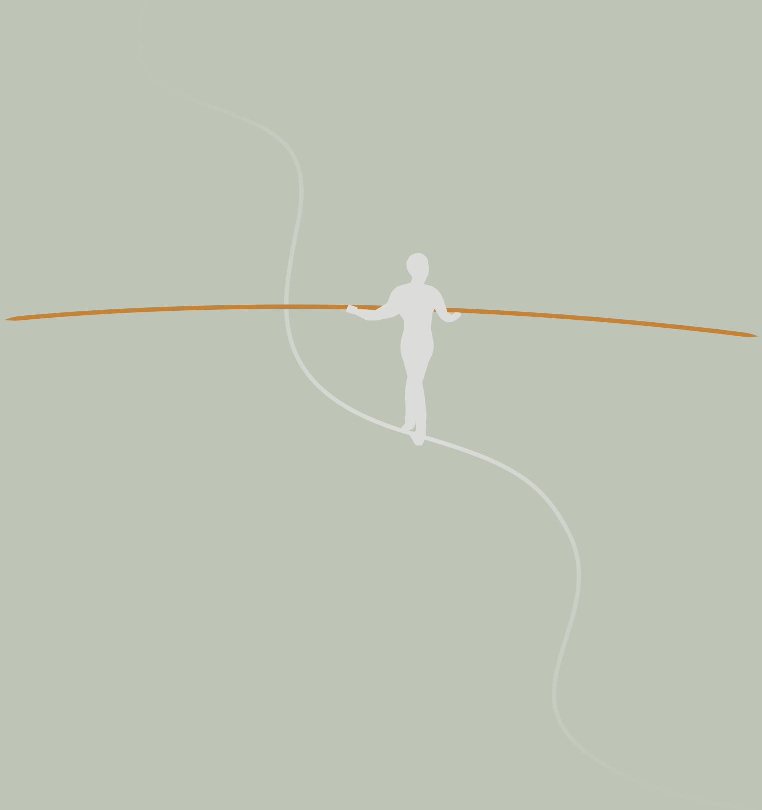
PARENTING A MIDDLE-AGED CHILD WITH CANCER:

A DELICATE BALANCING ACT FOR PARENTS, CHILDREN AND HEALTH CARE PROVIDERS



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LIESBETH VAN HUMBEECK

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PhD thesis Ghent University

2016 Nevelland Graphics

Lay-out by Stefanie De Buyser & Liesbeth Van Humbeeck

Cover illustration by Veerle Gevaert

ISBN: 9789073626379

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PARENTING A MIDDLE-AGED CHILD WITH CANCER: A DELICATE BALANCING ACT FOR PARENTS, CHILDREN AND HEALTH CARE PROVIDERS.

Liesbeth Van Humbeeck

Dissertation submitted in fulfillment of the requirements

for the degree of PhD in Health Sciences

Supervisor: Prof. dr. Nele Van Den Noortgate

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This PhD-dissertation has been financially supported by Kom op tegen Kanker, a campaign of Vlaamse Liga tegen Kanker VZW, from October 2011-March 2014.

ZWIJGEN IS OOK VOOR IEMAND ZORGEN, SOMS.

Griet Op De Beeck. Kom hier dat ik u kus (p. 366)

HET WAS EEN SPREKEND ZWIJGEN.

DAT DE AFSTAND TUSSEN HEN KON OVERBRUGGEN.

Birsen Taspinar. Moeders van de stilte (p. 243)

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CHAPTER 1. INTRODUCTION AND RESEARCH QUESTIONS

“You don't really understand human nature
unless you know why a child on a merry-go-round will wave
at his parents every time around- and why
his parents will always wave back.”
William D. Tammeus

1. INTRODUCTION

This introductory chapter provides a background to this dissertation by placing the separate studies in a broader societal context. The reader is provided with an appreciation of (1) existing knowledge related to ageing and cancer incidence in a Belgian context, (2) the joint survival-durable ties between parents and children, (3) the role of family caregivers in cancer and (4) the specific facets of a parent-child relationship in old age. Further on, the reasons to explore abovementioned topics by means of qualitative research will be addressed. The scope and aim of the dissertation is provided along with the research questions. We then conclude with an overview of the organisation of this dissertation.

1.1. SETTING THE SCENE

Ageing and the aged population

Worldwide there is a continuously growing number of older people living to old age. Global life expectancy at birth in 2015 was 71.4 years (73.8 years for females and 69.1 years for males). Moreover, average life expectancy at birth has increased by about 5 years between 2000 and 2015 (World Health Organization, 2015). By 2050 in Belgium, 24.5% of the population is projected to be over the age of 65 and 9.6% over the age of 80 (OECD, 2013). In addition, the older population in itself is progressively ageing. The proportion of oldest old (80 years and older) is growing faster than any other segment of the population and is projected to almost by 2060 (European Commission, 2010). This strong growth of oldest old and the further increase of life expectancy imply that an increasing proportion of the population will be facing an extended life period of great care dependency. In Belgium, an average of 8% of over-65s and 42% of the over-85s live in nursing homes (Van Den Bosch et al., 2011). This ageing of the population goes hand in hand with the emergence of new emotionally taxing events (Marengoni, 2010) such as the confrontation with a cancer diagnosis in a middle-aged child and parental bereavement in later life.

Changing intergenerational complexion of families

Demographic shifts have increased the number of generations but decreased the absolute number of relatives (S. Harper, 2005). Co-longevity has greatly increased the duration of family ties and as such parent and child life may overly by as much as 6-7 decades (Miles et al., 2016; Shapiro, 2004). About 60 per cent of individuals between the ages 40–50 years has at least one living parent (Bengtson, 2001; Settersten, 2007; Swartz, 2009). A 10-nation study, SHARE, finds substantial numbers of respondents (25%) having parents even in their sixties (Börsch-Supan et al., 2005). Intergenerational relations have become more and more important (Bengtson, 2001; Swartz, 2009). Increased co-longevity is one crucial part of demographic change as the last half century, living alone has become much more common for adults in all age groups (Klinenberg, 2012). Today, in western European countries, approximately one third of the population lives alone (Eurostat, 2010). As a consequence, given intergenerational connections, such as the middle-aged child[1]/older parent[2] tie, may become more socially prominent and personally significant.

Cancer incidence

In the early 21st century, it is less certain that children will outlive their parents (White & Beach, 2012) as the reality is that parents and their children are together becoming at risk for cancer, heart disease, stroke, and other major illnesses (Croker, 2007). The World Cancer Report documents that cancer rates are set to increase at an alarming rate globally (International Agency for Research on Cancer, 2014). Cancer is a major cause of morbidity and mortality, with approximately 14 million new cases and 8 million cancer-related deaths in 2012, affecting populations in all countries and all regions (Ferlay et al., 2013a). In 2012, there were just over 3.4 million new cases of cancer (excluding non-melanoma skin cancers) in Europe alone (Ferlay et al., 2013b). In 2013, 65.487 Belgians in total were diagnosed with

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[1] Middle-age is the period of age beyond young adulthood and before the onset of old age. In this dissertation we listed middle-age between the ages of 40 and 60.

[2] Older parents in this dissertation were defined as persons being 65 years or older and having an adult child with any type of cancer at any stage or whose adult child died due to cancer.

cancer, 53 % males and 47 % females, of whom approximately 25.000 Belgians between 40 and 60 years old (Belgian Cancer Registry, 2015). By 2025, the number of new cancer diagnoses in Belgium is expected to increase to almost 78.000. Prostate, breast, lung and colorectal cancer are the most common cancers sites in patients older than 45 years of age. One in three males and one in four females will develop cancer under the age of 75 years (Belgian Cancer Registry, 2015). In Belgium, cancer is leading cause of death in the aged less than 65. From the age of 45 years, lung cancer causes 1 out of every 3 male cancer deaths while breast cancer is responsible for 1 out of every 5 female cancer deaths (Belgian Cancer Registry, 2015). The shifting of cancer treatment to outpatient settings has placed the burden of care from health care providers to patients and their family caregivers (Northouse, Williams, Given, & McCorkle, 2012).

The parent-child relationship in later life

Having parents until late adulthood has almost become a ‘normal’ life situation, and compared to earlier times, the shared life span of parents and adult children is extended. At the same time this brings about new roles, expectations and potential sources of support but also sources of conflict and strain (Askham et al., 2007). A cancer diagnosis has implications for both patients and their family members from diagnosis through end of life (Hendriksen et al., 2015; Surbone et al., 2010). When a person develops cancer, family members provide the context for this experience, but they themselves are often profoundly affected by the disease (Kershaw et al., 2015). Family members often suffer doubly: they suffer with the cancer patient but also carry their own burden (Grypdonck, 1996; Lindholm, Rehnsfeldt, Arman, & Hamrin, 2002). This dissertation especially focuses on the parent-child relationship in light of a middle-aged child (40-60 years old) diagnosed with cancer for several reasons. First, parenting is one of the most fundamental roles experienced by adults, beginning at the moment they become parents and lasting all their lives (Fingerman & Birditt, 2011; Levitzki, 2009). Second, the child-parent relationship constitutes a very special type of relationship in which every human is personally involved. From its origin and throughout life, this relationship is very different from and longer than all other kinds of relationships (Logan & Spitze, 1996; Troll & Fingerman, 1996). For many, no relationship last longer than the connection between parents and children (Szydlik, 2016). This relationship is characterized by changes and transitions over time that may transform the amount and type of assistance given, the social interaction and the meaning of the relationship itself (Pillemer & McCartney, 2013). To move through developmental stages, middle-aged children and their parents typically depend on each other and seek assistance from one another. Yet, maintaining mutually enhancing relationships can be challenging for middle-aged children and aging parents (Deanow, 2011). Third, few clear-cut role expectations exist for parents and children as they age (Piercy & Chapman, 2001). Fourth, we reason that an adult cancer trajectory is characterized with a different enactment of the parental role in comparison with the paediatric oncology setting. Given young children's dependency on parents, they are always accompanied by their parents and/or extended family members who may also develop a close relationship with the health care team over time. Instead middle-aged children are legally responsible for themselves what has implications for the role that older parents are allowed to play and often results in parents' being formally excluded from decision making around care.

In addition, the few existing models on parenting in later life (Fingerman, Cheng, Birditt, & Zarit, 2012) highlight ambiguity on the enactment of the parental role in late life. Some scholars in the field of developmental psychology suggest that the parental role is not a central factor in older people's lives (Gower & Dowling, 2008; Milkie, Bierman, & Schieman, 2008) and mark the last stage of parenthood as ''disengagement'' (Rossi, 1968) and ''departure'' (Galinsky, 1981). Other scholars stress the continuation of the parental role and its on-going importance to older parents' identity, well-being, and psychological experience (Bengtson, 2001; Birditt, Miller, Fingerman, & Lefkowitz, 2009; Ryff, Lee, Essex, & Schmutte, 1994). These studies emphasize the linked lives of parents and middle-aged children and reveal multiple ways in which relationships with children remain an important influence on parental wellbeing throughout the life course (Fingerman et al., 2012; Ward, 2008). An immediate reciprocity pattern of support exchange is not characteristic of relationships between parents and their adult children. Thus, in Western Europe, support exchanges follow a life course pattern, with primarily downward transfers more likely up to advanced ages of the parent (60-80 years old), and primarily upward transfers emerging in the latest phase of the parents' life (above 80 years old). Older parents have a greater likelihood of being involved in support given to adult children than in support received from adult children. This pattern is applicable to both coresident households and independent households (Dykstra & Fokkema, 2011).

