the processes of data reduction, display, comparison, conclusion drawing and verification (Whittmore and Knaff, 2005).

Results: A majority of the reviewed studies included more women than men as participants. The studies' findings suggest that daily activities and routines are disrupted in bereavement, while certain coping strategies seem to sustain older persons in their everyday life. Many older persons face a pervasive sense of loneliness and difficult daily and yearly times. Health concerns prevail or intensify, and older persons have to negotiate their independence and new identity as widow/wr in a social context. Findings show changes in relationships with close others, which are both a challenge and resource for older widow/wr. Moreover, many older persons maintain connections with the deceased spouse.

Conclusions: This review suggests that constructing a new identity as widow/wr and striving for independence in the face of disrupted everyday activities and routines, loneliness, health concerns and changed relationships within the family and social network are essential features of older persons' bereavement experience. While many of the identified characteristics of the bereavement experience may not be specific to later life, they need to be considered when working with this population given the concurrent challenges of the ageing process and declining health.

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Follow-up to February 2011.
Appendix A (continued)

What is already known about the topic?

- Widowhood is characterized by a consistent age and gender pattern in the western world. A majority of persons become widowers in later life, with women being affected more often, at a younger age and for longer time periods than men.
- Conjugal bereavement in old age can be particularly difficult because of concurrent losses, failing health and increasing dependence on others. Research shows that grief affects older persons' health and well-being.
- Newer understandings of bereavement suggest that grief is a very individualized and yet pervasive and common experience that needs to be integrated into the biographical narrative and meaning of persons' lives.

What this paper adds?

- After spousal loss, many older persons face disruptions in their daily routines and activities and use various strategies to live with their loss. Often, they deal with a pervasive sense of loneliness, health concerns, and fluctuations in grief intensity.
- Older persons reconstruct their identity and have to negotiate their independence as widowers in a social context. They consider relationships with family, friends, and other persons a resource, and frequently continue their relationship with the deceased spouse in a number of ways.
- The findings of the reviewed studies support conceptualizations of grief as an existential experience that disrupts the taken-for-granted life-world of persons, and involves an ongoing relationship with deceased persons despite their physical absence.

1. Introduction

The loss of a close other through death is a pervasive experience in old age (Laline d’Epinay et al., 2008), with spousal loss being one of the most life-changing losses (Byrne and Raphael, 1994; Carr et al., 2001). Widowhood is characterized by a consistent age and gender pattern in the western world. A majority of persons become widowers in later life when they are in their early seventies. Women are affected more often, at a younger age and for longer time periods than men (Administration on Aging, 2011; Federal Interagency Forum on Aging-Related Statistics, 2012; Swiss Statistics, 2009). For instance, in Switzerland, around 26% of women and 21% of men between the age of 65 and 74 years become widowers, and a further one third between 75 and 84 years (Swiss Statistics, 2009). US data show that between the age of 75 and 84, about half of women are widowed, in contrast to 17% of men (Federal Interagency Forum on Aging-Related Statistics, 2012).

Even though spousal loss happens frequently at an advanced age, bereavement is considered particularly challenging for older persons because of concurrent losses outside a bereavement context (Jeffreys, 2011; Moss et al., 2001; Pilkington, 2005). Multiple losses pose many emotional and practical challenges, such as facing failing health and symptoms, struggling with one's limitations during everyday activities, living with an increased need for support, maintaining social connections and a sense of belonging, and reviewing one's life and having hopes for the future (Easley and Schaller, 2003; Hinck, 2004; Montbrialand, 2004; Wondolowski and Davis, 1991). Moreover, it has been found that newly widowed, older persons experience more depression, despair and distress (Bennett, 1997a,b, 1998; Ornstein and Ciuppers, 2006), higher rates of institutionalization and an increased mortality risk compared to non-bereaved peers (Elwer and Christakis, 2008; Marikainen and Valkonen, 1996; Rifkin and Marikainen, 2005).

Despite these challenges and potential negative consequences of spousal loss in old age, grief is foremost a pervasive and common, albeit existential human experience (Cowles, 1986; Cowles and Rodgers, 1981; Jacob, 1996a). Traditional views of grief as a linear and normative process that ends with its resolution, expressed in breaking bonds and moving on with life have been widely questioned (Attig, 1996; Florczak, 2008; Moules, 1998; Neimeyer, 2001; Pilkington, 2006). It has been suggested that such an objectivist stance leads to prescriptive models of nursing practice, which ignore human subjectivity, dismisses grieving as an unique, ongoing, intersubjective, and meaning-constructing experience and even adds to persons' suffering (Florczak, 2008; Moules et al., 2004; Pilkington, 2006). Newer understandings propose that the experience of loss disrupts life's narrative (Neimeyer, 2001, 2006), shatters persons' familiar and taken-for-granted world (Attig, 1991), and requires a complex coping process that shifts between focusing on the loss experience itself and attending to the everyday consequences of the loss (Stroebe and Schut, 1999, 2010). Thus, grieving is inherently about reconstructing life's meaning (Neimeyer, 2001, 2005), relearning to live everyday life following the loss (Attig, 1996, 2001), attending to the loss and its everyday consequences through a complex and dynamic coping process (Stroebe and Schut, 1999, 2010), and remembering the deceased person through an ongoing engagement (Attig, 2000; Hedake and Winslade, 2004; Klass et al., 1996). While such newer conceptualizations are useful guides for practice, research-based knowledge about the bereavement processes and characteristics is needed when working with older widowed persons.

Research shows that individual and group therapy-based interventions are often unnecessary and may only be beneficial for persons with a debilitating experience of grief (Jordan and Neimeyer, 2003; Schut et al., 2001). However, nurses and other health professionals regularly encounter and work with conjugal bereaved older persons in their clinical practice (Moules et al., 2007; White and Ferstl, 2005). At present, there is a lack of clarity about older persons' experience of conjugal bereavement, and how nurses can best support them in their everyday life after spousal loss. No review of the literature was identified that focuses on the characteristics of the bereavement experiences of conjugal bereaved older persons. A synthesis of research around conjugal bereavement in later life may facilitate more person-centred practice and support in service delivery to older people.
Appendix A (continued)

2. The review

2.1. Aim

The review aims to synthesize research studies that investigate the characteristics of the individual bereavement experience of older, widowed persons aged 65 years or older to contribute to an empirical knowledge base for clinical practice. The review was guided by the question: “What is the current state of knowledge in the health sciences literature about older persons’ bereavement experience after spousal death; that is, the meaning of the loss, everyday activities following the loss, and strategies that are used to live with the loss?”

2.2. Design

An integrative review methodology was used because it allows for the narrative integration of findings from qualitative and quantitative research around a particular phenomenon of concern (Whitemore & Knaff, 2008; Whitemore and Knaff, 2005). Integrative reviews employ a systematic procedure for searching the literature and for evaluating, analysing, and synthesizing data to arrive at a comprehensive understanding of the investigated topic, which is presented in a narrative form (Whitemore and Knaff, 2005).

2.3. Search methods

Electronic databases included Medline (1948–February 2011), CINAHL (1987–March 2011), PsycInfo (1806–February 2011), Sociological Abstracts (February 2011), and the Cochrane Library (July 2011) and were searched using the terms: (1) “bereavement”; (2) “loss of a loved one”, “death and dying”, “death of spouse”; (2) “widows and widowers”, “widowhood”, “spouses”; and (3) “old age”, “aged”, “elderly people”. A hand-search was conducted starting from 2005 of the journals Death Studies (to Vol. 35, Iss. 7), Bereavement Care (to Vol. 30, Iss. 2), and Omega: Journal of Death and Dying (to Vol. 64, Iss. 2).

To be included, conjugal bereavement studies had to be in English or German, the mean age of the sample had to be 65 years or above, or, when no mean age was given, the majority of the sample had to be above 65 years old, and the phenomenon investigated had to focus on the conjugal bereavement experience of older persons. Studies were excluded if they focused on particular bereavement issues, such as depression, insomnia, mortality, health care utilization, or social support, investigated individual perspectives of other populations, like caregivers, adult children, parents or siblings, or focused on widowhood experiences outside an explicit bereavement context, for instance the experience of loneliness, well-being or psychosocial health of widowers.

2.4. Quality appraisal

Quality appraisal was performed using the critical review forms developed by the McMaster University Occupational Therapy Evidence-Based Practice Research Group (Law et al., 1998/2007; Leitz et al., 2007). These guidelines were chosen because they provide separate appraisal tools for qualitative and quantitative studies in a comparable format yet with distinctive and appropriate criteria for each research approach.

Studies that were judged to be of low quality based on the critical appraisal tool were included, yet their findings were weighted less strongly when synthesizing results (Whitemore and Knaff, 2005). Moreover, caution was applied when drawing conclusions based on their findings.

2.5. Data abstraction and synthesis

Data synthesis followed the framework by Whitemore and Knaff (2005) and Whitemore (2008) (Table 1). All studies were read carefully, summarized in tables, and appraised for quality. To manage the data and aid the analysis (Whitemore and Knaff, 2005), studies were grouped into four thematic areas developed in response to the included studies: (1) experiential aspects; (2) everyday activities; (3) coping strategies/strategies to live with loss; and (4) grief reactions. Next, study data were extracted for each study separately and findings of each study were coded inductively (Whitemore, 2008). All codes were subsequently listed, and analyzed for commonalities and differences. Common codes were synthesized into themes and graphically displayed by drawing a conceptual mind map (Whitemore, 2008; Whitemore and Knaff, 2005). Findings from one study could be grouped into several different themes. A theme was defined as a key characteristic of the bereavement experience that was present in several studies. Initial themes were reorganized based on levels of abstraction until a clear discrimination between themes was evident. This included a creative process of comparing and contrasting displayed data, codes, and initial themes to discern commonalities and contradictions in the bereavement experience of older persons.

Table 1

<table>
<thead>
<tr>
<th>Data analysis used for integrative reviews.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Data reduction</strong></td>
</tr>
<tr>
<td><strong>Data display</strong></td>
</tr>
<tr>
<td><strong>Data comparison</strong></td>
</tr>
<tr>
<td><strong>Conclusion drawing</strong></td>
</tr>
<tr>
<td><strong>Verification</strong></td>
</tr>
</tbody>
</table>

3. Results

3.1. Characteristics of the studies

The search of the literature yielded around 2500 hits. 355 abstracts with conjugal bereaved older persons were screened, of which 59 publications were retrieved as full text (Fig. 1). Thirty-nine studies that investigated characteristics of the bereavement experience of widowed persons were included in this review (Table 2). The mean age of participants (n = 28) was 70.5 (SD 3.98) years. With 41% of studies with women only, and an average of 82% (0–100) of women participants; studies represent largely a female perspective. One third (31%, n = 12) of studies included different ethnic and other non-Western or clinical groups, such as African American widows, lesbian partners, or cancer caregivers, and 77% (n = 30) of the studies were conducted in North America. Twenty studies used a quantitative design, followed by qualitative (n = 17), and mixed methods approaches (n = 2). Twenty-five studies were of high or good quality, nine of moderate, and five of low quality. Through the analysis process, six major themes around conjugal bereavement of older persons could be identified (Table 3). In the following, each theme is presented.

3.2. Theme 1: everyday activities and routines

Nineteen studies entailed findings that are concerned with the everyday life of older widowed persons after the death of their spouse. Included studies show that older, widowed persons use various activities and strategies to live with their loss, in particular “keeping busy” and “being involved in routines and activities” (Anderson and Dimond, 1995; Brabant et al., 1992; Harrison et al., 2004; Hegge, 1991; Hegge and Fischer, 2006; Hockey et al., 2001; Holtslander et al., 2011; Jacob, 1986b; McIntyre and Howie, 2002; Rodgers, 2004; Shih et al., 2010; Steeves and Kahn, 2005). Studies report that involvement in church activities and the practice of one’s belief or religion, and the development of skills assisted older persons to live with their loss. “Handling unexpected emotions and reminders,” “seeking peace and being thankful,” or “learning to live with the pain that dissipates over time, but never goes away” were also described, albeit less often.

Two studies found that the most frequent leisure activities were talking or getting together with family or friends, gardening, religion, walking or sports, and reading or watching TV (Janke et al., 2008; Paterson, 1986). While the extent of participation in leisure activities fluctuated, the largest proportion of older persons kept or increased social contacts, in particular visiting. Remembrance activities were also used. The most frequent were talking to others about the deceased, displaying a photograph at home, spending time with people who were special to the deceased, and revisiting places with special memories (Vale-Taylor, 2009).

Notwithstanding the many strategies and activities that were helpful, studies show that older widowed persons experience times in a day or a year that are particularly difficult, such as mealtimes, bedtime, anniversaries and specific seasons, and that they face challenges in dealing with spare time (Anderson and Dimond, 1995; Brabant et al., 1992; Holtslander and Duggleby, 2010; Steeves, 2002). Planning life day-by-day is reported to be one way to deal with the difficulty of passing the time (Chan and Chan, 2011; Costello and Kendrick, 2000; Holtslander et al., 2011).

3.3. Theme 2: emotions

Twelve qualitative studies report that older persons often experience a pervasive sense of loneliness in daily life following the loss of their life-companion (Anderson and Dimond, 1995; Chan and Chan, 2011; Costello and
### Appendix A (continued)

<table>
<thead>
<tr>
<th>Author, year, and country</th>
<th>Design</th>
<th>Empowerment or phenomenology</th>
<th>Participants</th>
<th>N Age</th>
<th>% female</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anderson and Fransen, 1995 and USA Nursing</td>
<td>Qualitative study</td>
<td>Experiences of older</td>
<td>Widowers within 2 years after loss</td>
<td>12</td>
<td>51</td>
<td>49</td>
<td>Open-ended interviews at 3 weeks, G. 12, 24 months</td>
<td>Framework analysis based on semantic-relationship after loss</td>
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<tr>
<td>Bonnart et al., 2010 and USA Psychology</td>
<td>Mixed-method study</td>
<td>Performance of instrumental tasks before and after lost</td>
<td>Widows</td>
<td>23</td>
<td>74</td>
<td>100</td>
<td>Semi-structured interviews</td>
<td>X</td>
</tr>
<tr>
<td>Boyd and Magley, 2000 and USA Nursing</td>
<td>Qualitative study</td>
<td>Resilience experience</td>
<td>Loses after partner loss</td>
<td>6</td>
<td>50-70</td>
<td>100</td>
<td>In-depth, open interviews</td>
<td>Semi-structured interviews</td>
</tr>
<tr>
<td>Brunton et al., 2009 and USA Sociology</td>
<td>Qualitative descriptive study</td>
<td>Resilience</td>
<td>Widows of women deceased in hospital</td>
<td>30</td>
<td>64</td>
<td>0</td>
<td>Semi-structured interviews</td>
<td>X</td>
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<td>Cordon and Wilcox, 2003 and Feminism PARI/PHI</td>
<td>Cross-sectional descriptive study</td>
<td>Situation and adaptation during their last year after loss</td>
<td>Individuals after special loss</td>
<td>758</td>
<td>70</td>
<td>0</td>
<td>Structured interviews containing socioemotional and emotional resolution, finding meaning in loss, personal growth</td>
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<td>Cowley et al., 2003 and USAG Psychology</td>
<td>Longitudinal cohort study Data from Americans Changing Lives (ACL) study</td>
<td>Time course of adaptation to loss</td>
<td>Widows</td>
<td>108</td>
<td>67</td>
<td>28</td>
<td>ANOVA</td>
<td>X</td>
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<tr>
<td>Cooch and Lavelle, 1992 and USA Nursing</td>
<td>Cross-cultural study</td>
<td>Comparison of expected stress and coping with actual experience</td>
<td>Widows</td>
<td>105</td>
<td>67</td>
<td>28</td>
<td>ANOVA</td>
<td>X</td>
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<td>Crenshaw and Chang, 2011 and Hong Kong Social Work</td>
<td>Grounded theory study</td>
<td>Adjustment process</td>
<td>Widows</td>
<td>15</td>
<td>74</td>
<td>66</td>
<td>Clinical interventions and structured interview Scale; 4 weeks</td>
<td>Grounded theory after Crenshaw</td>
</tr>
<tr>
<td>Chesser and Chang, 2006 and USA Nursing</td>
<td>Qualitative study</td>
<td>Nature of change in self-care</td>
<td>Widows</td>
<td>74</td>
<td>70</td>
<td>0</td>
<td>Clinical interventions and structured interview Scale; 4 weeks</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Costa and Eriedisch, 2005 and USA Nursing</td>
<td>Qualitative study</td>
<td>Grief experience</td>
<td>Widows</td>
<td>74</td>
<td>70</td>
<td>0</td>
<td>Grounded theory</td>
<td>Not described</td>
</tr>
<tr>
<td>Gast, 1987 and USA Nursing</td>
<td>Cross-sectional descriptive-convoluted study</td>
<td>Appraisal of bereavement, coping patterns, resilience and functioning</td>
<td>Widows before less than a year</td>
<td>106</td>
<td>75</td>
<td>30</td>
<td>Grounded theory</td>
<td>ANOVA with Scheffe post hoc test</td>
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<tr>
<td>Gast, 1991 and USA Nursing</td>
<td>Cross-sectional descriptive-convoluted study</td>
<td>Appraisal of bereavement, coping patterns, resilience and functioning</td>
<td>Widows before less than a year</td>
<td>106</td>
<td>75</td>
<td>30</td>
<td>Grounded theory</td>
<td>ANOVA with Scheffe post hoc test</td>
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<td>Haukoos et al., 2004 and USA Nursing</td>
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<td>Coping processes</td>
<td>Widows</td>
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<td>0</td>
<td>81</td>
<td>Structured interviews</td>
<td>X</td>
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<tr>
<td>Kiesler et al., 2001 and Canada Nursing</td>
<td>Qualitative study</td>
<td>Differences in grief expression of older and adult-old persons</td>
<td>Widows aged 60-74 and 75-89</td>
<td>22</td>
<td>0</td>
<td>100</td>
<td>Structured interviews</td>
<td>X</td>
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<tr>
<td>Kiesler et al., 2001 and USA Nursing</td>
<td>Cross-sectional study</td>
<td>Relationships of hope, coping skills, well-being and impaired health of older adults</td>
<td>Widows</td>
<td>75</td>
<td>75</td>
<td>62</td>
<td>Questionnaires; Hugg, scaled between a 4-24, 0 weeks</td>
<td>Hugg and Taylor</td>
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<tr>
<td>Higginbottom et al., 2004 and USA nursing</td>
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<td>Health-related quality of life</td>
<td>Widows aged 60-74 and 75-89</td>
<td>22</td>
<td>0</td>
<td>100</td>
<td>Interventions</td>
<td>Grounded theory analysis after Hugg</td>
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<tr>
<td>Hofstetter et al., 2010 and USA Nursing</td>
<td>Qualitative study based on grounded theory study</td>
<td>Psychological content of bereavement</td>
<td>Widows after completing for spouse</td>
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<td>60-70</td>
<td>100</td>
<td>Constant comparative method and thematic analysis</td>
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<tr>
<td>Hoffmeister et al., 2011 and Canada Nursing</td>
<td>Constructive grounded theory study</td>
<td>Intimacy</td>
<td>Widows after completing for spouse with advanced cancer</td>
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<td>73</td>
<td>64</td>
<td>Grounded theory analysis</td>
<td>X</td>
</tr>
<tr>
<td>Jochy, 1996 and USA Nursing</td>
<td>Grounded theory study</td>
<td>Greece conceptual definition of grief</td>
<td>Widows after completing for spouse with advanced cancer</td>
<td>4</td>
<td>73</td>
<td>64</td>
<td>Grounded theory analysis</td>
<td>X</td>
</tr>
<tr>
<td>Jonas et al., 2008 and USA Nursing</td>
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<td>Change frequency and duration of activities, relationship to physical and mental health</td>
<td>Widows</td>
<td>154</td>
<td>89</td>
<td>0</td>
<td>Constant comparative method</td>
<td>X</td>
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<tr>
<td>Kim et al., 2011 and USA Nursing</td>
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<td>Change frequency and duration of activities, relationship to physical and mental health</td>
<td>Widows</td>
<td>105</td>
<td>72</td>
<td>0</td>
<td>Constant comparative method</td>
<td>X</td>
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<td>Kline and Brookland, 2001 and USA Nursing</td>
<td>Cross-sectional descriptive-convoluted study</td>
<td>Physical and psychological symptoms of grief</td>
<td>Widows</td>
<td>173</td>
<td>40</td>
<td>60</td>
<td>Structural equation modeling analytic framework</td>
<td>Phenomenological process of current analysis after loss</td>
</tr>
</tbody>
</table>