The role of older parents in the care of middle-aged cancer patients

The caregiving literature focuses almost entirely on care provided to the older adult, and much less on care by the older adult (Abrahamson, 2015). This literature concerns the well-being of middle-aged children becoming the caregiver of an older parent diagnosed with cancer (Caughlin, Mikucki-Enyart, Middleton, Stone, & Brown, 2011; Fisher, 2010; Kim, Wellisch, & Spillers, 2008; Sumner, Wellisch, Kim, & Spillers, 2015), frailty (Lopez Hartmann et al., 2016) or dementia (Bastawrous, Gignac, Kapral, & Cameron, 2015; McCann, Bamberg, & McCann, 2015). Less is known about the reverse constellation, that is, the influence that children's life events may have on parents' well-being and health (Fingerman et al., 2012; Greenfield & Marks, 2006; Milkie et al., 2008; Schwarts & Ayalon, 2015). Poor psychological well-being has been documented among middle-aged and older parent caregivers of children with mental health or developmental problems (Ha, Hong, Seltzer, & Greenberg, 2008). Some findings suggest that spousal and child caregiving tend to be more stressful and detrimental to older caregivers’ mental health than caring for others (Penning & Wu, 2015). Several studies (Gilligan, Suitor, Rurka, Con, & Pillemer, 2015; Kahana, Kahana, Johnson, Hammond, & Kercher, 1994) argue that the presence of an adult child with a serious health condition may reshape the intergenerational exchanges expected as parents enter their later years and children reach midlife.

Prior research in a cancer context has tended to shed light on a limited number of relational contexts and almost exclusively stem from parent-young child dyads (Kars, Grypdonck, de Bock, & van Delden, 2015; Sulkers et al., 2015) and patient-spouse dyads (Hendriksen et al., 2015; Senden et al., 2015); on the contrary the parent-adult child dyad received less attention (Van Humbeeck et al., 2013). Nevertheless, of those aged 45 and older 5 % primarily provide care to an adult child (Penning & Wu, 2015). Some research exists on how older parents find themselves in the role of a caregiver to their middle-aged child with a psychological disorder (Copeland & Heilemann, 2011; Hsu & Tu, 2014; Seltzer et al., 2009), or developmental disability (Band-Winterstein, Smeloy, & Avieli, 2014; Johansson et al., 2015; Richardson, Cobham, Murray, & McDermott, 2011; Smith, 2012).

Grief and loss in late life

Old age is a time of multiple and sequential losses (Moss, Moss, & Hansson, 2001). A cancer diagnosis in a middle-aged child can be regarded as a loss experience; more specifically the loss of a healthy child and possibly the loss of the child due to death. In spite of the high prevalence of later-life nonspousal family loss, spousal loss dominates geriatric bereavement research (Arbuckle & de Vries, 1995), with the terms “bereavement” and “spousal loss” often appearing synonymously in the literature (Williams, Baker, & Allman, 2005). Only a few studies describe the experiences of older people whose middle-aged child has died of cancer (Chapter 2). This contrasts with the more developed literature on bereaved adult children (Umberson, 2003), and on the experience and impact of the death of a young child for young parents (M. Harper, O'Connor, & O'Carroll, 2014; Klassen et al., 2007; Schweitzer, Griffiths, & Yates, 2012). Too frequently, however, older persons suffer the loss of a child. Generally, no less than 1 in 10 parents over the age of 60 have to deal with the death of an adult child (Audenaert & Vanderleyden, 2003). Often less consideration is given to these parents as the health care team isn’t aware of the likelihood of having parents still alive and the impact this bereavement has.

1.2. JUSTIFICATION OF THIS WORK

As cancer becomes more prevalent in Belgium and touches an increasing number of families, its impact on those families warrant scholarly study. At present, however, when researchers examine family involvement over the course of a cancer trajectory, they tend to mainly look at the nuclear family, as spouses and children are widely considered the key source of support for cancer patients (Manne & Schnoll, 2001). Demographic changes have reshaped population pyramids, altered the composition of family networks and changed the rhythm of individual lives. As part of abovementioned demographic evolutions, older parents become an important stakeholder group in the care for adult cancer patients as life expectancy continues to rise and the chance that the parents of adult cancer patients are still alive continues to increase. Aging parents may be particularly vulnerable to the vicissitudes of an adult child's illness as they face the dual challenge of caring for their child while also attending to their own aging.

Whilst there is some evidence regarding older parents with a child with developmental problems or a psychiatric condition, there is a paucity of cancer-related research. We reason that in case of a mental illness/psychiatric condition in a middle-aged child, a different relationship dynamic exists in comparison to being confronted with an acute onset of cancer in a middle-aged child. There are several reasons why we assume this relationship dynamic to be different. A first characteristic that distinguishes these parents from their age peers who don't have children with life-long disabilities is the continued co-residence of the child with the parent well past the time when most children leave home and establish an independent residence (Seltzer et al., 2011). Another unique challenge is the history of caregiving in parents of adults with chronic mental illness or developmental disabilities. They are confronted with a diagnosis of a developmental disability at the birth of the child or in early childhood. The diagnosis of a mental illness is often situated in adolescence or early adulthood. So these parents generally serve as supports and caregivers for their children throughout their lives as launching often does not result in complete independence for the adult child and most parenting responsibilities continue. Hence, these perpetual parents may have greater mastery over the caregiving situation in contrast with their peers being confronted with the acute onset of symptoms related to a cancer diagnosis.

By describing and trying to understand the perspectives of both older parents and middle-aged children with cancer (Part I and Part II), the understanding of this situation will be enriched with more detailed and contextual information. It is important to understand how a patient's wider family (including the parents) adjusts because that may determine how supportive they can be, which in turn has ramifications for the patient's well-being. Further, failing to understand the experience of loss and grief among older parents risks disenfranchisement of these experiences. The third part of this dissertation will further our understanding of nursing staffs' response to grieving residents in general. Given the accumulation of loss in old age, a particular concern for nursing staff (nurses and care-assistants) in nursing homes must be meeting the loss-related needs of older people (Moss et al., 2001). Grief in old age and its impact has been under study, while nursing staffs' care actions in assisting grieving older individuals are less researched (Holman, 2008; Stephen et al., 2009).

Findings from the first two parts of this dissertation will (1) contribute to our understanding of the process that older parents go through and how they give meaning to the illness trajectory/death of their middle-aged child, and (2) give us insight in the middle-aged cancer patients perspective vis-à-vis their older parents. This dissertation is a necessary building block toward understanding the unique dynamic of the middle-aged child-older parent relationship in a complex cancer context. From a practice standpoint, this dissertation is relevant and timely for the health care sector as modern care philosophy espouses the virtues of holistic and relationship-centred care. Our studies provide health care providers (HCPs) from different practice (oncology, palliative care, geriatric care and primary care) settings the necessary knowledge to better understand middle-aged oncology patients and their older parents. Findings from the third part of this dissertation contribute to an improved understanding off the current ways that nursing staff in nursing homes deal with loss and bereavement.

2. GENERAL OBJECTIVE AND RESEARCH QUESTIONS

This dissertation involves the perspectives from different actors. First, we focus on how older parents and adult oncology patients experience their life when characterized by the presence of a demanding health-related condition such as cancer. Second, we study the experience of nursing staff (nurses and care-assistants) dealing with grief and loss in residents of a nursing home.

A literature review was conducted via a systematic electronic and hand search or relevant literature (Chapter 2) and tried to answer the following research question:

1. What is the current state of knowledge on older parents having an adult child with a serious illness ?

Based on these findings we elaborated on two questions from the parents' perspective (Chapters 3 and 4):

2. What does it mean to a parent to care for a middle-aged child with cancer and how do parents give meaning to their parental role throughout their child's illness trajectory?
3. What is the experience of older parents outliving an adult child who died of cancer ?

Along this line, we decided to also focus on the middle-aged child's perspective (Chapter 5):

4. How do middle-aged cancer patients experience cancer vis-à-vis their parents (and wider environment) ?

The interviews with nursing staff (nurses and care-assistants) in nursing homes specifically focused on their experiences of grief care actions and on dealing with grieving residents (Chapter 6):

5. What are the experiences and perceptions of nursing staff working in nursing homes in Flanders concerning care actions focused on loss ?

3. METHODOLOGICAL APPROACH

3.1. ADOPTING A QUALITATIVE PARADIGM

Qualitative research was chosen as it can provide an in-depth insight and an understanding of the perspectives of older parents, middle-aged children with cancer and HCPs (Holloway & Wheeler, 2010). Four major interpretive paradigms structure qualitative research: positivist and post positivist; constructivist-interpretive; critical and feminist post-structural (Denzin and Lincoln 2005, p22). Of these, the constructivist-interpretive paradigm was chosen for this dissertation, in acknowledgement of the subjective nature of the research and the multiple realities of those involved in the different studies. A constructivist research paradigm assumes a relativist ontology (there are many realities) and a subjectivist epistemology (participant and researcher co-create understandings) (Denzin and Lincoln 2005, p24).

3.2. JUSTIFICATION FOR THE CHOICE OF METHODOLOGY

Constructivist grounded theory was selected as the specific qualitative methodology utilized in this dissertation for several reasons. This approach was primarily chosen because it suited the research aims and because it reflects my own perception of the world. Second, it was chosen because of our aim to improve our understanding by identifying commonalities, differences and relations in order to reconstruct processes that explain what was seen to take place in our participants. In addition, constructivist grounded theory focuses on giving participants a voice, which was important given my literature review showed that the experiences of these older parents were scarcely studied. A further substantiating rationale for selecting constructivist grounded theory is in the use of the literature which is seen as having potential for stimulating thinking and being intertwined with the researchers developing theoretical reconstruction. An additional reason that grounded theory was chosen was my personal familiarity with the method; I had previously utilized a grounded theory approach for my master thesis and had learned about the method. Data were analysed using a method that was similar to the QUAGOL method (Dierckx de Casterle, Gastmans, Bryon, & Denier, 2012).

3.3. DATA COLLECTION

Individual face-to-face interviews were the main data source. We choose interviewing as we aimed to understand how the participants feel, perceive and give meaning to their situation (Charmaz, 2014). We used non-probability sampling, where the sample numbers were unknown at the commencement of each study. We selected participants according to the needs of the study and made sampling decisions based on analytical grounds developed in course of each study. Purposive sampling was used in the initial stages of the studies. So the purposeful sampling preceded the theoretical sampling in Chapters 3 and 5. For these studies, purposive sampling was used within the framework of theoretical sampling to identify participants for the separate studies. In Chapter 4 and 6 only purposive sampling was used as theoretical sampling was not done because theoretical sampling wasn't feasible. Theoretical sampling in this dissertation sought out particular characteristics that had been identified through an analysis of the previously collected data as being potentially important for further exploration. In this dissertation, theoretical sampling was undertaken, but this part of the process was not straightforward. Careful consideration was required to determine how this crucial component of a grounded theory study was to be achieved as recruitment of both older parents as middle-aged cancer patients was often hindered by protective mechanisms.