**Table 2** Summary of included conjugal bereavement studies.
### Table 2 (Continued)

<table>
<thead>
<tr>
<th>Authors and Journals, 2004 and Psychology Today</th>
<th>Cross-sectional descriptive study</th>
<th>Perceived or phenomenon</th>
<th>Participants</th>
<th>N</th>
<th>Age</th>
<th>% female</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>McNally and Henric, 2003 and Journals of Therapy</td>
<td>Qualitative case study</td>
<td>Meaningful occupation</td>
<td>Woman middle-aged</td>
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<td>160</td>
<td>3.8:6</td>
<td>50</td>
<td>Not described</td>
<td>X</td>
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<tr>
<td>Confalonieri et al., 2007 and USA Sociology</td>
<td>Longitudinal cohort study</td>
<td>Length of time in Vygotsky's (1978) model</td>
<td>Served as spouse</td>
<td>344</td>
<td>50</td>
<td>69</td>
<td>4.8:6:10 months</td>
<td>Hierarchical cluster procedure with Ward agglomeration method</td>
<td>X</td>
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<tr>
<td>Patterson, 2009 and American Journal of Sociology</td>
<td>Cross-sectional longitudinal study</td>
<td>Literature review</td>
<td>Woman middle-aged</td>
<td>60</td>
<td>64</td>
<td>72</td>
<td>Interview with use of</td>
<td>Pearson correlation</td>
<td>X</td>
</tr>
<tr>
<td>Richardson and Rich, 2007</td>
<td>Cross-sectional longitudinal study</td>
<td>Factors that explain</td>
<td>Woman middle-aged</td>
<td>200</td>
<td>74</td>
<td>0</td>
<td>Structural questionnaire</td>
<td>Multiple regression</td>
<td>X</td>
</tr>
<tr>
<td>Richardson and Rich, 2007</td>
<td>Cross-sectional longitudinal study</td>
<td>Factors that explain</td>
<td>Woman middle-aged</td>
<td>230</td>
<td>71</td>
<td>72</td>
<td>Structural questionnaire</td>
<td>Multiple regression</td>
<td>X</td>
</tr>
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<td>Robinson, 2005 and USA Sociology</td>
<td>Descriptive case-study</td>
<td>Relationship of</td>
<td>Woman middle-aged</td>
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<td>63</td>
<td>100</td>
<td>Pearson correlation</td>
<td>X</td>
<td></td>
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<tr>
<td>Rodman, 2004 and US Nursing</td>
<td>Descriptive case-study</td>
<td>Special translation</td>
<td>African American women</td>
<td>11</td>
<td>63</td>
<td>100</td>
<td>In-depth interviews</td>
<td>Factor analysis</td>
<td>X</td>
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<tr>
<td>Sink, 2007 and USA</td>
<td>Cross-sectional longitudinal study</td>
<td>Care Plan</td>
<td>Woman middle-aged</td>
<td>81</td>
<td>60</td>
<td>100</td>
<td>Semi-structured interviews</td>
<td>X</td>
<td></td>
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<td>Shih et al., 2010 and Taiwanese Journal of Nursing</td>
<td>Mixed method study</td>
<td>Difficulties and differences between</td>
<td>Woman middle-aged</td>
<td>20</td>
<td>73</td>
<td>100</td>
<td>Etiology</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

3.4. Theme 3: life as a single person in a social context

The findings of eight studies indicate that older, bereaved persons have to reorient themselves in their social world (Anderson and Dimond, 1995; Chan and Chan, 2011; Harrison et al., 2004; Hegge, 1991; Holtslander et al., 2011; Holtslander and Duggleby, 2010; Rodgers, 2004; Wilson and Supiano, 2011). Studies show that older persons have difficulty appearing in public alone and to socialize as a single person. Findings suggest that women in particular had to develop a new identity as widows, which was important for women’s mastery; that is, their ability to pro-actively shape their lives, to experience self-growth, or to learn new skills and assuming new roles. Moreover, studies report that older widowers experienced a sense of discontinuation of time, or a disruption between the past, present, and the future, and a new perception of the future as limited and fraught with uncertainty (Chan and Chan, 2011; Holtslander et al., 2011; Holtslander and Duggleby, 2010).

The literature reports that as widowers, older persons have to negotiate their independence in the face of adversities. Functional impairments were found to limit the use of public space (Hockey et al., 2001), determine the amount of hours spent doing housework (Utz et al., 2004), and the extent of widows’ self-perceived independence (Bennett et al., 2010). Concerns about finances and house ownership are also reported (Holtslander and Duggleby, 2010; Steeves and Kahn, 2005). It was not possible to determine from the reviewed studies whether dependence on family is increased by widowhood or other factors, such as old age and health status, but some studies report that the availability of family seems to influence the amount of support older persons receive (Bennett et al., 2010; Utz et al., 2004).

Studies show that relationships with family, friends, neighbours and other widowers are a resource in bereavement (Bent and Magiby, 2006; Carlsson and Nilsson, 2007; Harrison et al., 2004; Hockey et al., 2001; Holtslander and Duggleby, 2010; Jacob, 1996b; Robinson, 1995; Rodgers, 2004; Wilson and Supiano, 2011). While adult children seem to be an important source of support, previous difficult relationships can become further strained. Some support might not be wanted or is not considered helpful, for instance when it entails tasks that older persons prefer doing themselves.

Nine studies provide consistent findings that widowers, experienced a continued engagement with their lost partner as a source of comfort (Anderson and Dimond, 1995; Carlsson and Nilsson, 2007; Carnelley et al., 2006; Costello and Kendrick, 2000; Harrison et al., 2004; Hegge and Fischer, 2006; Hockey et al., 2001; Vale-Taylor, 2009; Wilson and Supiano, 2011). This engagement included conversations, sensing the presence of the other, reliving the past through memories and dreams, being together through previously shared activities or by taking up an activity of the deceased, and having tokens of remembrance in the home, like a particular chair or fresh flowers.

3.5. Theme 4: health and symptoms

Older persons reported in six studies that they experience health problems during bereavement. Sleep difficulty was the most prominent health concern (Anderson and Dimond, 1995; Carlsson and Nilsson, 2007; Hegge, 1991; Holtslander et al., 2011; Holtslander and Duggleby, 2010; Kowalski and Bondmass, 2008). One study reported that 15% of the widows suffered from a disrupted sleep pattern within 2 years after the loss (Kowalski and Bondmass, 2008), and another study found that insomnia decreased to a statistically significantly extent within the first year from 65% to 15% of widowers (Carlsson and Nilsson, 2007). Fatigue and the lack of energy were also reported (Anderson and Dimond, 1995; Carlsson and Nilsson, 2007; Holtslander and Duggleby, 2010; Kowalski and Bondmass, 2008). Loss of appetite and nausea were further health concerns, with 22% of women reporting gastrointestinal issues, such as loss of appetite or weight changes (Kowalski and Bondmass, 2008).
Appendix A (continued)

3.6. Theme 5: grief over time

Seven studies reported how grief and other indicators of bereavement, such as depression, distress, mental health or personal growth develop over time. A statistically significant decline in grief over time was found in three studies that followed a cohort of widowers up to 30 months (p < .01 to p < .001) (Carlsson and Nilsson, 2007; Olt et al., 2007; Thompson et al., 1991). In contrast, when widows were grouped into 12-month time intervals since the death of their spouse, no statistically significant difference existed in grief between groups (Kowalski and Bondmass, 2008). For women, age and grief correlated positively (Sable, 1991).

Depression and distress were found to decrease over a time period up to 30 months while mental health increased over a period of 18 months (p < .001) (Olt et al., 2007; Thompson et al., 1991). In comparison to matched, non-bereaved controls, bereaved older adults had lower well-being over a 4-year period (Richardson, 2007). Recently bereaved (cut off at 500 days) older widowers had also lower well-being (p < .01), less positive (p < .05) and more negative (p < .05) affect compared to older men further from bereavement (Richardson and Balasumanya, 2001). Personal strength (i.e. learned, by own strength, proud about how well one manages, feeling a stronger person, increased self-confidence) increased over the years (Carnelley et al., 2006; Kim et al., 2011). In contrast, the process of finding meaning as well as involvement with the deceased by means of memories, conversations, and anniversary reactions was stable over time (Carnelley et al., 2006).

3.7. Theme 6: coping and its relation to grief and other outcomes

Coping was investigated in seven studies using a cognitive stress, appraisal and coping framework. Emotion-focused coping seems to be more used by bereaved women and early on in bereavement (Chovan and Chovan, 2006; Lalitha and Jamuna, 2004). In comparison to non-bereaved older persons, bereaved persons' self-perceived coping ability with their loss was statistically significantly higher (p < .001) than the expected coping ability of those who were not bereaved, even though more than two third found that the death of their spouse was the most stressful thing that ever happened to them (Caserta and Lund, 1992). In contrast, appraisal of the loss event seems to impact on coping processes, with a tendency towards less effective coping (i.e. wishful thinking, self-blame) (p < .05) when a person considered the loss as particularly threatening to her life (Gass, 1987, 1988).

A clearer picture emerges when coping is examined in relation to grief resolution (Herth, 1996; Robinson, 1995), health dysfunction (Gass, 1987, 1988), or social support (Robinson, 1995). While more positive coping styles (i.e. confrontive, optimistic, supportive, palliative, etc. coping) and grief resolution were positively associated in one study (p < .001) (Herth, 1996), Robinson (1995) found that the effectiveness (how helpful coping style is) and not the use of various coping styles were associated with an adaptive reaction to grief (p < .03). Similarly, the use of many different coping styles was not associated with lower health dysfunction, in contrast to the use of coping styles deemed adaptive (p < .05 to p < .001) (Gass, 1987). The combination of the use of many coping styles and high effectiveness was associated with good social integration (p < .05) (Robinson, 1995). These studies show that coping type and effectiveness, and not the amount used, is positively associated with grief resolution and good health function.

4. Discussion

This integrative review adds new insights about key characteristics of the bereavement experience in a later life context. Reviewed studies suggest that daily activities and routines are disrupted in bereavement, while certain coping strategies seem to sustain them in their everyday life. Nevertheless, after spousal loss, older persons; that is, in particular women, face a pervasive sense of loneliness and difficult daily and yearly times. Health concerns prevail or intensify, and older women have to negotiate their independence and new identity as widows in a social context. Changes in relationships with others and the deceased persons are both a challenge and resource.

The reviewed conjugal bereavement studies represent mainly a female perspective, and limit conclusions about older persons in general. Such a gender focus may be a result of the fact that some consider widowhood a women's health issue due to the feminization of old age (Williams et al., 2006). Yet even researchers who aim to have a mixed sample may be likely to recruit more women than men into their studies because of the higher proportion of widowed women (Administration on Aging, 2011; Federal Interagency Forum on Aging-Related Statistics, 2012; Swiss Statistics, 2008). Although this review included studies with particular ethnic, gender or clinical groups, it is not possible to make any inference regarding particular subgroups of widowers. Because a majority of studies stem from North America, research in other cultural contexts, and with particular groups are needed to understand cross-cultural as well as situational aspects of the bereavement experience in old age.

4.1. Limitations of review

While considerable effort has been made to employ a transparent and systematic procedure using the framework by Whittemore and Knell (2005), personal assumptions and theoretical pre-understandings will inevitably have influenced the synthesis of results. Because of the focus of this review, studies focusing solely on particular bereavement issues and health outcomes were excluded, which could potentially add clarity to the findings around coping and shed light on the relationship between health, old age, and bereavement. Given the focus on spousal bereavement, this review provides less insight into the loss experience after the death of another family member, or family bereavement. Caution is also warranted when drawing conclusions about older persons in general, since a majority of study participants were widowed women.
4.2. Everyday and relational practices in bereavement

The reviewed studies provide evidence about widower/ers' participation in various activities and use of certain strategies in their everyday life to live with loss. Based on a phenomenological perspective, these findings can be conceptualized as practices. Practices arise as persons are engaged in their everyday lives through activities, relations, and concerns (Benner and Wurzel, 1969; Heidegger, 1926/2001). According to Attig (2004), bereavement threatens taken-for-granted life-worlds and disrupts life's narrative, leading to "an unravelling of the daily life and disruption of the flow of our life stories that we have accomplished through primary pre-reflective, non-deliberative, active, caring engagement with the world" (p. 348). Hence, bereavement necessitates a process that Attig (1996, 2000, 2004) calls "relearning the world"; which is a deliberate engagement with the world through daily practices and relationships.

The reviewed studies suggest that taken-for-granted, everyday and relational practices are disrupted for older, bereaved persons. The breakdown of a familiar world is evidenced in study findings in relation to difficult daily times and occasions, the challenge of filling the time, and the need to develop strategies to handle unexpected turmoil and to live with a sense of loneliness and the emotional upheavals of loss. In contrast, some of the reported everyday practices, like keeping busy, staying involved in leisure and other activities and pleasurable daily routines, or developing new skills, seem to provide familiarity and orientation for older, bereaved persons. Studies show that changes in relationships occurred on many levels. The rhythm of relationship with others shifts during bereavement, and new relational practices are developed to continue the relationship with the deceased. Study findings around the loss of identity as a spouse, and the sense of a changed perception of the life time add empirical confirmation of Attig's (1996, 2000, 2004) idea that the loss of a close person disrupts the narrative of a person's life.

Moreover, some findings of the reviewed studies are reflected in other studies, such as widow/wers' sense of loneliness (Byrne and Raphael, 1997; Costello, 2002; Stewart et al., 2001; Stroebbe, 2008), and their continued relationships with the deceased spouse (Boerner and Schulz, 2009; Field and Filano, 2010; Field and Friedrich, 2004; Field et al., 2003; Sanger, 2009). Other findings, such as the reformulation of identity or changes in independence are less established, albeit other existing research shows that a reorganization of social connections occurs in bereavement (Balaswamy et al., 2004; Ha, 2008, 2010; Ha et al., 2006; Lund et al., 1990; Stelle and Uchida, 2004).

4.3. Old age, health and bereavement

This review indicates that health concerns, such as sleep disruption, fatigue and loss of appetite persist or intensify after spousal loss. These findings are consistent with studies investigating the impact of bereavement on health issues, which show that at least half of the bereaved persons experience sleep disruption (Carter, 2005; Monk et al., 2008; Richardson et al., 2003), and which suggest that grief affects psychosocial health, depression and well-being (Bennett, 1997a,b; Byrne and Raphael, 1997, 1999; Fry, 2003; Mendes de Leon et al., 1984; Onrust and Gulipiers, 2006; Orl and Luenger, 2002; Turvey et al., 1998; van Grootheest et al., 1999). However, since health symptoms, caregiving and compromises to independence are pervasive in old age (Heeb et al., 2008), understanding the interrelationship between, and the impact of grief on these factors is complex.

4.4. Grief and coping

While there is at least moderate evidence in this review to support a decrease of grief over time, findings regarding coping and its impact on adjustment are inconclusive due to methodological weaknesses or variability in study findings. Another reason for the inconclusive evidence might be that the cognitive theory of stress and appraisal used in most studies, which considers coping as adaptive or maladaptive, is potentially inadequate when such a complex phenomenon like bereavement is the stressor (Stroebe and Schut, 1999). Alternative approaches, such as the dual process model of coping with bereavement, suggest that bereavement involves different sources of stress (Stroebe and Schut, 1999, 2010). These stressors occur from bereavement itself (loss-orientation) or from consequences of the loss (restoration-orientation) and require coping styles that fit the particular type of stressor. It is suggested that use of various coping styles, which shift between confronting the loss or attending to restorative aspects of living with the loss (oscillation) enables successful adjustment (Stroebe and Schut, 1999). The findings of this review point to the value of such newer understandings because studies propose that coping effectiveness; that is, the fit between style and stressor, and not a particular coping style, is important for grief resolution and positive health outcomes.

5. Recommendations for practice and research

Albeit more research is needed to fortify the existing knowledge base around conjugal bereavement in old age, implications for practice can be derived based on this review. When working with older, bereaved persons, nurses and other health professionals need to address the disrupted and sustaining everyday and relational practices. This involves support to change everyday practices, to maintain old or develop new ones, to learn to live with difficult emotions and times, and to negotiate relationships. Additionally, nurses and other health professionals need to be aware that loneliness and relational practices with the deceased are pervasive. Health challenges, symptoms and existential fears regarding dependence and an uncertain future also warrant attention. It is necessary to identify needs and concerns, conduct appropriate assessments, and to discuss strategies to manage symptoms and health problems, such as sleep disruption, fatigue and exhaustion, lack of appetite, pain or symptoms of persistent illness. Intensity of grief and
adverse mental health may decrease over time, in contrast to other aspects attributed to grief, such as finding meaning in the loss or difficult times and anniversary reactions. Since there is a lack of evidence, nurses and other health professionals are called upon to refrain from making judgments regarding "adaptive and maladaptive" coping styles. It seems to be more appropriate to focus on the meaning of the loss and on the individual strategies used to deal with other losses occurring simultaneously or as a consequence. Furthermore, it is important to note that men and women might experience bereavement differently and have different needs.

Further research investigating the everyday life world of older, bereaved persons, with a focus on meaning patterns and everyday practices is necessary. It is likely that qualitative approaches will yield the richest insights and in-depth understanding of the everyday experiences and their meanings. Research that addresses the relational practices of older persons is also called for, in particular because more persons will experience spousal loss in oldest-old age, with family members playing a crucial part in supporting them in everyday life following the loss. Therefore, future bereavement research should explicitly address relational dimensions of grief, such as family relations, interactions, and processes, and include several family members. Both, qualitative and quantitative research approaches are useful to study the family bereavement experience, and allow for the collection of individual and systemic family data and the use of the family as the unit of analysis (Feetham, 1991; Ganong, 2011; Gilliss, 1983; Gilliss and Davis, 1992).

While some knowledge about frequent health problems and symptoms exist, there is a lack of research about the interrelationship of old age, frailty, health and independence in relation to bereavement and widowhood. Further research that illuminates the relationship between coping and grief outcomes is also needed. Newer models, such as the dual process model of coping in bereavement (Richardson, 2010; Stroebe and Schut, 2010) provide a useful framework that accounts for the complexities of bereavement as stressor and the variety of coping styles used in an oldest-old population.

6. Conclusions

In this review, empirical findings about key characteristics of spousal bereavement in later life were synthesized. Thirty-nine studies that focused on the bereavement or grief experience of older persons were included, and findings grouped into six main themes. This review suggests that disrupted everyday activities and routines, as well as changed relationships within the family and social network are key aspects of the bereavement experience of older persons. Together with health concerns, threats to independence, a changed social identity, and a pervasive sense of loneliness that were identified in this review, older, widowed persons face many challenges following the loss of their spouse that shape their ability to manage life alone in the community. While many of the identified characteristics of the bereavement experience may not be unique to later life, they need to be considered when working with this population in clinical practice, in particular because older persons may also face challenges associated with the aging process and declining health in their daily lives. Because a majority of these studies included more women than men, and were carried out in North America, the identified themes represent to a large part a female, North American perspective. A consequent need for research that gives particular consideration to the experiences of older men and the impact of grief upon masculinities in later life, as well as to cultural diversity is therefore called for. Nevertheless, the existing evidence-base provides nurses and other health professionals with insights about the conjugal bereavement experience of older persons and equips them with research-based knowledge for their clinical practice. Moreover, existing research knowledge supports newer conceptualizations around grief as a very individualized, yet pervasive and common experience that needs to be integrated into the biographical narrative and meaning of persons' lives. Hence, such theoretical understandings seem to be useful guides for a more person-centered practice with older, bereaved people who lost their spouse.

Conflicts of interest: No conflicts of interest have been declared by the authors.

Funding: None.

Ethical approval: None.

References


Appendix A (continued)


Vale, T.D. 2009. We will remember them: a mixed method study to explore which post-war remembrance activities are most significant and important to bereaved people living with loss, and why those particular activities are chosen. Palliative Medicine 23, 537-544.


Appendix B: Recruitment algorithm

Recruitment algorithm – Living with loss study

Partner organization

Create list of persons 75+ who meet inclusion criteria

Database

Letter of invitation
Study information sheet
Flyer / Poster

Potential participants are contacted by key recruiting person, receive information, and are invited to participate

Is the person interested?

Yes

Does person 75+ consent to contact details be given to the researcher?

Yes

Information to Rahel Naef
rahel.naef@zhaw.ch
058 934 63 72

Target population:
✓ community-dwelling persons 75 years or older who have lost their spouse or life partner through death within the two previous years
✓ at least one other family member

Inclusion criteria: Potential participants are persons who...
✓ speak and understand German
✓ are cognitively able to understand and participate in the study
✓ experience loss and are willing to talk about their experience with the researcher and other participating family members
✓ are at least 18 years of age (family members)

Exclusion criteria: Persons cannot participate if they...
✓ were diagnosed with dementia
✓ suffer from mental illness
✓ live in an institution

Researcher

Phone call to potential participant 75+ to explain study

End

Does person 75+ like to participate?

Yes

Person 75+ identifies family members who can be invited into study and asks them if they are willing to participate

Phone contact with each potential family participant to explain study

Does the family member would like to take part?

Yes

Arrangements for first family group interview

No

End
Appendix C: Study flyer

Herzliche Einladung zur Teilnahme an einer Studie

Die Verlusterfahrung von Familien nach dem Tod eines älteren Familienmitglieds.