In all parts, researchers triangulation was used to enhance the trustworthiness of the findings (Morse, Barrett, Mayan, Olson, & Spiers, 2002). All members of a research team read (parts of) the transcripts and interpretations were thoroughly discussed. Thoughts and reflections evoked by some passages were noted in the margins of the text as memos (Boeije, 2005). The developed substantive theory (Chapter 3, 4 and 5) is relevant to the population from which it was developed as it is developed from their experiences and directly attempts to offer insight, enhance understanding, and inform action (Charmaz, 2014). A brief description of the methods employed in each chapter is included in Table 1. and described in more detail in the subsequent chapters.

4. OUTLINE OF THE DISSERTATION

The dissertation consists of three parts, each with different objectives and research questions. The chapters of this dissertation are based on four published or accepted articles and one article submitted for publication in international peer reviewed journals.

PART I – The perspective of older parents

In the first part several aspects of parenting an adult child with cancer from the older parents' perspective are described. **Chapter 2** provides a comprehensive overview of the best available evidence concerning older parents having an adult child with a serious illness. Specifically this review sought to detect possible gaps in the existing literature. **Chapter 3** contains a description of the essence of parenting an adult child with cancer. **Chapter 4** focuses on the experience of parents (≥70 years) outliving an adult child.

PART II – The perspective of middle-aged cancer patients

The second part of this dissertation concerns the middle-aged cancer patient's experience vis-à-vis their older parents (and close environment). **Chapter 5** aims to shed light on the parent-child relational challenges that occur following a cancer diagnosis seen from the perspective of the middle-aged child with cancer.

PART III – The perspective of health care providers

The third part of this dissertation addresses how nurses and care-assistants deal with loss and grief in nursing homes. **Chapter 6** examines nursing staffs' experiences of being confronted with loss and grief in old age and of being involved in grief care.

The general discussion in **Chapter 7** will highlight the most important findings of Chapters 2 to 6. Subsequently, some methodological considerations, and challenges for policy, clinical practice and education are raised. Finally, recommendations for future research will be outlined.

Table 1. Overview of studies and methods in each chapter of this dissertation

Perspective	Chapter	Methods
Older parents	Aged parents' experiences during a critical illness trajectory and after the death of a middle-aged child (Chapter 2)	Literature review Search in MEDLINE (1950–2012), Web of Science (1900–2012), Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1982–2012) and Google Scholar. 19 studies (7 quantitative and 12 qualitative) were included.
	The experiences of older parents who have a middle-aged child with cancer (Chapter 3)	Qualitative study Semi-structured interviews with 25 parents (20 mothers and 5 fathers) of 22 adult children
	The experience of outliving a middle-aged child that died of cancer (Chapter 4)	Qualitative study Semi-structured interviews with 9 grieving parents (1 father and 8 mothers)
Adult cancer patients	Cancer patients' experience of their illness trajectory vis-à-vis their older parents (Chapter 5)	Qualitative study Semi-structured interviews with 11 adult cancer patients (10 women and 1 men)
Health care providers	Experience of health care providers working in a nursing home of being confronted with bereavement and loss in old age (Chapter 6)	Qualitative study Semi-structured interviews with 14 health care providers (13 women and 1 men)

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PART I Experiences of older parents

CHAPTER 2. AGED PARENTS' EXPERIENCES DURING A CRITICAL ILLNESS TRAJECTORY AND AFTER THE DEATH OF AN ADULT CHILD: A REVIEW OF THE LITERATURE

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2013; 27(7), 583-595.

doi: 10.1177/0269216313483662

AGED PARENTS' EXPERIENCES DURING A CRITICAL ILLNESS TRAJECTORY AND AFTER THE DEATH OF AN ADULT CHILD: A REVIEW OF THE LITERATURE

ABSTRACT

Background: Given the growing life expectancy, the likelihood increases that health-care providers are confronted with older people having an adult child with a life-limiting disease.

Aim: This literature review aimed to (1) explore the experiences of aged parents with regard to their position and role as a parent of an adult child with a life-limiting illness, (2) detect gaps in the existing literature and (3) make recommendations for future research.

Design: A literature search of English articles, including both quantitative and qualitative designs.

Data sources: Four electronic databases and the reference lists of included studies.

Results: In total, 19 studies (7 quantitative and 12 qualitative) were included. Few studies describe the experiences of older people whose adult child has cancer or has died of cancer. Existing studies are merely descriptive and give no concrete recommendations for health-care providers in daily practice. The studies suggest that aged parents carry deep burdens from the prospect of losing their adult child. Aged parents want to stay involved but need to reconfigure their parent role. As soon as the cancer diagnosis is disclosed, parents are confronted with a re-awakening of parental nurturing, which clashes with the autonomy of the adult child. Even after the adult child is deceased, older parents retain the image of themselves as parents.

Conclusions: There is a need for more in-depth research to understand the lived experience of these parents and what health-care providers can do to assist them.

Keywords: Adult children, parents, aged, critical illness, death, grief, review

INTRODUCTION

The number of people in the European Union aged 80 years and above is expected to almost triple in the next decades, rising from 22 million in 2008 to about 62 million in 2060.[1] Given the growing life expectancy, the likelihood that older people are confronted with the diagnosis of a serious illness in an adult child and that parents will outlive their adult child increases. Generally, no less than 1 in 10 parents over the age of 60 have to deal with the death of a child.[2,3] Hearing the diagnosis of a serious illness is a major event that may affect the physical, mental and social well-being of both the adult patient and also the immediate family.[4–7] Perhaps, aged parents rely on the adult child for social contacts, and in case of illness, this may bring additional social isolation.[8] However, aged parents of adult children with a serious illness are often not included in the scope of the care process, getting little formal support from health-care workers.[9] Although the parent–child relationship changes over time, parents continue to give affection, support and care to their adult children. Parents want to maintain a close involvement, and yet need to keep an adequate distance from their adult children. This relationship pattern is often characterised as a 'distant closeness',[10–13] but this family dynamic is frequently not addressed. Adult patients are questioned about spouses and children, but frequently, the parents' role in patient's lives is not regarded essential beyond the paediatric age group.[8]

This literature review aimed to (1) summarise the current knowledge on the experiences of older parents regarding their position (i.e. status) and role (i.e. prescribed or expected behaviour) as a parent of an adult child with a serious illness, (2) detect possible gaps in the existing literature and (3) make recommendations for future research. An integrative review methodology was used because it allows the narrative integration of findings from qualitative and quantitative research around a particular phenomenon of concern.[45]

METHOD

SEARCH STRATEGY AND DATA SOURCES

Pilot searches were carried out on seven electronic databases in December 2011. Included databases are shown in Figure 1 (three databases, namely, Cochrane, PsycINFO and Embase, were excluded after they yielded little in pilot searches). We conducted an extended search in MEDLINE (1950–2012), Web of Science (1900–2012), Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1982–2012) and Google Scholar. These databases were chosen to reflect multiple disciplines across medicine, nursing, allied health and social science, with wide geographical coverage.

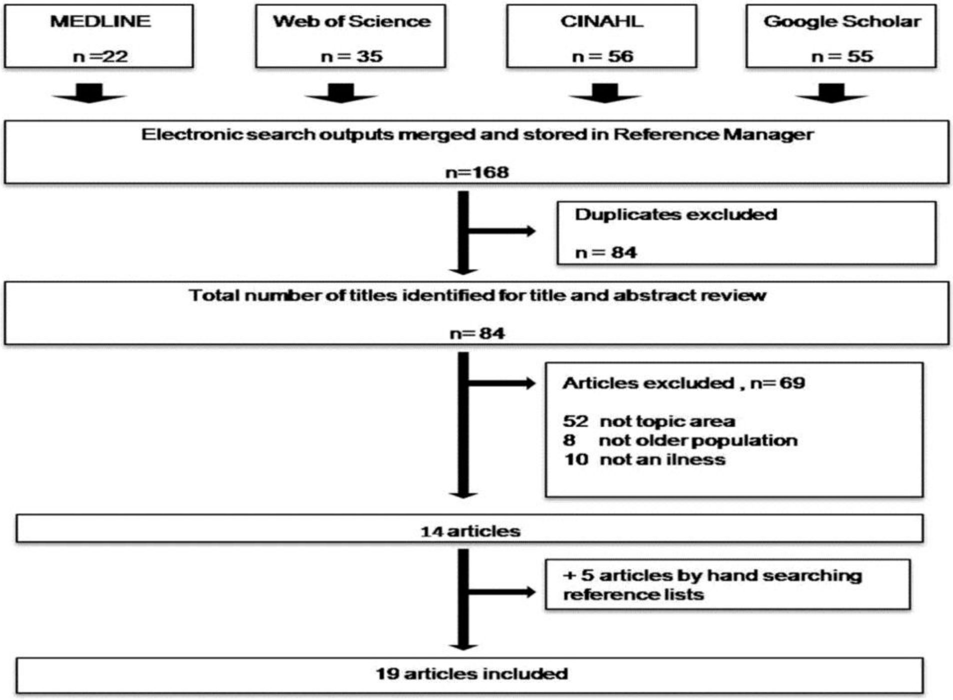

Figure 1. Flow chart of selection process of studies

Note. CINAHL: Cumulative Index to Nursing and Allied Health Literature.

In each database, every term listed in Figure 2 was searched in the thesaurus, and the free-text/keyword method was used. Synonyms and modified versions of these terms were searched to best utilise each database/thesaurus. The MeSH or entry-terms were used in combination with different keywords. In addition, the reference lists of retained studies were hand searched. The searches were updated until March 2012. Both qualitative and quantitative studies with different designs were included to cover the broadest possible field of research.

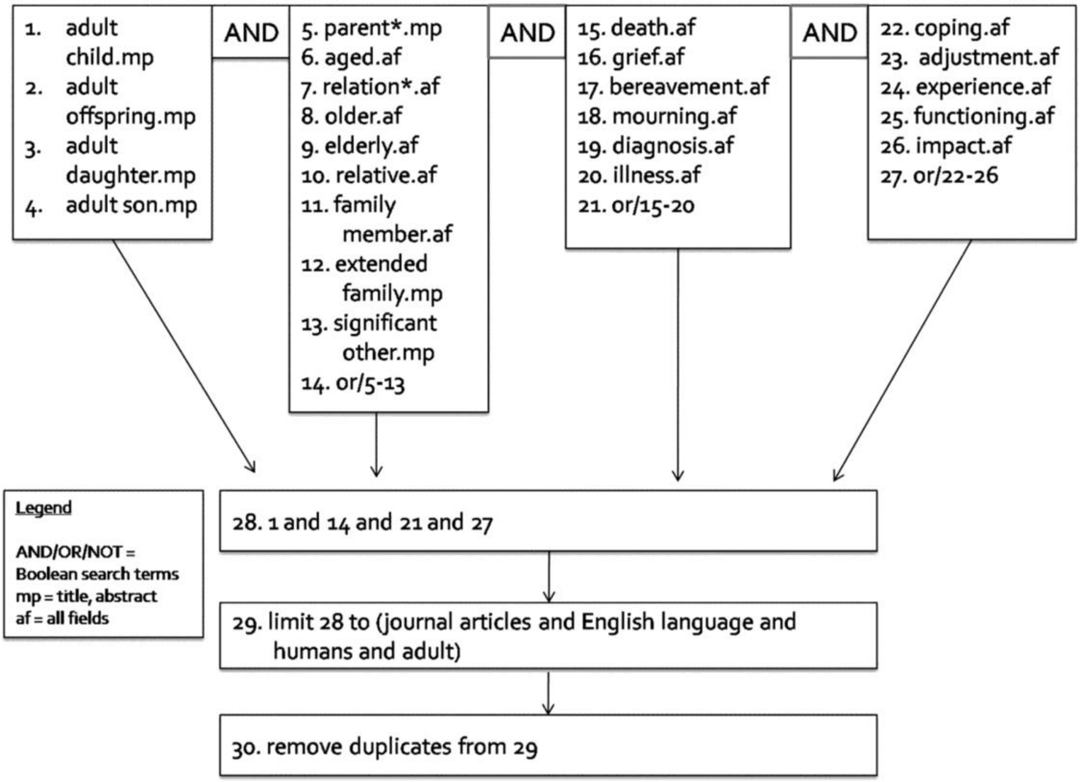

Figure 2. Search strategy

INCLUSION AND EXCLUSION CRITERIA

Inclusion criteria were (a) empirical study using quantitative or qualitative methodology, (b) focusing on the perspective of parents having an adult child with a critical illness in which death is possible or imminent and (c) written in English. Studies wherein parents participated as part of a larger group of next of kin were also included. Exclusion criteria were (a) children under the age of 18 years and (b) case studies and non-empirical work such as commentaries, reviews or theoretical articles.