Sehr geehrte Damen, Sehr geehrte Herren,

Wir möchten Sie gerne einladen, an einer Studie zur „Verlusterfahrung von Familien nach dem Tod eines älteren Familienmitglieds“ teilzunehmen.

Wer kann an der Studie teilnehmen?
Wir laden folgende Personen ein:

- Personen die 75 Jahre oder älter sind und innerhalb der letzten zwei Jahre den Tod ihrer Ehe- oder Lebenspartnerin oder ihres Ehe- oder Lebenspartners erlebt haben.
- Mindestens eine ihr nahestehende Person, z.B. Kind, Geschwister, Enkelkind oder ein anderes Familienmitglied, aber auch Freunde oder Nachbarn.

Was ist das Ziel der Studie?
Das Ziel dieser Studie ist es, von Familien zu erfahren, wie sie mit ihrer Trauer und dem Verlust ihres älteren Familienmitglieds umgehen.

Warum braucht es diese Studie?
Für Pflegefachpersonen ist es wichtig zu wissen, was es heisst, im Alltag mit dem Verlust eines nahestehenden Menschen zurecht zu kommen. Dieses Wissen wird Pflegefachpersonen helfen, gezielt Pflege und Unterstützung für Familien und ältere Menschen anzubieten, welche den Tod einer ihr nahestehenden Person erlebt haben.

Was beinhaltet die Teilnahme?
Sie werden als Familie eingeladen, Ihre Trauer und Ihr Leben mit dem Verlust Ihrer angehörigen Person im Alltag zu beschreiben. Dazu finden drei Interviews verteilt auf ca. 12 Wochen statt. Das erste Interview ist ein Familieninterview. Das zweite und dritte Interview kann entweder ein Familien- oder ein Einzelinterview sein, oder mit einer Auswahl von Familienmitgliedern durchgeführt werden. In den Interviews geht es darum, was dieser Verlust für Sie bedeutet, welche Auswirkungen er auf Ihre Familie hat und wie Sie mit diesem einschneidenden Erlebnis in Ihrem Alltag umgehen.

Wer führt die Studie durch?
Diese Studie wird in Zusammenarbeit zwischen dem Institut für Pflege der Zürcher Hochschule für Angewandte Wissenschaften und der Universität Manchester in England durchgeführt. Sie findet im Kanton Zürich statt.

Wo erfahre ich mehr?
Sie können sich unverbindlich erkundigen oder schriftliche Informationen anfordern bei:

KONTAKTDETAIL
Winterthur, 07. Juli 2012

Verlust & Trauer Studie

Herzliche Einladung zur Teilnahme an einer Studie

Wie leben ältere Menschen und ihre Familien mit dem Verlust ihres Familienmitglieds?

Sehr geehrte Damen und Herren,

Wir möchten Sie herzlich zur Teilnahme an der Studie „Verlusterfahrung von Familien nach dem Tod eines älteren Familienmitglieds“ einladen. Es ist eine Studie des Instituts für Pflege der Zürcher Hochschule für Angewandte Wissenschaften und der Universität Manchester.

Die Studie richtet sich an Personen, welche 75 Jahre oder älter sind, sowie an nahestehende Personen. Als ältere Person haben Sie innerhalb der letzten zwei Jahre den Tod Ihrer Ehe- oder Lebenspartnerin oder Ihres Ehe- oder Lebenspartners erlebt. Sie und mindestens eine Ihnen nahestehenden Person (z. B. Kind, Geschwister, Freund/in) nehmen 3 Mal an einem Interview teil.

Ziele des Forschungsprojekts sind:

- Die Lebenserfahrung für ältere Menschen und ihre Familien nach dem Verlust eines älteren Familienmitglieds besser zu verstehen.
- Wissen zum Umgang mit dem Verlust im Alltag zu gewinnen.

Beiliegend finden Sie eine detaillierte Beschreibung der Studie. Sollten Sie Fragen zur Studie haben oder teilnehmen wollen, können Sie sich jederzeit an uns wenden (Telefon 058 934 63 72). Wir möchten uns an dieser Stelle herzlich für Ihr Interesse bedanken.

Mit freundlichem Gruss

Zürcher Hochschule für Angewandte Wissenschaften

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Appendix E: Study information sheet for older persons

Information zur Studienteilnahme

Die Verlusterfahrung von Familien nach dem Tod eines älteren Familienmitglieds.

Sehr geehrte Damen, sehr geehrte Herren,

Wir möchten Sie gerne einladen, an einer Studie zur „Verlusterfahrung von Familien nach dem Tod eines älteren Familienmitglieds“ teilzunehmen.

Wir möchten Sie mit diesem Schreiben informieren, damit Sie wissen, was eine Teilnahme an dieser Studie für Sie bedeutet. Frau Rahel Naef steht Ihnen auch persönlich zur Verfügung um die vorliegende Information und persönliche Fragen zu besprechen. Wir möchten uns an dieser Stelle herzlich für Ihr Interesse bedanken.

1. Auswahl der Studienteilnehmer/innen (Familien)

Wir laden Menschen, welche 75 Jahre oder älter sind, sowie mindestens eine nahestehende Person zur Studienteilnahme ein. Sie als ältere Person haben innerhalb der letzten zwei Jahre den Tod Ihrer Ehe- oder Lebenspartnerin oder Ihres Ehe- oder Lebenspartners erlebt.

Sie geben der Studienmitarbeiterin an, wer Ihre nahestehende Person ist, die ebenfalls für die Studie eingeladen werden kann. Die nahestehende Person kann zum Beispiel ein Kind, Geschwister, Enkelkind oder ein anderes Familienmitglied, aber auch jemand aus Ihrem Freundes- oder Bekanntenkreis sein.

Es ist auch möglich, dass mehrere nahestehende Personen in der Studie teilnehmen. Sollte eine grössere Anzahl nahestehender Personen in der Studie teilnehmen wollen, könnte es sein, dass nur eine Auswahl dieser Personen in die Studie eingeschlossen werden kann. Wenn hingegen nur Sie mitmachen möchten, ist eine Teilnahme an der Studie leider nicht möglich.

2. Ziel der Studie


3. Allgemeine Informationen zur Studie

Diese Studie wird in Zusammenarbeit zwischen dem Institut für Pflege der Zürcher Hochschule für Angewandte Wissenschaften und der Universität Manchester in England durchgeführt. Das Studienteam besteht aus folgenden Fachpersonen:

<table>
<thead>
<tr>
<th>ZHAW</th>
<th>Universität Manchester</th>
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<tbody>
<tr>
<td>Rahel Naef, dipl. Pflegefachfrau &amp; Wissenschaftliche Mitarbeiterin</td>
<td>Prof. Gunn Grande, Professorin für Palliative Care</td>
</tr>
<tr>
<td>Prof. Romy Mahrer Imhof, Professorin für Familienpflege &amp; Leiterin Master in Pflege</td>
<td>Dr. Richard Ward, Projektmitarbeiter</td>
</tr>
</tbody>
</table>
Appendix E (continued)


4. Freiwilligkeit der Teilnahme

Ihre Teilnahme an dieser Studie ist absolut freiwillig. Wenn Sie auf die Teilnahme an dieser Studie verzichten, haben Sie oder Ihre nahestehende Person keinerlei Nachteile zu erwarten. Das gleiche gilt, wenn Sie Ihre Einwilligung zu einem späteren Zeitpunkt widerrufen. Diese Möglichkeit haben Sie jederzeit. Einen Rücktritt von der Studie müssen Sie nicht begründen. Im Falle eines Widerrufes werden die bis zu diesem Zeitpunkt erhobenen Daten weiter verwendet.

Für eine Entscheidung zur Teilnahme können Sie sich so viel Zeit nehmen, wie Sie brauchen.

5. Studienablauf

Es handelt sich um eine qualitative Studie. Das heißt, Sie werden als Familie eingeladen, Ihre Trauer und Ihr Leben mit dem Verlust Ihrer angehörigen Person im Alltag zu beschreiben. Dazu finden drei Interviewserteilt auf ca. 12 Wochen statt. In den Interviews geht es darum, was dieser Verlust für Sie bedeutet, welche Auswirkungen er auf Ihre Familie hat und wie Sie mit diesem einschneidenden Erlebnis in Ihrem Alltag umgehen.

Das erste Interview ist ein Familieninterview. Das zweite und dritte Interview kann entweder ein Familien- oder Einzelinterview sein, oder mit einer Auswahl von Familienmitgliedern durchgeführt werden. Sie werden als Familie zusammen mit der Studienmitarbeiterin entscheiden, wer an den folgenden Interviews teilnimmt.

Jedes Interview dauert ca. 1-1.5 Stunden. Die Dauer ist davon abhängig, was Sie und Ihre Familienmitglieder erzählen möchten.

Das Interview kann bei Ihnen zu Hause, an der Fachhochschule (ZHAW) oder an einem anderen Ort Ihrer Wahl stattfinden.

Am Anfang der Studie werden Sie zudem zu Ihrer Person und Ihrer Familiensituation befragt (Alter, Geschlecht, Beruf, Beziehung zum verstorbenen Familienmitglied etc.).

Sollten sich nach Abschluss dieser drei Interviews nochmals Fragen ergeben, könnte es sein, dass Sie für ein zusätzliches Interview angefragt werden. Es ist auch möglich, dass Sie noch etwas ergänzen, oder etwas genauer beschreiben möchten. In einer solchen Situation können Sie entscheiden, ob Sie nochmals an einem weiteren Interview teilnehmen möchten oder nicht.

6. Nutzen für die Teilnahme

Es ist möglich, dass Sie es hilfreich finden, über Ihre Erfahrungen zu sprechen oder sich mit Ihren Familienmitgliedern auszutauschen. Dank Ihrer Studienteilnahme können die Ergebnisse auch anderen älteren Menschen in einer ähnlichen Lebenssituation und deren Angehörigen zugute kommen.

7. Risiken und Unannehmlichkeiten

Wir nehmen an, dass die Teilnahme für Sie keine negativen Folgen haben wird. Allenfalls können durch das Sprechen über Ihre Situation unangenehme
Erinnerungen und Gefühle aufkommen. Sie entscheiden, wenn Sie gewisse Fragen nicht beantworten möchten, das Interview unterbrochen oder gestoppt werden soll. Wenn Sie möchten, vermittelt Ihnen die Studienmitarbeiterin eine Fachperson, welche Sie weiter unterstützen kann.

Sollten Sie während der Studie Fragen oder Sorgen haben, können Sie das Forschungsteam jederzeit kontaktieren. Sie können sich direkt an Rahel Naef unter 058 934 63 72, rahel.naef@zhaw.ch oder an Romy Mahrer Imhof unter 058 934 63 44, romy.mahrer@zhaw.ch wenden.

8. Vertraulichkeit der Daten


Eine korrekte Durchführung der Studie wird kontrolliert. Im Rahmen von solchen Kontrollen kann die zuständige Ethikkommission Einsicht in die Originaldaten nehmen. Während der ganzen Studie und bei den erwähnten Kontrollen wird die Vertraulichkeit strikt gewahrt.

Ihr Name wird in keiner Weise in Berichten oder Publikationen, die aus der Studie hervorgehen, veröffentlicht. Es kann jedoch sein, dass Dinge, die Sie gesagt haben, in einem Bericht oder einer Veröffentlichung wörtlich zitiert werden.

9. Entschädigung für die Teilnahme an der Studie

Für die Teilnahme an dieser Studie erhalten Sie keine Entschädigung.

10. Deckung von Schäden

Die Zürcher Hochschule für Angewandte Wissenschaften (ZHAW) ersetzt Ihnen Schäden, die Sie gegebenenfalls im Rahmen der Studie erleiden. Zu diesem Zweck hat die ZHAW zu Ihren Gunsten eine Versicherung abgeschlossen. Stellen Sie während oder nach der Studie gesundheitliche Probleme oder andere Schäden fest, so wenden Sie sich bitte an die verantwortliche Prüferin Romy Mahrer Imhof. Sie wird für Sie die notwendigen Schritte einleiten.

11. Kontakt

Bei Unklarheiten, Notfällen, unerwarteten oder unerwünschten Ereignissen, die während der Studie oder nach deren Abschluss auftreten, können Sie sich jederzeit an die untenstehende Kontaktperson wenden:

KONTAKTDIVELS
Information zur Studienteilnahme

Die Verlusterfahrung von Familien nach dem Tod eines älteren Familienmitglieds.

Sehr geehrte Damen, Sehr geehrte Herren,

Wir möchten Sie gerne einladen, an einer Studie zur „Verlusterfahrung von Familien nach dem Tod eines älteren Familienmitglieds“ teilzunehmen.

Wir möchten Sie mit diesem Schreiben informieren, damit Sie wissen, was eine Teilnahme an dieser Studie für Sie bedeutet. Frau Rahel Naef steht Ihnen auch persönlich zur Verfügung um die vorliegende Information und persönliche Fragen zu besprechen. Wir möchten uns an dieser Stelle herzlich für Ihr Interesse bedanken.

1. Auswahl der Studienteilnehmer/innen (Familien)

Wir laden Menschen, welche 75 Jahre oder älter sind, sowie mindestens eine nahestehende Person zur Studienteilnahme ein. Sie wurden eingeladen, weil Sie eine nahestehende Person von einer ältere Person sind, welche innerhalb der letzten zwei Jahre den Tod ihrer Ehe- oder Lebenspartnerin oder ihres Ehe- oder Lebenspartners erlebt hat.

Es ist auch möglich, dass mehrere nahestehende Personen in der Studie teilnehmen. Sollte eine grössere Anzahl nahestehender Personen in der Studie teilnehmen wollen, könnte es sein, dass nur eine Auswahl dieser Personen in die Studie eingeschlossen werden kann.

2. Ziel der Studie


3. Allgemeine Informationen zur Studie

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<tbody>
<tr>
<td>Rahel Naef, dipl. Pflegefachfrau &amp; Wissenschaftliche Mitarbeiterin</td>
<td>Prof. Gunn Grande, Professorin für Palliative Care</td>
</tr>
<tr>
<td>Prof. Romy Mahar Imhof, Professorin für Familienpflege &amp; Leiterin Master in Pflege</td>
<td>Dr. Richard Ward, Projektmitarbeiter</td>
</tr>
</tbody>
</table>

Bei dieser Studie handelt es sich um die Doktorarbeit von Rahel Naef. Sie wird nach international anerkannten Grundsätzen für wissenschaftliche Projekte durchgeführt.
Die Studie wird während ca. einem Jahr laufen. Es werden bis 30 Familien in die Studie eingeschlossen.

4. Freiwilligkeit der Teilnahme

Ihre Teilnahme an dieser Studie ist absolut freiwillig. Wenn Sie auf die Teilnahme an dieser Studie verzichten, haben Sie oder Ihre nahestehende Person keinerlei Nachteile zu erwarten. Das gleiche gilt, wenn Sie Ihre Einwilligung zu einem späteren Zeitpunkt widerrufen. Diese Möglichkeit haben Sie jederzeit. Einen Rücktritt von der Studie müssen Sie nicht begründen. Im Falle eines Widerrufes werden die bis zu diesem Zeitpunkt erhobenen Daten weiter verwendet.

Für eine Entscheidung zur Teilnahme können Sie sich so viel Zeit nehmen, wie Sie brauchen.

5. Studienablauf

Es handelt sich um eine qualitative Studie. Das heisst, Sie werden als Familie eingeladen, Ihre Trauer und Ihr Leben mit dem Verlust Ihrer angehörigen Person im Alltag zu beschreiben. Dazu finden drei Interviews verteilt auf ca. 12 Wochen statt. In den Interviews geht es darum, was dieser Verlust für Sie bedeutet, welche Auswirkungen er auf Ihre Familie hat und wie Sie mit diesem einschneidenden Erlebnis in Ihrem Alltag umgehen.

Das erste Interview ist ein Familieninterview. Das zweite und dritte Interview kann entweder ein Familien- oder Einzelinterview sein, oder mit einer Auswahl von Familienmitgliedern durchgeführt werden. Sie werden als Familie zusammen mit der Studienmitarbeiterin entscheiden, wer an den folgenden Interviews teilnimmt.

Jedes Interview dauert ca. 1-1.5 Stunden. Die Dauer ist davon abhängig, was Sie und Ihre Familienmitglieder erzählen möchten.

Das Interview kann bei Ihnen zu Hause, an der Fachhochschule (ZHAW) oder an einem anderen Ort Ihrer Wahl stattfinden.

Am Anfang der Studie werden Sie zudem zu Ihrer Person und Ihrer Familiensituation befragt (Alter, Geschlecht, Beruf, Beziehung zum verstorbenen Familienmitglied etc.).

Sollten sich nach Abschluss dieser drei Interviews nochmals Fragen ergeben, könnte es sein, dass Sie für ein zusätzliches Interview angefragt werden. Es ist auch möglich, dass Sie noch etwas ergänzen, oder etwas genauer beschreiben möchten. In einer solchen Situation können Sie entscheiden, ob Sie nochmals an einem weiteren Interview teilnehmen möchten oder nicht.

6. Nutzen für die Teilnahme

Es ist möglich, dass Sie es hilfreich finden, über Ihre Erfahrungen zu sprechen oder sich mit Ihren Familienmitgliedern auszutauschen. Dank Ihrer Studienteilnahme können die Ergebnisse auch anderen älteren Menschen in einer ähnlichen Lebenssituation und deren Angehörigen zugute kommen.

7. Risiken und Unannehmlichkeiten

Wir nehmen an, dass die Teilnahme für Sie keine negativen Folgen haben wird. Allenfalls können durch das Sprechen über Ihre Situation unangenehme Erinnerungen und Gefühle aufkommen. Sie entscheiden wenn Sie gewisse Fragen nicht beantworten möchten, das Interview unterbrochen oder gestoppt werden soll.
Wenn Sie möchten, vermittelt Ihnen die Studienmitarbeiterin eine Fachperson, welche Sie weiter unterstützen kann.

Sollten Sie während der Studie Fragen oder Sorgen haben, können Sie das Forschungsteam jederzeit kontaktieren. Sie können sich direkt an Rahel Naef unter 058 934 63 72, rahel.naef@zhaw.ch oder an Romy Mahrer Imhof unter 058 934 63 44, romy.mahrer@zhaw.ch wenden.

8. Vertraulichkeit der Daten


Eine korrekte Durchführung der Studie wird kontrolliert. Im Rahmen von solchen Kontrollen kann die zuständige Ethikkommission Einsicht in die Originaldaten nehmen. Während der ganzen Studie und bei den erwähnten Kontrollen wird die Vertraulichkeit strikt gewahrt.

Ihr Name wird in keiner Weise in Berichten oder Publikationen, die aus der Studie hervorgehen, veröffentlicht. Es kann jedoch sein, dass Dinge, die Sie gesagt haben, in einem Bericht oder einer Veröffentlichung wörtlich zitiert werden.

9. Entschädigung für die Teilnahme an der Studie

Für die Teilnahme an dieser Studie erhalten Sie keine Entschädigung.

10. Deckung von Schäden

Die Zürcher Hochschule für Angewandte Wissenschaften (ZHAW) ersetzt Ihnen Schäden, die Sie gegebenenfalls im Rahmen der Studie erleiden. Zu diesem Zweck hat die ZHAW zu Ihren Gunsten eine Versicherung abgeschlossen. Stellen Sie während oder nach der Studie gesundheitliche Probleme oder andere Schäden fest, so wenden Sie sich bitte an die verantwortliche Prüferin Romy Mahrer Imhof. Sie wird für Sie die notwendigen Schritte einleiten.

11. Kontakt

Bei Unklarheiten, Notfällen, unerwarteten oder unerwünschten Ereignissen, die während der Studie oder nach deren Abschluss auftreten, können Sie sich jederzeit an die untenstehende Kontaktperson wenden:

KONTAKTDETAILS
Appendix G: Interview guide

Main Questions (English translation):
- Tell me about how your family member died?
- What has happened since then?
- Please tell me about your family member who died. Do you have a story, memory or event that might begin to capture who s/he was?
- Could you tell me about your family? Who is in your family? (draw genogram)
- Tell me about a time following the loss where things were particular difficult?
- When do you miss your family member most? What do you miss most now?
- Tell me about a situation where your loss has been less difficult.
- In everyday life, for instance last month, how were you aware of (name)’s death? How does your daily life look now?
- What has changed since the death of your family member (for you as a family, spouse, son, daughter etc.)?
- What do you think is this / has this been like for (name of other participating or non-participating family members)?