STUDY SELECTION

A two-stage selection procedure was applied. First, screening was performed by title and abstract. Second, all potentially relevant studies were sought in full article format and reviewed. The methodological quality of each included article was checked by two researchers. The assessments were done on full-text articles before data extraction. The criteria to assess the methodological quality of the studies were built on those suggested in the literature.[14,15] A subdivision was made between the clarity of reporting and the robustness of the study methods.

For each study, a data extraction sheet was made, which was independently reviewed by two authors (L.V.H. and S.V.C.). Based on these sheets, a final decision was made on the eligibility of each selected study. If there was disagreement, discussion occurred until achievement of consensus. A third reviewer (R.P.) made the decision in cases of unresolved disagreement. Figure 1 provides an overview of the selection process. An early evaluation of the literature revealed the clear predominance of cancer-related articles. Ultimately, 19 (7 quantitative and 12 qualitative) studies were included in this review. Tables 1 and 2 summarise the main characteristics of the retained articles, namely, authors, country, year of publication, methodology, sample, limitations and quality assessment. The data extraction tables literally present relevant findings, without the interpretation of the reviewers. An analysis of the extracted data showed several main topics. More comprehensive tables can be consulted as supplementary files (see Tables S1 and S2 in Appendix I). Due to heterogeneity of the findings, meta-analysis of the quantitative studies or meta-synthesis of the qualitative studies wasn’t considered as a possibility. Therefore, the synthesis of the findings are reported in a narrative way.

Table 1. Characteristics of qualitative studies (N=12).

A = Clarity of reporting (0-8), B = Robustness of the study methods (0-5), C = Quality assessment sum-score (0-13).

Study	Country	Methodology	Sample	Limitations	A	B	C
Cacace and Williamson[24]	United States	Semi-structured interviews Grounded Theory	*N*=7 (4 mothers, 3 fathers) Age range parents: 60-72 y. Age range children: 18- 45 y. Cause of death: cancer	Relatively small and self-selected sample. Inclusion of only one ethnic group. No longitudinal analysis.	6	4	10
Dean et al.[21]	Canada	Semi-structured interviews Latent content analysis	*N*=13 (9 mothers, 4 fathers) Age range parents: 40-77 y. Age range children: 21-54 y. Cause of death: cancer	Inclusion of one ethnic group. No longitudinal analysis.	7	6	13
Edvardsson and Ahlström[20]	Sweden	Interviews Latent content analysis	*N*=28 (of which 8 parents) Age range parents: 25-77 y. Diagnosis: low-grade glioma	Focus on one type of cancer. Small subsample of parents. No data on age children.	6	4	10

Table 1. Characteristics of qualitative studies (N=12).

A = Clarity of reporting (0-8), B = Robustness of the study methods (0-5), C = Quality assessment sum-score (0-13). ***[Continued]***

Study	Country	Methodology	Sample	Limitations	A	B	C
Fisher[26]	United States	Semi-structured interviews	*N*=78 (diagnosed women and their mothers/daughters): three age groups Diagnosis: breast cancer	No longitudinal analysis. Only mothers. No data on the exact number of mothers that participated.	8	3	11
Goodman et al.[16]	United States	In-depth interviews Ethnography	*N* =29 mothers Age range parents: 61-93 y. Cause of death: violent and non-violent	No description of analysis and no longitudinal analysis. No sociodemographic details about deceased children. Fail to address the potential role of cultural issues within interview context.	6	3	9

Harper et al.[23]	UK	Interviews Interpretative phenomenological analysis	Convenience sample *N*=13 bereaved mothers Age range parents: 32-64 y. Age range children: 0-29 y. Cause of death: cancer, acute illness, suicide, accident	The interviewer was also a bereaved parent. Interviews with mothers only. No longitudinal analysis.	7	6	13
Lindholm et al.[6]	Sweden Finland	Interviews Phenomenological case study approach	*N*=33 (17 women with breast cancer and 16 significant others) 1 mother included as significant other (6% of total sample) Age range women: 35-69 y. Diagnosis: breast cancer	Different family members included. No longitudinal analysis. Only small subsample of older parents. Only mothers. No sociodemographic data of significant others	7	7	14

Table 1. Characteristics of qualitative studies (N=12).

A = Clarity of reporting (0-8), B = Robustness of the study methods (0-5), C = Quality assessment sum-score (0-13). ***[Continued]***

Study	Country	Methodology	Sample	Limitations	A	B	C
Persson and Sundin[30]	Sweden	Narrative interviews Phenomenological approach	*N*=12 (6 women, 6 men): 5 partners, 6 children, 1 parent (8% of total sample) Age range participants: 24-83 y. Diagnosis: inoperable lung cancer	Only one parent included. No longitudinal analysis.	7	6	13
Raveis et al.[28]	United States	In-depth interviews Content analysis	*N* =13 mothers Age range mothers: 56-78 y. Age range daughters: 34-56 y. Diagnosis: breast cancer	Focus on one type of cancer. No longitudinal analysis. Only mothers.	6	6	12

Smith et al.[31]	United States	Focus groups Hermeneutical approach	*N*=31parents (28 mothers, 3 fathers) Mean age parents: 72.63 y. Causes of death: heart disease, cancer, suicide and homicide	It's questionable if focus groups are ideal method to investigate lived experience of these parents. No longitudinal analysis.	5	4	9
Toller[34]	United States	Semi structured interviews Grounded theory	*N*=53 (36 mothers, 17 fathers) Age range parents: 27-64 y. Causes of death: violent and non-violent	Large variation in time since death. Inclusion of parents whose children died at birth and children who died as adults. No longitudinal analysis.	8	4	12
Wideheim et al.[5]	Sweden	Interviews Prospective study Content analysis	*N*=3 patients (1 men, 2 women): *N*=5 next of kin (2 partners, 2 parents and 1 adult child) Age range patients: 25-88 y. Diagnosis: malignant glioma	The analysis is done by a person other than the interviewer. Small sample size. No longitudinal analysis. No sociodemographic data of next of kin.	6	5	11

Table 2. Characteristics of quantitative studies (N=7).

A = Clarity of reporting (0-8), B = Robustness of the study methods (0-5), C = Quality assessment sum-score (0-13). [Continued]

Study	Country	Methodology	Sample	Limitations	A	B	C
Arbuckle and de Vries.[19]	United States	Questionnaire	3 groups (bereaved parents, bereaved spouses, non-bereaved) Bereaved parents: *N*=41 (22 women, 19 men) Mean age parents: 71.1 y.	Modest coefficients of reliability of used instruments. Instruments tested on and developed for younger populations. Reliance on secondary data. No data on age children and causes of death. Only small number of bereaved parents within the sample for analysis.	6	1	7
Azaiza et al.[32]	Israel	Questionnaire	*N*=97 (49 bereaved parents, 48 non-bereaved parents) Mean age parents: 74 y. Age range children: birth-52 y. Cause of death: violent and nonviolent	Lack of socio-demographic details. Recruitment from one specific geographical region and cultural context. Small sample size. No differentiation in analysis between violent and nonviolent death.	7	3	10

Ell et al.[18]	United States	Structured interviews	*N*=230 (152 spouses and 78 non-spouses): 120 women, 110 men Age of range (non)-spouses: 14-86 y. Mean age patients: 60 y. Patient's first diagnosis of breast, colorectal or lung cancer.	No specification of category non-spouses. No insight in how many were parents. Possible sampling bias: significant differences found between participants and non-participants with regard to gender, ethnicity and age.	6	2	8
Gilbar and Refaeli[22]	Israel	Questionnaire	*N*=41 parents (29 women,12 men) of an adult married cancer-diagnosed child Mean age parents: 68.5 y. Mean age child: 40.1y.	Small sample size. One-time assessment. Interviews with just one parent. Wide age range of both the patients and the parents.	8	3	11
Gilbar[27]	Israel	Questionnaire	*N*=41 parents (29 women,12 men) of an adult married cancer-diagnosed child Mean age parents: 68.5 y. Mean age child: 40.1y.	Small sample size. One-time assessment. Wide age range of both the patients and the parents.	6	3	9

Table 2. Characteristics of quantitative studies (N=7).

A = Clarity of reporting (0-8), B = Robustness of the study methods (0-5), C = Quality assessment sum-score (0-13). ***[Continued]***

Study	**Country**	**Methodology**	**Sample**	**Limitations**	**A**	**B**	**C**
Lesher and Bergey[25]	United States	Structured interviews	*N*=18 (women) Age range mothers: 79-96 y. Cause of death: no details	Participants had to be widowed as well as bereaved of an adult child. Authors don't provide reasons for limiting study to only bereaved mothers. No socio-demographical data.	6	3	9
Milberg et al. [17]	Sweden	Questionnaire	*N*= 233 (144 women, 89 men): 5 parents (2% of total sample) Age range next of kin: 31-91 y. Age range patients: 23-94 y. Diagnosis: different types of cancer	Questionnaire not been tested for test-retest reliability, criterion and construct validity. Only small subsample of parents.	8	3	11

RESULTS

Analysis of the existing literature showed that the older parents' journey can be divided into (1) their experiences during their child's illness trajectory and (2) their experiences after the death of their adult child.

DURING THE CHILD'S ILLNESS TRAJECTORY

Multitude of intense feelings

From the moment that parents are informed about the cancer diagnosis of their adult child, they are completely preoccupied with the situation. Parents describe this period as a terrible experience and an extremely stressful period because they enter a world of uncertainty and helplessness.[6,20,21,28,30] Different components[6,17,30] are found to contribute to this sense of powerlessness and helplessness. A first component is the parents' perception of their son's or daughter's suffering. A second component is the perception of fading away, that is, the confrontation of parents with the deterioration of the health status and the degeneration of the body of their child. These two components add to a third component, namely, a sense of incapacity and insufficiency. The parents have the desire to play an active role, but they lack the skills and strength to reduce or stop the patient's suffering.