Hauptfragen (German original):
- Können Sie mir erzählen, wie Ihr Familienmitglied gestorben ist?
- Was ist seither passiert?
- Erzählen Sie mir von Ihrem verstorbenen Familienmitglied. Können Sie mir eine Geschichte, Erinnerung oder Ereignis erzählen, das aufzeigt, was diese Person ausgemacht hat?
- Können Sie mir etwas zu Ihrer Familie erzählen? Wer ist Ihre Familie? (Genogramm zeichnen)
- Erzählen Sie mir von einer Zeit, die für Sie speziell schwierig war.
- In welchen Situationen fehlt Ihnen Ihr Familienmitglied am Meisten? Was fehlt Ihnen jetzt am Meisten?
- Können Sie mir von einer Situation erzählen, wo der Verlust nicht so im Vordergrund stand?
- Wie ist Ihnen der Tod von (Name) im Alltag bewusst? Zum Beispiel im vergangenen Monat? Wie gestalten Sie den Alltag jetzt?
- Was hat sich für Sie (als Familie, Ehepartner, Sohn, Tochter etc.) seit dem Tod verändert?
- Wie ist / war das für (Name von anderen teilnehmenden oder nicht-teilnehmenden Familienmitgliedern)?
Appendix G (continued)

To seek more depth and clarity (English translation):

• Go on…
• What was / is this like for you?
• What does this mean for you?
• Could you give me an example of that? Could you tell me about the last time this happened?
• Can you tell me about a time recently that was memorable or meaningful?
• Please tell me more about your experience of loss.
• Please relate what you are saying to your experience of loss.
• Can you think of anything else that would help me to understand your experience of loss?

Um mehr Tiefe und Klarheit zu suchen (German original):

• Erzählen Sie weiter…
• Wie war / ist das für Sie?
• Was heisst / bedeutet das für Sie?
• Könnten Sie mir ein konkretes Beispiel erzählen? Könnten Sie mir vom letzten Mal erzählen, wo das passiert ist?
• Könnten Sie mir ein Beispiel erzählen, dass Sie besonders in Erinnerung haben oder für Sie besonders bedeutungsvoll war?
• Könnten Sie mir mehr über Ihren Verlust erzählen?
• Wie hängt das, was Sie mir gerade erzählt haben, mit Ihrem Verlust zusammen?
• Gibt es noch weiteres, was mir helfen könnte, Ihren Verlust und / oder Ihre Erfahrungen im Alltag zu verstehen?
### Angaben zu Ihrer Person

#### Persönliche Angaben

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Alter:</td>
<td>_____ Jahre</td>
</tr>
<tr>
<td>2. Geschlecht:</td>
<td>1 weiblich</td>
</tr>
<tr>
<td>3. a) Haben Sie Kinder?</td>
<td>1 ja</td>
</tr>
<tr>
<td>b) Wenn ja, wie viele?</td>
<td>Anzahl: _____</td>
</tr>
<tr>
<td>4. Wie lange waren Sie verheiratet oder in Partnerschaft lebend?</td>
<td>_____ Jahre</td>
</tr>
<tr>
<td>5. Wer gehört zu Ihrer Familie?</td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Wie war Ihre Wohnsituation vor dem Tod Ihres Familienmitglieds?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 Gemeinsame Wohnsituation (z.B. in Wohnung oder Haus)</td>
</tr>
<tr>
<td></td>
<td>2 Getrennte Wohnsituation (Partner/in z.B. in Alterszentrum oder Pflegeheim oder eigener Wohnung / Haus)</td>
</tr>
<tr>
<td></td>
<td>3 Andere Situation</td>
</tr>
<tr>
<td>7. Wie ist Ihre Wohnsituation seit dem Tod Ihres Familienmitglieds?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 In selber Wohnung oder Haus</td>
</tr>
<tr>
<td></td>
<td>2 Neue Wohnsituation, nämlich</td>
</tr>
<tr>
<td></td>
<td>3 Andere</td>
</tr>
</tbody>
</table>
**Appendix H (continued)**

Verlusterfahrung von Familien

8. Wie viele Jahre Schulbildung haben Sie?

| □ | 1 ≤ 9 Jahre | □ | 3 13-16 Jahre |
| □ | 2 10-12 Jahre | □ | 4 > 16 Jahre |

9. Was war Ihr Beruf / Ihre Tätigkeit vor der Pensionierung?

|  
|  

10. Wie kommen Sie mit dem gesamten monatlichen Einkommen zurecht? Würden Sie sagen, es ist....

| □ | 1 sehr schwierig | □ | 4 ziemlich einfach |
| □ | 2 schwierig | □ | 5 einfach |
| □ | 3 ab und zu schwierig | □ | 6 sehr einfach |

11. Wie geht es Ihnen zur Zeit gesundheitlich?

| □ | 1 ausgezeichnet | □ | 4 schlecht |
| □ | 2 gut | □ | 5 sehr schlecht |
| □ | 3 mittelmässig |  

12. Leiden Sie an einer Krankheit oder bestimmten Beschwerden?

|  
|  

---

Demographische Angaben ältere Person 75+, Verlust und Trauer Studie, 07. Juli 2012, Version 1.0, Studienummer 02b
Appendix H (continued)

Verlusterfahrung von Familien

Angaben zu Ihrem verstorbenen Familienmitglied

13. Wie alt war Ihr Partner / Ihre Partnerin, als er / sie starb?
   __________________________ Jahre

14. Wann ist Ihr Partner / Ihre Partnerin gestorben?
   Datum: __________________________

15. Wo ist Ihr Partner / Ihre Partnerin gestorben?
   □ 1 zu Hause  □ 3 Pflegeheim
   □ 2 Spital  □ 4 Anderer Ort __________________________

16. Woran ist Ihr Partner / Ihre Partnerin gestorben?
   __________________________

17. Benötigte Ihr Partner / Ihre Partnerin Pflege und Unterstützung?
   □ 1 Ja  □ 2 Nein

18. Wenn ja, wer war die primäre Person, die Ihren Partner / Ihre Partnerin unterstützt oder gepflegt hat (eine Antwort möglich)?
   □ 1 Sie selber  □ 5 Enkel/in
   □ 2 Tochter  □ 6 Freund/in
   □ 3 Sohn  □ 7 Nachbar/in
   □ 4 Schwester oder Bruder  □ 8 Andere Person

19. Wer hat sonst noch bei der Pflege geholfen (mehrere Antworten möglich)?
   □ 1 Sie selber  □ 5 Enkel/in
   □ 2 Tochter  □ 6 Freund/in
   □ 3 Sohn  □ 7 Nachbar/in
   □ 4 Schwester oder Bruder  □ 8 Andere Person

20. Hatten Sie Hilfe von aussen, z. B. Spitex?
   □ 1 Ja  □ 2 Nein

Demographische Angaben ältere Person 75+, Verlust und Trauer Studie _07, Juli 2012, Version 1.0 / Studienummer 02b
Appendix I: Demographic form for family members

Angaben zu Ihrer Person

Persönliche Angaben

1. Alter: ________ Jahre

2. Geschlecht:
   □ 1 weiblich
   □ 2 männlich

3. Zivilstand:
   □ 1 verheiratet / Partnerschaft
   □ 2 verwitwet
   □ 3 ledig / alleinstehend
   □ 4 geschieden / getrennt

4. a) Haben Sie Kinder?
   □ 1 ja
   □ 2 nein
   Anzahl: ________

   b) Wenn ja, wie viele?

5. In welcher Beziehung stehen Sie zum verstorbenen Familienmitglied?
   Sind Sie....
   □ 1 Tochter
   □ 2 Sohn
   □ 3 Schwiegertochter
   □ 4 Schwiegersohn
   □ 5 Schwester
   □ 6 Bruder
   □ 7 Schwägerin
   □ 8 Schwager
   □ 9 Enkelin
   □ 10 Enkel
   □ 11 Freund / Freundin
   □ 12 Nachbar / Nachbarin
   □ 13 Anderes Familienmitglied
   □ 14 Andere Person

6. Wie viele Jahre Schulbildung haben Sie?
   □ 1 ≤ 9 Jahre
   □ 2 10-12 Jahre
   □ 3 13-16 Jahre
   □ 4 > 16 Jahre

7. Was ist Ihr Beruf / Ihre Tätigkeit?


Demographische Angaben_Familienmitglied_Verlust und Trauer Studie _07. Juli 2012_Version 1.0/ Studiennummer 06d
### Appendix I (continued)

**Verlusterfahrung von Familien**

<table>
<thead>
<tr>
<th>8. Wie kommen Sie mit dem gesamten monatlichen Einkommen zurecht? Würden Sie sagen, es ist ....</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ 1 sehr schwierig</td>
</tr>
<tr>
<td>□ 2 schwierig</td>
</tr>
<tr>
<td>□ 3 ab und zu schwierig</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>9. Wie geht es Ihnen zur Zeit gesundheitlich?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ 1 ausgezeichnet</td>
</tr>
<tr>
<td>□ 2 gut</td>
</tr>
<tr>
<td>□ 3 mittelmässig</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>10. Leiden Sie an einer Krankheit oder bestimmten Beschwerden?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
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<tr>
<td></td>
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<tr>
<td></td>
</tr>
</tbody>
</table>
Appendix J: Transcription rules

1. Sprache

2. Titel

<table>
<thead>
<tr>
<th>Studiennummer</th>
<th>Teilnehmende</th>
<th>Interview</th>
<th>Datum</th>
<th>Dauer</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>01PW, 01FM, 01FW</td>
<td>1</td>
<td>08.08.2011</td>
<td>60 min</td>
</tr>
</tbody>
</table>

3. Personenbezeichnung

<table>
<thead>
<tr>
<th>Person</th>
<th>Regel</th>
<th>Beispiel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview/er</td>
<td>Initialen</td>
<td>RN</td>
</tr>
<tr>
<td>Person 75+</td>
<td>Studiennummer, P, Geschlecht</td>
<td>01PW</td>
</tr>
<tr>
<td>Familienmitglied1</td>
<td>Studiennummer, F, Geschlecht</td>
<td>01FM</td>
</tr>
<tr>
<td>Wenn weitere Familienmitglieder</td>
<td>Studiennummer, F2, Geschlecht</td>
<td>01F2W</td>
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</tbody>
</table>

4. Satzzeichen

<table>
<thead>
<tr>
<th>Typ</th>
<th>Regel</th>
<th>Beispiel</th>
</tr>
</thead>
<tbody>
<tr>
<td>?</td>
<td>Fragen und steigend / hoch endende Stimmführung</td>
<td></td>
</tr>
<tr>
<td>.</td>
<td>Abgeschlossener Gedanke, meist auf dem Grundton endende Stimmführung</td>
<td></td>
</tr>
<tr>
<td>,</td>
<td>kurzes Zögern, Gedanke wird jedoch fortgesetzt</td>
<td></td>
</tr>
<tr>
<td>;</td>
<td>abgebrochener Gedanke, gefolgt von einem anderen Gedanken</td>
<td></td>
</tr>
</tbody>
</table>

5. Weiteres

<table>
<thead>
<tr>
<th>Typ</th>
<th>Regel</th>
<th>Beispiel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nicht verbale Äusserungen</td>
<td>in Klammern kommentiert ()</td>
<td>(lacht), (weint), (stöhnt), (Seufzer)</td>
</tr>
<tr>
<td>Pausen: länger als 3 Sekunden</td>
<td>in Klammern vermerken ()</td>
<td>(Pause)</td>
</tr>
<tr>
<td>Gleichzeitiges Sprechen</td>
<td>mit Trennstrich vermerken //</td>
<td>// ja genau //</td>
</tr>
<tr>
<td>Wörtliche Reden und Zitate</td>
<td>Anführ- und Schlusszeichen „0“</td>
<td>„es war sehr schlimm“</td>
</tr>
<tr>
<td>Wortabbrüche</td>
<td>Bindestrich -</td>
<td>merkwü-</td>
</tr>
<tr>
<td>Orts- und Namensbezeichnung</td>
<td>Anonymisieren</td>
<td>W. (Ort), U. (Name), U (Spital)</td>
</tr>
</tbody>
</table>
Appendix K: Exemplar of constructing a story of a good death

The Brown family (P4: 53-183).

In the following interview excerpt, Victoria and her father Henry talk about the day their close other died. Henry had been his wife’s primary carer for 4.5 years during which she suffered from Alzheimer’s disease. Victoria had spent one day a week with her parents to support her father. Their close other died on Christmas day of pneumonia on a special dementia unit, where she had sojourned for respite on a regular basis during the year preceding her death.

Victoria: // And we’ve had; it was a happy Christmas. We were thoughtful //
Henry:    // Yes, yes, it went well //
Victoria: // Our children are adults. And then the phone rang and they said at the [name of clinic] – they had already given her morphine and she had not been well at all the whole day; [name of brother] was totally shocked, the breathing that happens when you are dying -
Henry:    // Yes //
Victoria: And they said, if we would like to, we should make sure that those who want to come by do so [..]
Henry:  Yes.
Victoria: It was not like; but everybody indeed came, the brother, his girlfriend, the children, my sister-in-law. She was not responsive in that sense. She had; well [name], or what is her name? [Name of girlfriend] was totally shocked, she felt that; but she did breathe like someone breathes in such a situation (seeks words). I’ve had a hard time. I thought: “Do I have to leave for her to die?” And because so many people came by, I was outside the room quite a bit. [...] And then she really, yes. We had; we discussed; for me, it was clear: I’ll also stay for the night. That was a discussion we had //
Henry:   // Yes, that was that. They had made a bed ready //
Victoria: // I said: “I stay here”; that is what we said. It was a room for two beds. Our [name of her daughter] left after 5 o’clock and you [Henry] were on the phone with [name of brother] and they had a shift change. She [the nurse] came in with the angel. This was very special for me. I would never have thought that my mother would die looking at an angel with a trumpet. I think this is just unbelievable.
Henry:  Yes, yes.
Victoria: We hang it up and I simply saw it. And the nurse left; yes, she did; that is how it was. I mean, well, they had given her morphine once again and something else. They’ve had washed her because she had been sweating. I think she died; she died basically calmly (emotional). Everybody had come by //
Henry:  // I have to say, in that sense, it is for me; there was no rearing up. //
Victoria: // it was just this single day //
Henry: // somehow a leashing out towards others. Just because of her heavy breathing, Victoria //
Victoria: // this has bothered you a lot. [Name of son] almost flipped out [because of her heavy breathing] //
Henry: But look, Victoria, I have to tell you one thing: Mom often, already at home breathed real loudly …[Henry explains that his wife always breathed laboriously, to the extent that he could hear her from his bedroom upstairs when she was sleeping downstairs, and that he often went down if he did not hear her to check on her]….It just did not use to be so extreme like at the end.
Victoria: // Yes, this was rather strange. This was strange. But, nevertheless, yes, it was, it was basically a good day. This has to be said. One has to acknowledge that //

Henry: // Yes, one has to find the positive in the whole situation.

[left out: lines 88 - 96]

Henry: In that sense, I don’t have to say that we have to feel bad, well, if we had tried out something else and if we would have gone to [region in Switzerland where many natural healers practice] or something else. Maybe it would have taken a bit longer.

Victoria: Well, I am basically gl-; I was very glad to be present.

Henry: Oh yes, the same for me. //

Victoria: // Definitively //

Henry: // The whole year, when I look back, I think it was positive. Otherwise, you would always tell you-; I am just; I was thinking about, if you [to Victoria] would have gone alone with Mom [to bring her into respite care] and I would not have come with you and I would, for instance, not have seen her anymore simply because it would have happened earlier, I would have felt really, really bad afterwards and say: Well, „God dam it, you did not even stood your ground“ as it, yes.

Victoria: Although it is common knowledge that many people can’t die when you are there. You can sit there for three days and go once to the toilet and it happens. But that is not really helpful. I am very glad that I was present, yes, I am glad. I am also glad that everybody could go by and naturally; yes, this was peculiar for those, I mean, she looked, well yes, yes. From this point, I think it was a rather good experience, it is not something negative //

Henry: // I myself see it as very positive, also from the grandchildren. Let’s say it like this: No one has to have reproaches that they have not said goodbye to grandma (pause) because…//

Victoria: // It was clear to everybody too that this is the last time. That was so. //

Henry: // Yes, yes, that way anyw-; it was clear when they were there //

Victoria: Well, I do know now that for some; with [name of brother's girlfriend] I've, no, she said: “Victoria, how could you write in the death notice” – I don't know anymore what we wrote....

Henry: After all.

Victoria: She [brother's girlfriend] thought that she [deceased] was; she did not suff-; she was breathing, like one breathes then; she did not suffer.

Henry: No.

Victoria: Definitively. She had morphine. She did not suffer, not at all //

Henry: // No, no. I’ve said, it is not...//

Victoria: One could say this honestly; it is because, it is, yes, I did not experience it as suffering. I mean...//

Henry: We wrote: “She peacefully fell into her last sleep”.

Victoria: // Something like this, I don’t recall it. //

Interviewer: [to Victoria] You said that you were glad to be present. What did this; this memory, or this experience to be there, how did this help you afterwards, or did it help at all? Maybe I am making an assumption here.
<table>
<thead>
<tr>
<th>Victoria:</th>
<th>Well it has, yes it has, I do think it was helpful. I’ve also, I’ve also helped to wash, dress, and get her ready. Yes, so – yes it did help indeed. Ehm, I’ve also seen that; I have to say that, frankly spoken, I was glad that she could die. I can say that. Everything that had come before was much worse than dying or everything that came afterwards – for me. Because of this I really found that it has been a good conclusion, because, you never know otherwise, don’t you? And I’ve also been relieved that she could die in the [name of the clinic]. I’m absolutely sure that at home, we could not have handled it, the two of us. We would have to; I’ve also said this to [name of family physician]; that is. I have to frame it like this: we never talked about it, but it was probably my Mom’s wish to die at home because she disliked doctors and alike. If I am real honest, I have to admit that it would not have been her wish. That is, definitively, we would not have handled it because you (to Henry) would have tried to give her something to eat an hour before. Well, we would have, well, of course we would have handled it somehow, but I think it was a good place, where we could, well, be alone and know nonetheless: you only have to ring the bell and you have immediately a professional with you. That gave a good feeling (Henry agrees) And this is also why it was a good ex-; well yes, I was very impressed when [name of her daughter who is a nurse] sent me a text message that this is a good environment, and that it would turn out well. Well, I think, this gives me a good feel, yes, definitively.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviewer:</td>
<td>Mh.</td>
</tr>
<tr>
<td>Henry:</td>
<td>And you would have, when you would not have been around or somewhere else, you would have felt bad. You would have thought all the time that you would have abandoned us two. //</td>
</tr>
<tr>
<td>Victoria:</td>
<td>// Yes, it depends where I would have been. //</td>
</tr>
<tr>
<td>Henry:</td>
<td>// Depending on how it would have been, that I got. //</td>
</tr>
<tr>
<td>Victoria:</td>
<td>// Yes, it depends; probably yes.</td>
</tr>
<tr>
<td>Interviewer:</td>
<td>[to Henry] How did you experience it, how was it like for you?</td>
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<tr>
<td>Henry:</td>
<td>I’ve already told that, basically, with the phone and all that, how it was. For me it is; when we were there, this question did not exist: “How long will Mom make it?” It continued to be on this side. Well, it seems that I did not want to see it. But I did not fall into despair, Victoria, did I? //</td>
</tr>
<tr>
<td>Victoria:</td>
<td>// No, no. But you have not; for you, it has not yet been //</td>
</tr>
<tr>
<td>Henry:</td>
<td>// Yes, that is for sure. But it is now about: how you experienced it in that sense. //</td>
</tr>
<tr>
<td>Victoria:</td>
<td>I think that maybe exactly because you [father] did not; that you could not acknowledge it consciously, it was such a good day.</td>
</tr>
<tr>
<td>Henry:</td>
<td>Yes.</td>
</tr>
<tr>
<td>Victoria:</td>
<td>If you, perhaps; panic is totally the wrong word, but…I can imagine that//</td>
</tr>
<tr>
<td>Henry:</td>
<td>Yes, yes.</td>
</tr>
<tr>
<td>Victoria:</td>
<td>Also for her; I believe also for her, it was good. (Pause)</td>
</tr>
<tr>
<td>Interviewer:</td>
<td>Did I understand you right that for you, it was clear that she was dying</td>
</tr>
<tr>
<td>Victoria:</td>
<td>// Yes //</td>
</tr>
<tr>
<td>Interviewer:</td>
<td>and for you, it came rather as a surprise on that day?</td>
</tr>
<tr>
<td>Henry:</td>
<td>If surprising; I just have; I’ve had this hope, let’s say it like this; that it would not be the time just yet, although during the day, it became different. Let’s say, in contrast to what she [Victoria] has said: that she was glad to bring her to the dementia unit to die. That was not the case for me: “Mom goes there” [to die]. Also, when we had to bring her there, the only thing that was clear to me was: the situation like I’ve had it on the Sunday is the limit. This is just; I would have needed to say that if it had been like Sunday also on Monday, and Tuesday, that would have been somehow bad. I can’t say why. I would...//</td>
</tr>
<tr>
<td>Victoria:</td>
<td>// Yes, this would have been bad. //</td>
</tr>
<tr>
<td>Henry:</td>
<td>// That would have been bad. //</td>
</tr>
<tr>
<td>Victoria:</td>
<td>// Definitely bad. //</td>
</tr>
<tr>
<td>Henry:</td>
<td>This would have been real bad. This has happened because of all these years.</td>
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</tbody>
</table>