Part of the emotional suffering of older parents is related to their search for a cause and to the existence of self-blame, as illustrated by questions as 'Why is this happening to my child?, Did I do something wrong in my life that could cause this?, Is there anything I could do?, Is there something I could have done better?'. Some older mothers impute the cancer to the genes that they have given to their daughters. These mothers experience a sense of injustice, as they themselves are being spared of the disease, while their daughters have developed breast cancer.[28]

Exclusion and loss of control

Unlike parents of young children, older parents have little opportunity to influence the choices of their adult children. They no longer have the legitimacy to be involved in decision-making. Some mothers expressed that their daughters were now self-reliant and self-sufficient and that they had to be careful with what they said and how they put things.[28] Moreover, they no longer have the right to be informed. Parents should be satisfied with obtaining information through their own child, their child's partner or their grandchildren. This uncertainty about the course of the disease, the treatment effects and the remaining time with their son or daughter often leads to frustration and a feeling of helplessness. Parents seek answers to the following questions: 'How sick is the patient?, What's the patient's view on the situation?, What support can we offer?, How does the patient feel? What impact has this illness on the patient?, and What care is provided by the caregivers?'[21]

Transformation of the parent role

The diagnosis of a life-limiting illness seems to trigger a fundamental transformation of the parent role. While over the years, the mutual involvement within the parent–child relationship has naturally evolved from an intense concern and commitment to a growing independence and a greater distance between the two generations, the diagnosis seems to undo this independence by re-awakening the parental need to nurture. Parents experience a desire to provide care and protection for their child as if their child was still a minor.[21,27] Some mothers saw it as their parental duty to care for their adult daughters with breast cancer. A re-awakening of this maternal nurturing and a resumption of mothering responsibilities arose from an instinctive sense of responsibility. Mothers imposed their assistance, even when help was not needed, because they needed to feel that they were doing something as they were powerless to change the outcome.[28] The need of parents to do all that is possible for their sick adult child and their strong intention to take control may clash with their desire to respect the autonomy of their adult child. The changes and uncertainty in the parent role due to this conflict seems to be stronger if the adult child is married.[21] The result is that parents enact their parent role in another way. While in the past, they tried to assume a directive and active role by keeping a vigilant watch, they are now present in a different way. A need emerged 'to stand by' and 'to be there' in service of the needs of the sick adult child to do whatever they could for their child.[21] This 'being there', with a physical and emotional component, can function adaptively (e.g. companionship and feeling of presence with respect of each other's space) or maladaptively (e.g. asking too many questions, talking to the physician without the daughter).[26] The parent's relationship with the partner of the adult child, the quality of the parent–child communication, the quality of intra-familial relationships and the social relationships outside the family all may influence the smoothness of the transformation from an active caregiving parent role towards a more passive 'on-the-sidelines' parent role.[21]

Coping and adjustment

Mutual protection and positive thinking have mainly been described as important coping strategies of older parents of ill adult children. A complex and self-sustaining process of mutual protection occurred. The sick adult child hides the actual suffering to protect his or her parents. Yet, at the same time, this protection deprives the parents of their possibility to fight together against the suffering. This reservation of the sick adult child to talk to his or her parents is often interpreted by the parent as if their child is concealing something. This in turn increases the parents' feelings of anxiety, which they on their part often keep to themselves as they do not want to increase the burden of their loved one.[6,28]

In addition, parents often have a sense of a tragic future when dealing with the illness of their next of kin. They are afraid of the imminent future and try to suppress all thoughts about that future because it is too stressful to be aware of the incurable illness and the impending death. This anxiety, caused by the knowledge that their relative is probably going to die, is countered by positive thoughts.[5,21,30] As such, they oscillate between feeling terrified and trying to banish this kind of thinking and live as normal a life as possible. Yet, the engagement in positive thinking can function maladaptively, when it nourishes mutual protection and prevents both parties from openly communicating with each other.[26]

In addition to these two most-cited strategies, other less mentioned strategies such as social support can be reported. A possible positive correlation between the psychological and psychosocial adjustment of parents to the illness of their adult child and the amount of social support perceived by the parents was indicated.[22,27] Gilbar[27] pointed out that less social support is related to greater psychological adjustment problems. Parents adjust better to the illness when they receive more social support and when their child feels less distressed. However, the age of the child exerts a less important influence on the parents' adjustment. Therefore, parents continue to support their adult child after marriage, although the child is of an older age. Another study[18] reported no correlation between the adjustment of cancer patients and the adjustment of non-spousal carers. On the contrary, both studies found a correlation between the adjustment of patients and the adjustment of their partners.

AFTER THE DEATH OF THE ADULT CHILD

By the time a child reaches adulthood, parents have extensively invested in their child. As a result, the death of this child can cause intense feelings and signifies a tremendous ordeal for older parents.[31] Depending on the closeness of the relationship, the aged parents may have lost a friend, companion and/or helpmate in old age.[16]

Older people and grief

Because of the fundamentally different life stage and developmental tasks, older people experience grief in a different way than young or middle-aged people. Late life is a time in which transition and loss issues become more frequent. Indeed, older people expect that they may survive their older siblings, their friends or even their spouse, but not one of their adult children.[29] Several authors[24,25,31] enumerate reasons why the death of a child is more difficult to cope with for aged parents compared to younger parents. First, the aged parents have fewer opportunities to invest in other relationships after losing their son or daughter. Second, they have fewer distractions, such as work, to temporarily find relief of their emotional pain. Third, older parents get less support because they can less actively search support and/or because they are less recognised by others as grieving. Health and transport difficulties may prevent them from participating in bereavement groups or other forms of support. In addition, they often experience less social support because of a shrinking social network. Many parents are widowed or separated, and an adult child often yielded social contacts and improved their social embedding. The impact of the loss is often underestimated and dismissed as ‘obvious’. The focus of contemporary society lies mainly on the nuclear family (the partner and children of the deceased adult child). The parents are rarely involved in rituals that can help in processing the loss, such as arranging the funeral, as the partner of the deceased takes on such responsibilities.[31] Fourth, the loss of their adult child may change the relationship with their grandchildren. This is especially the case if there is a strained relationship with their child’s partner or if their child’s partner remarries. Fifth, older parents are more often prescribed medication that may interfere with the grief process. Sixth, adult children are often caregivers for their parent(s). The loss of an adult child may, therefore, have another negative consequence, namely, the increased probability of admission to a nursing home.[31]

Impact on functioning

Most studies investigate grief of older parents by focusing on the impact of the loss of their child on specific factors, such as reduced social functioning and psychiatric morbidity.[19,25] One study reported a significant increase in the mean number of reported diseases and levels of psychological distress since the death of the adult child. The bereaved mothers in this study reported an increased cohesion with the children of the surviving adult child(ren), but this was not the case with the children of the deceased adult child.[25] Bereaved parents had significantly lower scores on self-efficacy (i.e. self-esteem and mastery) than non-bereaved parents, with women reporting significant lower levels than men. The experience of later life parental bereavement did not differ from later life spousal bereavement.[19]

Survivor’s guilt

The death of an adult child is perceived as unfair because life cycle expectations are confounded. In the view of parents, the possibility of the death of a child cannot be foreseen, and the actual death may cause survivor’s guilt or a feeling of unnatural survivorship in parents.[24] Many parents find themselves searching for what they did wrong to cause this tragedy to befall them. Older parents also question why their life was spared while their child died in the prime of life. This survivor's guilt can increase their grief's intensity and can make their mourning period more difficult.[24,31]

Lack of perspective

Unlike younger people, older people often suffer a lack of perspective: the death of an adult child often induces a heightened concern about their future (e.g. 'who is going to take care of me?'). The death of an adult child shatters parents' images of the future, and parents may feel as though they have lost a part of themselves. The death of the adult child shakes the foundations of everyday existence, resulting in questions about the value of life and future prospects.[31] The situation seems hopeless and desperate for the older persons. Common questions are 'What should I do with my life now?, What is the value of my life?, And what has life to offer me?'. Moreover, an awareness of their own mortality and impending death may arise. In one study, bereaved parents had significantly higher scores in terms of dying anxiety compared to non-bereaved parents. Dying anxiety and death anxiety were not associated with the nature of the child's death and the time elapsed since the death of the child.[32] For others, an ambivalent attitude exists, because the awareness of their own mortality just gives rise to a longing for one's own death. Death is welcomed to end the actual suffering and/or to achieve a reunion with the deceased child.[23] At the same time, parents expressed the fear that the deceased child would die forever when they themselves died. Their own death would mean 'a second symbolic death', a loss of the child's inner representation.[33] A loss of an adult child may represent a loss far beyond the personal boundaries of the immediate relationship. For Jewish bereaved mothers, the death of their adult son or daughter means a threat to the continuity and survival of the Jewish culture.[16]

Further transformation of the parent's identity and the parent role

As children grow and leave home, the parent role changes significantly. Still, this change does not imply its end. Irrespective of the age of their child, parents still view themselves as parents. Even after the death of their child, parents maintain the image of themselves as parents. Yet, as the death of a child is equivalent to the loss of a unique and central role, a transformation of oneself in relation to one's family and one's environment and a different outlook on life and death are required.[19,21] As a result, parents are faced with the paradoxical identity of 'being a parent without a child to parent'. Because people around them talk about the life of their own children, the grieving parents are constantly reminded of the death of their child while they feel that their child is still a part of their life.[34] Many parents experience difficulties in talking about their child and their loss, because this may cause inconvenience to others. They feel that members of their social network treat them differently causing them to feel as outsiders. Bereaved parents monitor their communication and control their relationships with the purpose to protect themselves against the judgement and the comments of others. Besides, bereaved parents try to reach out to others who have also lost a child. This gives a confirmation of their 'insider' identity and a sense of oneness with other bereaved parents. This shared experience enables them to grieve together and to share their grief with others.[34]

The unbreakable bond

Although some parents adapt relatively well to the death of their child and find some meaning to it, this does not mean that they loosen or even break the tie with the lost child. On the contrary, many parents hold on to the memories and the internal psychological representations of their adult child. They continually search for ways to stay emotionally connected with their deceased child by means of keeping belongings, performing rituals, organising commemorations and talking about (or with) the deceased child.[33] This continued bond can take many forms. Some parents seem to have a need for continued physical contact, for example, by carrying around ashes in a bag or visiting the graveside. Others seek an object that has a direct association with the child to stay connected, for example, a specific article of clothing. Still others describe a less concrete representation of their child, for example, a flock of ladybirds.[23] Reminders can also appear in the form of dreams and physical manifestations (e.g. similarities in grandchildren).[24]

DISCUSSION

PRINCIPAL FINDINGS

Research on the subject of the impact of serious illness of and/or death of an adult child on older parents is rather scarce. Existing research tends to focus on the experience and impact of serious illness and/or loss on young children,[35–39] and on the experience and impact of serious illness and/or loss on a spouse at old age.[40–44] The included studies suggest that aged parents carry deep burdens from the prospect of losing their adult child. Older parents are watching their adult child cope with serious life-limiting illness and frequently do not know how to help. Faced with the adult child's illness and possible death, older parents are confronted with overwhelming feelings often underestimated by their close environment.[6,17,20,21,28,30] The adult child's distress triggers a re-awakening of the parent's protective instinct,[21,26–28] but due to the independence of the adult child, parents no longer have the possibility to keep vigilant watch.[21,28] There is also evidence that aged parents want to stay involved but need to reconfigure their parent role to cope with this situation.[21,26–28] Other important coping strategies are mutual protection[6,28] and positive thinking.[5,21,26,30] Once the death of their adult child has occurred, aged parents experience further transformation of their parent role[19,21,34] and may continue to face difficulties due to the profound impact on their functioning,[19,25] their guilt about outliving their child,[24,31] and a possible loss of perspective and purpose in life.[16,23,31,33] Most of the parents experience a strong desire to continue bonds with their deceased child.[23,24,33]

Yet, a number of methodological problems are identified in terms of previously conducted quantitative and qualitative research into this topic. The current quantitative research is based on small convenience samples and often has a limited range of outcome variables. Moreover, it failed to examine the context in which bereavement is experienced. In addition, little information about the cultural, ethnic and religious background of aged parents is given. Equally, the majority of included studies were cross-sectional in design with no longitudinal data on the impact of the disease process and/or death of an adult child on the well-being of aged parents. Therefore, a more fine-grained approach is needed instead of a fragmented perspective. Furthermore, no studies were found related to the views of the oldest old (whether community dwelling or in residential care). Finally, studies that directly address the relationship of these older parents with health-care professionals were not found in this literature review. Therefore, several questions remain unanswered, and it seems that the parents' lived experience of the illness and/or loss of an adult child is still insufficiently investigated.

IMPLICATIONS FOR PRACTICE

Given the current state of the art of the domain, formulating concrete practical implications seems too premature. However, the findings described in the current review highlight some important general principles of care. First, health-care providers can ask adult patients whether their parents are still alive, and if so whether they are actively involved or not. Several studies[18,20,22] point out that health-care providers should pay specific attention to the needs and the emotional state of parents. Yet, to date, information is lacking about which interventions are most effective and appropriate in the care for this population. Second, findings from this literature review emphasise the importance of an understanding of the beliefs about the illness held by parents, their perception of the seriousness of the disease, their expectation about the illness and its probable disease course, as well as their sense of culpability and perception of their role in the disease outcome. Health-care workers should attempt to acknowledge the perspectives of the multiple family members who may be affected by and involved in the patients' illness and treatment. Third, by understanding and addressing the needs of family caregivers, family-centred care may reduce the experienced strains and stressors and enhance family functioning during illness. This will also beneficially affect the patients' medical and psychosocial well-being. Fourth, notwithstanding the evolution of the parent–child relationship towards a more distant one in adulthood, the current findings underscore the importance of recognising older parents as potentially significant sources of support and strength for an ill adult.

IMPLICATIONS FOR FUTURE RESEARCH

The studies reviewed have not fully addressed several important clinical questions. With this in mind, some suggestions for further research on the following areas are made to improve the quality of care for these parents. First, qualitative studies that elucidate the interaction between a sick adult child and his or her aged parents are essential to learn more about the lived experience of these older parents. Second, insight into what kind of support is required and mostly appreciated by ill adult children and their parents is key to support parents in finding a balance between the inclusion of protective parenting and respecting the autonomy of the sick adult child. Third, another area for research concerns the differences between the experience of parents of a minor child versus parents of an adult child, and how these differences might affect the organisation of health care. Fourth, studies to initiate the use of distress screening programmes are necessary as an initial step to integrate older parents in the programme of care.

STRENGTHS AND LIMITATIONS

To the best of our knowledge, this is the first review that specifically addresses the known literature on this topic. This study had an explicit, comprehensive search strategy performed by two independent reviewers, covering four databases and the reference lists of the included studies. Despite these strengths, some limitations should be acknowledged. Even though a sensitive search with broadly defined search criteria was performed, it is possible that relevant articles have been missed. Since this was an exploratory review, a broad range of study types were considered relevant in order to give a comprehensive review of the existing literature. The above-mentioned challenges that are pervasive in this literature, including small sample sizes and mixed populations, make it more difficult to draw generalisable conclusions. Notwithstanding these issues, we are of the opinion that this review provides an adequate representation of current literature concerning this topic. This review identifies a need for acknowledging and recognising these disenfranchised parents as potential caregivers, and it is hoped that this review contributes to an incremental focus of attention on this scarcely explored topic.

CONCLUSION

A minimal amount of research has been directed towards the subject of the impact of serious illness in an adult child and/or parental loss of an adult child. In this review, various limitations and gaps in the current literature were identified. There is need for more in-depth research to understand the lived experience of these parents and what health-care providers can do to assist these older people.

ACKNOWLEDGEMENTS

Our thanks go to the other members of the Steering and Working Committee: M. Grypdonck, M. Deveugele, K. Versluys and E. Decoene.

ETHICAL APPROVAL

Not required

FUNDING

This work was supported by the Flemish League against Cancer (VLK A11/TT/0756). The funding source had no involvement in the research conduct nor in the preparation of the article.

CONFLICT OF INTEREST

All authors have no conflict of interest and are fully responsible for the content of the manuscript.

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CHAPTER 3. TIGHTROPE WALKERS SUFFERING IN SILENCE: A QUALITATIVE STUDY INTO THE EXPERIENCES OF OLDER PARENTS WHO HAVE A MIDDLE-AGED CHILD WITH CANCER

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Based on an article published in International Journal of Nursing Studies.

2015; 52(9), 1445-1453.

doi: 10.1016/j.ijnurstu.2015.05.010

TIGHTROPE WALKERS SUFFERING IN SILENCE: A QUALITATIVE STUDY INTO THE EXPERIENCES OF OLDER PARENTS WHO HAVE AN ADULT CHILD WITH CANCER

ABSTRACT

Background

Given the worldwide ageing of the population and the changes in the structure of society and family, the likelihood increases that older parents face a serious illness in an adult child and will even outlive their child.

Objectives

To gain insight into older parents' experiences, concerns, and dilemmas regarding their position and role as a parent of an adult child with cancer.

Design

Qualitative interview design.

Setting

A geriatric ward and four oncology wards of a university hospital, several nursing homes, local health service agencies.

Participants

Twenty-five parents (age range 65–91 years) of 22 adult children with cancer (age range 33–66 years) of differing stages and types (with a preponderance of breast cancer).

Methods

Using a qualitative research methodology underpinned by grounded theory, we conducted semi-structured interviews with a fairly open framework.

Results

Suffering in silence emerged as the core category encapsulating three interrelated balancing acts: (1) shielding their child while being shielded by their child, (2) being involved while keeping an adequate distance, and (3) shifting attentional priorities between their child, themselves, and others. The emotional interconnectedness between older parents and their adult child with cancer becomes tangible in the transformational process of their parental role and position described in the three balancing acts.

Conclusions

Faced with their child's illness and possible death, older parents experience overwhelming feelings often underestimated by their (close) environment. Nurses need to be susceptible for the needs and experiences of these older parents. For care by nurses to make a difference, their attention must be directed to how older parents can be invigorated in their parenthood while respecting the child's autonomy.

Keywords

Adult children; cancer; caregiver stress; family relationships; grounded theory; older adults; parenthood; qualitative research; role

What is already known about the topic?

- With increased life expectancy the chance that older people face a cancer diagnosis in an adult child augments.
- Data relating to the experience of older parents in the face of a cancer diagnosis in one of their adult children are scarce in the current literature.
- Attention in oncology is widened from patient to include nuclear family members; yet the parents’ role in adult patient's lives is mostly not regarded essential beyond the pediatric age group.

What this paper adds

- Older parents’ situations can be envisioned as facing energy-consuming and delicate balancing acts on three areas (1) shielding while being shielded, (2) between being involved while keeping an adequate distance, and (3) shifting attentional priorities between their child, themselves, and others.
- Health care providers are in a unique position to give recognition for the tremendous tight roping act a lot of these parents are performing by means of family-centred care.
- Narrative care seems a promising venue for health care providers to help these parents give a voice in and during care.

INTRODUCTION

Across the globe, the number of older people (65+) is expected to more than triple, increasing from 784 million in 2011 to 2 billion in 2050 (World Population Prospects, 2011). That the ageing of the population pressurizes the affordability and organization of health care has become commonplace. Yet the emergence of new emotional events, such as older parents seeing their adult child being seriously ill and dying, has received less coverage in media and research (Cacace and Williamson, 1996; Goodman et al., 1991; Marengoni, 2010; White and Beach, 2012). The likelihood of experiencing this pain will only increase given the rising prevalence of chronic diseases in people of 40 years and above (Centers for Disease Control and Prevention, 2013).

A life-threatening illness, such as cancer, has far-reaching consequences for both the patient and his family (Coyne et al., 2012; Goren et al., 2014; Williams, 2014). Although, insights in the impact of cancer on immediate family members of an adult cancer patient (viz., spouse or children) are growing, the experiences and needs of the older parents often remain hidden (Van Humbeeck et al., 2013). Beyond the paediatric age group, the role of parents in patients' lives is often not regarded essential (White and Beach, 2012). Indeed, the parent-child relationship generally changes over time towards decreasing levels of parental involvement while a strong and meaningful connection of the parents with their adult child continues (Smith and Pardasani, 2014). This continuation of intrinsic affection, support and care of older parents towards their adult children is regularly overlooked in clinical practice.

Also the research literature mainly highlights the experience and impact of serious illness and/or loss of a young child on parents (O'Connor and Barrera, 2014; Sulkers et al., 2015). A recent literature review could detect 19 studies (7 quantitative and 12 qualitative) on the experiences of older people whose adult child has cancer or has died of cancer (Van Humbeeck et al., 2013). Yet due to methodological problems (e.g., small sample sizes, almost exclusive focus on bereavement at the expense of the prior illness process) these studies only gave a fragmented description of the experiences and perceptions of these parents, leaving nurses relatively empty-handed. Therefore, the purpose of the present study was to gain insight into older parents' experiences, concerns, and dilemmas regarding their position and role as a parent of a middle-aged child with cancer.

METHODS

DESIGN

A qualitative research design using semi-structured interviews was used based on a constructivist grounded theory approach (Charmaz, 2014), as it allows for an in-depth exploration of how older parents experience the illness of their child. The study protocol was approved by the Ethics Committee of the Ghent University Hospital (B670201112271). The authors used the COREQ-checklist as a guideline in reporting their qualitative research (Tong et al., 2007).

PARTICIPANTS

Participants were recruited and interviewed between December 2011 and March 2014. A convenience sample of parents was attained from the geriatric ward of the Ghent University Hospital, several nursing homes, local health service agencies and by contacting sick adult children via oncology wards at the Ghent University Hospital. Parents above 65 years who had a middle-aged child with any type of cancer at any stage or whose middle-aged child died due to cancer, were eligible for selection. Adult oncology patients between 40 and 60 years old and/or potential participants were approached by a trusted health care provider (HCP). Only when permission was given, contact information was passed on to the researcher. Mechanisms of protection emerged early in our study, during the time of recruitment of participants. We noted that a handful of patients refused to allow us to contact their parent(s), saying they wished to protect their parent(s) from what could be a stressful and upsetting interview. Major reasons for parents' refusal included being overwhelmed, lack of interest and being too ill. The qualitative study was exploratory in nature, and part of a larger project designed to examine the relationship dynamics between oncology patients and their older parents. Only the results of the parents' experience of having an adult child with cancer are presented here. The findings concerning the parents' experience having lost their adult child due to cancer will be reported elsewhere.

DATA COLLECTION

One-time semi-structured interviews with an open character were conducted by a female researcher. The interviewer had no previous relationship with the participants. The researcher (LVH), a nurse and junior researcher, was trained and coached by an experienced qualitative researcher (MG). The interview topic list was developed on the basis of literature and input from clinical and academic experts. To ensure sufficient depth, older parents were encouraged to tell their story by means of an open-ended question: ''What has it been like for you since your son/daughter has been diagnosed with cancer?''. The participant's story determined the order of the topics. Interviews were audio-recorded and transcribed at verbatim. All data were anonymized and treated confidentially.

DATA ANALYSIS

Interviews were analyzed by the principles of a grounded theory approach (Charmaz, 2014). First, interviews were read entirely to obtain an overall picture of the interview before being coded. By comparing interviews and coded fragments, concepts were developed that guided the next wave of data collection. Subsequently, the emerging concepts, categories, and relationships between categories were clarified by carrying out new interviews, and reanalysing previous interviews. Figure 1. gives the reader more insight into the analytical process. Participants were enrolled until the point of data saturation was reached. All data analyses were supported by the software program NVivo10 (QSR International).

	Categories							
	Suffering in silence		Redefinition of parental role			Shifting attentional priorities		
	Subcategories							
	Shielding	Being shielded	Involved parenting	Bystander parenting	Helpless parenting	Focus on child	Focus on others	Self-care
Controlling expression	x							
Not being downhearted	x							
Displaying upbeat attitude	x							
Positive thinking	x							
Not inquiring too much		x						
Difficulty accessing information		x						
Closely observing child		x						
Constant worrying		x	x	x	x			
Sharing everything			x					
Occupying frontal position			x					
Being on call 24/7			x					
Standing by as long as possible				x				
Stepping in as needed				x				
Not being intrusive				x				
Caring with trial and error				x				
Not able to support child					*x*			
Being care-dependent					*x*			
Being left in the dark					*x*			
Caring is not my responsibility					*x*			
Putting life on hold			x	x		*x*		
Taking one day at a time						x		
Staying connected wih others							x	
Responding to needs of others							x	
Having nothing left to give to others							x	
Having to compromise						x	x	x
Being emotionally drained								x
Hiding physical impact								x
Ignoring alarm signs								x
Giving own health low priority								x
Difficulty attending to own needs								x

Figure 1. Analytical process

VALIDITY AND TRUSTWORTHINESS

Validity of data collection was enhanced by peer review of the interview style. Field notes describing contextual elements about the interview were recorded by the first author. Several strategies were used to increase the trustworthiness of our results (Lincoln and Guba, 1985). To achieve credibility and confirmability, investigator triangulation was realized by four researchers (LVH, LD, RP, MG). While the principal investigator (LVH) read and coded all interviews, three other investigators (LD, RP, and MG) read and coded a number of interviews and discussed the provisional findings among each other. In order to realize credibility, emerging findings were regularly discussed in a broader advisory group of researchers and clinicians in the field of psychology, oncology and medicine. To enhance dependability, the research and interpretation process was written down by means of an audit trail. Research methods were described in detail which enhanced transferability.

RESULTS

PARTICIPANTS

A sample of 25 parents (20 mothers and 5 fathers) of 22 cancer patients was attained. Parents, aged 65–91 years, were all Caucasians with diverse levels of education, ranging from low (primary school) to high (university or higher vocational education). The children, aged 33– 66 years, differed in stages of illness and treatment, with a preponderance of breast cancer. The interviews had a mean duration of 89 min (ranging from 21 to 199 min) and were held at the place preferred by the participants; for 22 parents this was their (nursing) home and for three parents an interview room in the hospital. The characteristics of the older parents and their children are listed in Table 1.

Table 1. Demographic variables and disease-related characteristics of older parents and their child

	Older Parent *N* = 25	Child *N* = 22
Demographic characteristics		
Gender, *N* (%)		
Male	5 (20)	10 (45)
Female	20 (80)	12 (55)
Age (years), *N* (%)		
< 40		1 (4)
40 - 50		7 (32)
51 – 60		9 (41)
61 – 70	6 (24)	5 (23)
71 – 80	8 (32)	
81 – 90	10 (40)	
> 90	1 (4)	
M (SD); range	77.9 (8.3); 65 - 91	53 (8.7); 33-66
Partner status, *N* (%)		
Partner (married or living together)	10 (40)	19 (86)
Divorced	2 (8)	2 (9)
Widowed	13 (52)	1 (5)
Living arrangement, *N* (%)		
Home	19 (76)	
Nursing home	6 (24)	
Education level, *N* (%)		
Low[a]	12 (48)	
Middle[b]	3 (12)	
High[c]	10 (40)	
Disease characteristics		
Type of cancer, *N* (%)		
Lung cancer		4 (20)
Throat cancer		3 (15)
Breast cancer		7 (25)
Gastro-intestinal cancer		5 (25)
Other		3 (15)

Note. [a]low: primary school, lower secondary general, lower vocational; [b]middle: higher secondary general, intermediate vocational education; [c]high: higher vocational education, university

EXPERIENCE OF OLDER PARENTS HAVING A MIDDLE-AGED CHILD WITH CANCER

Below we will set out the key categories emerging from the stories of older parents. Although each category will be discussed separately and in a linear fashion, they are interwoven in multiple and complex ways. Therefore, it is important to keep in mind the interconnected nature of our findings. The illustrative quotes have been slightly edited for reading ease.

Suffering in silence while living in a house of cards

Many of the older parents relived and recounted the events of learning about their child's diagnosis. The uncertainty with regard to the diagnosis, the treatment, and the survival of their child was experienced as terrible and anxiety-ridden. Parents reacted with shock, disbelief, fear and felt overwhelmed by a sense of powerlessness. The incomprehensibility and intrusiveness of having a child diagnosed with cancer was reflected in statements as: ''my whole world had collapsed'', ''her announcement came as a real bombshell''. Parents felt as if they were living in a house of cards reporting unpredictability and instability in their lives due to cancer in their child.

> But yeah, if the first bad message comes ... Then your world turns upside down. Because you do not want that ... That YOUR child is ill, you can't live with that. (IV 7, 70 years old mother of a 41 years old daughter with acute lymphoblastic leukaemia).

Taken as a whole, the parents' coping with these sudden and ongoing changes can be described as 'suffering in silence'. This core category should be understood in a multifaceted way. First, it refers to the parents' feeling alone in their experience, because others (viz., peers or HCPs) were often simply not able to fully understand what it was like parenting a sick child, or even to acknowledge the impact it had on their role and feelings as older parents. Second, it refers to the parents' feeling of being kept in silence by their child and their wider environment. For several parents it took a long time to receive the full spectrum of information, as their middle-aged child disclosed information on a 'here and now' basis. Parents understood this lack of inclusion and involvement as an act of protection by their child. In sum, suffering in silence in its multidimensional meaning forms the emotional undercurrent of three interrelated balancing acts (see Fig. 1), which make up how older parents cope with cancer in their child.

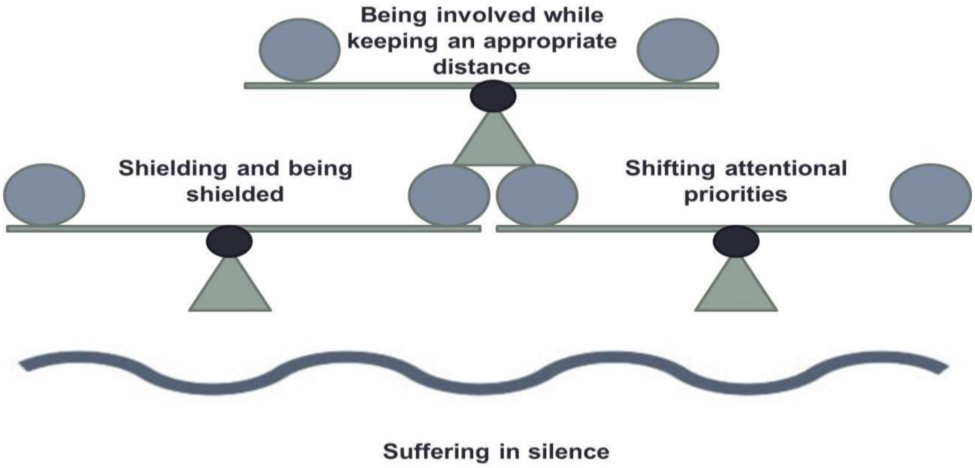

Figure 2. Three interrelated balancing acts

Parenting a sick middle-aged child as balance artistry

Older parents' experience a delicate balancing act on three areas (1) shielding their child while being shielded by their child, (2) being involved while keeping an adequate distance, and (3) shifting attentional priorities between their child, themselves, and others.

Shielding and being shielded.

This first balancing act contains two areas of protection which are both grounded in and contribute to the parents' suffering in silence. Our analyses further indicated underlying thought processes (e.g., avoiding psychological distress and the belief in positive thinking) as having an important role in shaping this phenomenon.

Shielding. When they are with their child, older parents felt restricted in sharing their actual feelings and worries. They repeatedly referred to the importance of controlling their expression of emotional upset vis a vis their child in terms of having to be strong, not allowing themselves to become downhearted and avoiding 'giving away' to emotion. A belief that was either internally modulated or perceived as an expectation by their child or close environment. This tactful withholding of their worries was considered to support their child, as the parents think that their child needed strong and supportive parents or didn't want to see or hear emotional upset.

> It's really horrible. How should we approach our son? (...). He closes himself off. He arms himself against it. (...) So we have to handle him with kid gloves, I would say. Not burdensome, so that he won't be upset. With caution. I would almost say that we don't want to stimulate his grief and distress. (IV 2, 72 years old mother and father of a 43 years old son with lung cancer)

Positive thinking and displaying upbeat attitudes were ways of controlling the continually experienced spectrum of emotions, and maintaining some sort of normalcy. Others modified their behaviour to protect their child from having to think or talk about the illness. As these parents have to contend with a kaleidoscope of feelings in the same way and to a comparable degree as the patients themselves, their suffering in silence requires considerable emotion work.

> Yes. But to my mind, I can't share my feelings about the fact that this is going badly with her. I cannot do that. I feel isolated with these feelings because I can't tell this to my other children. It wouldn't be proper to tell oh no. (...) I need to comfort her and hope that it will be all right.(IV 7, 70 years old mother of 41 years old daughter with acute lymphoblastic leukaemia)

However, aged parents sometimes had to struggle to keep an optimistic view. Being positive posed challenges, particularly if they had depressive thoughts and did not feel they could openly express them and if they perceived the prognosis and the chance of cure as poor.

Being shielded. The other side of the first balancing act is about walking fine and tactful lines to access secondhand information. Many parents oscillated between giving and getting information in an appropriate manner. Parents were sometimes afraid of making their child more worried by asking or inquiring too much. As a consequence, the parents' ''waiting stance'' left them groping in the dark with an impossibility to access information and adapt accordingly.

> At last, they've said it. (...). Yes. I had already seen it. I actually already knew it. But no, she never said it to me directly. She did not want to burden me. (IV 5, 91 years old mother of a 66 years old daughter who died of liver and gallbladder cancer)

Most parents had the feeling of being silenced in the margin of events and acted as close observers of wordless (mostly visual) cues and the body language of their child:

> I've intensively observed my son for the past two years and nine months. When he got out the car I watched whether he was seriously ill or not, whether he was comfortable or not or when he was at loss with something I noticed all those things, without wasting words. (IV 13, 75 years old mother of a 48 years old son with bladder cancer)

Some parents didn't experience this situation as a problem, especially if they received enough information through their in-laws or other children. A minority purposely did not want information, as it could further confuse and distress them.

Being involved while keeping an appropriate distance.

Parents described a second balancing act between being at the forefront and being overshadowed. Over the years, most parents had taken gradual steps back from direct parental care towards decreasing levels of parental involvement, but due to the cancer diagnosis a redefinition of the parental position takes place. Being aware of limits imposed by their child or themselves, parents struggled with this redefinition. The ensuing involvement was influenced by the degree of perceived understanding and agreement between themselves, their child, and their child’s spouse, the former relationship with their child, their own capacity to provide help, their child’s marital status, and the match of coping styles. Although many parents perceived their new role as valuable, the majority expressed frustration that they were not in a position to offer more emotional and/or instrumental support for their (grand)children. A few parents expressed feelings of failure, inadequacy and dissatisfaction with their role. Some parents indicated that they were not given enough information or freedom to be involved, but they respected the wishes of their child and/or in-laws. In this way, the parents’ stories were encased with many forms and intensities of ‘‘being there’’: involved parenting, bystander parenting and helpless parenting.

Involved parenting mostly occurred when the child was divorced or widowed, the parents were in good health, and there was a good fit of coping styles of both parties. Under these conditions, parents could occupy a frontal position and ‘‘be there’’ unconditionally and no matter what for their child. This mirrors a level of involvement reminiscent of the protective early bonding between parents and infant now present between older parents and their child at a time of crisis. Symbolically sharing the illness, in particular facing the illness together, seemed to be an underlying tenet. Involved parents were on call 24/7 ensuring that their child did not feel alone or abandoned. They took on a key supportive role in order to maintain a semblance of normality.

> I actually find it awful that her new boyfriend is going to take over my role. I have been doing this for my daughter the past three years and now this is taken away from me. It’s not entirely her boyfriend’s fault because I suggested it myself but yeah. And I can join them now Thursday during the consultation with the oncologist, but he (the new boyfriend) has to get the feeling of looking after her. Just like I did, for more than three

> years, I had to do that. It is my duty as a father (IV 11, 70-year-old father of 45-year-old daughter with breast cancer in the beginning of a new relationship)

Bystander parents described themselves as background figures (‘feeling curbed as a parent’, ‘like an appendage’) stepping in as needed. They wanted to be supportive, engaged and involved but at the same time they were afraid of being too intrusive. Consequently, they were constantly searching their place and tuning in on boundaries set by their child. Parents realized that they could not take over and had to be satisfied with being a parent on the sidelines, still taking part of things but not having an influence on all things. These parents periodically stepped in as substitute parents for their grand-children by taking care of their daily routines. They identified this type of involvement as giving their child some relief to look after oneself.

> We are on call 24/7, but they must indicate when they need us. We keep our distance, that sounds crazy. He is very close to us but yet there is that distance ... This is maybe the result of our behaviour in the past when our first grandson was born. Then we were, I think, too patronizing. That was getting on his nerves. (...) He will not allow us to yeah ... They just don’t want that, so be it. And I really want to step into his shoes if I could. (IV 2, 72 years old mother and father of a 43 years old son with lung cancer)

Helpless parenting was especially noticed in the frailest parents residing in a nursing home, living far away from their child, suffering from health problems and not being able to offer practical help. Although they still were concerned about and interested in their child, they did not describe themselves as the active participants they once had been. In many cases role reversal between parent and middle-aged child had occurred. Other parents didn’t regard it as their responsibility anymore to take care of their sick child as they acknowledged the spouse as having priority as caregiver. For others their impossibility to intervene was so frustrating that they saw no other option than having to resign themselves to alienation.

> I asked my son-in-law whether I could stay with them for one week. But yeah, that wasn't an option. I can't use my arm and walking around is even more difficult. I myself am dependent on the help of others (…). I really wanted to help my son-in-law, but now he had to manage it alone. I could only reach them by telephone. But it became more difficult to contact her by telephone because her voice was becoming fainter. (…) My husband has early stage dementia and his driving license was revoked and I don't have a driving permit. So yeah, I had to rely on my other children in order to visit my daughter. (IV 6, 83 years old mother of a 56 years old daughter with end-stage breast cancer)

Shifting attentional priorities between your child, yourself, and the others.

This balancing act relates to the parents having thought for their child while not getting ahead of themselves and meanwhile staying connected with others. Since the diagnosis, an overwhelming sense of helplessness and constant worrying dominated the parents' lives. Some parents experienced a strong wish to swap places with their sick child. Participants mentioned putting their life on hold just because they were not able to move forward until everything was safe and well with their child (''being totally consumed'').

> But now, my life and my world revolves around her. And around her household. (…)But I have to be careful that I don't lose sight of my other son. You have to compromise a bit (IV 21, 65 years old mother of a 33 years old daughter with breast cancer)

As the lack of control over the future frightened them, taking one day at a time was a helpful strategy. Even then they struggled with their own limitations and continuously fought not to lose their foothold. Participants described how they felt that they had to be stronger than they actually were, leaving them emotionally, physically, and mentally drained. Older parents lived out a juxtaposition of their own needs while wanting to respond to the needs of their ill child and other (grand)children spending a great deal of energy in hiding changes from the children and pretending that all was fine.

> It’s not just our daughter who is suffering, but also her husband and her adult children. That’s a total package where I focus on. (IV 18, 72 years old mother of a 52 years old daughter with colon cancer)

Although helping out provided a sense of purpose and remedied the helplessness instilled by cancer, several alarm signs (such as sleeping problems, concentration problems, lashing out at someone) showed how this went at the expense of their own health. They felt compelled to stand by as long as possible and try to do their best even when they became a physical and emotional wreck. Their own health had low priority, because they regarded their child’s situation as much worse.

> Actually, the operation on my knee was nothing compared to her diagnosis. (...) My knee will probably get better in time. But her cancer, that’s something completely different. But yeah, that knee of mine was an additional burden, I literally dragged that leg. I made every effort to get on with it. Fighting of the pain with painkillers. Trying to postpone the operation. I was all over the place. Bringing the children to school, picking them up, preparing their meals etc. But yeah, that is a minor consideration, her health is of major concern. The most important thing is that she recovers. (IV 7, 70 years old mother of 41 years old daughter with acute lymphoblastic leukemia)

DISCUSSION

PRINCIPAL FINDINGS

The current study provides unique insights in how older parents experience their child’s cancer journey. Key findings relate to (a) the overwhelming uncertainty and silent suffering instigated by the cancer diagnosis and (b) the ensuing redefinition of one’s parental role. The stories of the older parents in our study corroborate and at the same time extend the idea that cancer is a family affair (James et al., 2007; Kayser et al., 2007; Pitceathly and Maguire, 2003). This ripple effect is often understood and studied as pertaining to the nuclear family around the patient (Lo et al., 2013; Semple and McCaughan, 2013; Wadhwa et al., 2013). Yet, older parents clearly indicated how the cancer diagnosis instigated an emotional turmoil leaving them in a landscape of uncertainty, change, anxiety and frustration, which is often underestimated by their close environment and caregivers (Dean et al., 2005; Edvardsson and Ahlström, 2008; Raveis et al., 2010).

Additionally, our findings show how cancer affects a family as a unit causing family members to react to the diagnosis as an 'emotional system' (Burkhalter and Bromberg, 2003; Hagedoorn et al., 2008). Cancer may change the relational dynamics as reflected in the parents' perception of changes in their personal relatedness with their sick child (cf. balancing acts) and their feeling that the oral communication became more guarded (cf. being shielded). In the interviews the emotional interdependence between parents and their sick child becomes tangible in the redefinition of the parental role described in the three balancing acts.

In accordance with others (Dean et al., 2005; Fisher, 2010; Gilbar, 2002) we found that how parents can rearticulate their position is intrinsically bound by what they perceive as the boundaries set by their child and his/her nuclear family and by relationship patterns built up in the past. Our analyses further indicate how both silent suffering and parental redefinition can only be understood when one closely listens to the delicate balancing artistry older parents engage in. More concretely, to understand the experience of these parents one should acknowledge the undertone of the balancing act ''shielding and being shielded'', namely mutual protection; one of the often cited coping strategies of older parents of ill adult children (Van Humbeeck et al., 2013). More broadly, in event of serious illness avoidance of family communication and withholding of information is a common protective mechanism (Caughlin et al., 2011; Hay et al., 2009; Zhang and Siminoff, 2003). Most older parents in our study talked about this avoidance of emotional sharing in terms of being positive and not dwelling on any negative emotions and/or thoughts in order to protect themselves and their child from emotional upset. Our analyses clarified how this asked a lot of emotion work, often hidden for the environment (cf. suffering in silence) and only shown by physical ailments. We observed that when silence was practiced, older parents could feel increasingly lonely and hopeless, while worries and anxiety build up in their minds.

To understand the category of parental redefinition it is important to acknowledge the continued importance for these parents of presence and availability as a parental response on the (perceived) vulnerability of the child, but that these can't be fully exerted anymore. Feeling compelled to take care for their child parents (Dean et al., 2005; Fisher, 2010; Gilbar, 2002; Raveis et al., 2010; White and Beach, 2012) engaged in a complex evaluation process weighing whether their involvement was appropriate and in accordance with what the child and his/her partner desired. A categorisation of care and carers based on a ‘‘hierarchy of obligations’’ (Ungerson, 1987) may help to explain the emotional loading of this process. This hierarchy may give rise to a set of informal rules by which individuals assume responsibility for the care of other family members. In the hierarchy of obligations, the partner is the primary carer and parents in that instance constitute the secondary carers. When a middle-aged child is married and has children, there was often a culturally rooted tendency to emphasize the independence and integrity of this family unit, as seen in bystander parents in our study. Parents can play a pivotal supportive role that is both different and as important as spousal support (Coyne et al., 2012), yet our study shows how this asks for delicate balancing.

As a lot of parents described their relationship with their child as being altered by the illness shaping their new role resulted in many forms and intensities of ‘‘being there’’. Only one earlier study pointed towards the importance of ‘‘being there’’ as a typical manifestation of the parental nurturing (Dean et al., 2005). Our study unveiled a continuum of ‘‘being there’’ in many forms and intensities originating from a complex interplay between what parents want, can, and are permitted to do by their child and environment. This interplay points towards an important caveat. There is the danger that involved parenting is regarded as the ‘ideal’ stance to hold and to facilitate in practice. However, as emerged in this study, not all parents necessarily wanted and could occupy this frontal position at all points in times. At times and in particular situations, older parents were satisfied with remaining in the background as passive bystanders, a position that also asks for respect from nurses.

METHODOLOGICAL CONSIDERATIONS

Findings must be considered in light of some limitations. It should be noticed that our findings mainly pertain to Caucasian, Dutch speaking, articulate, self-reflective, mothers of breast cancer patients. In addition, the majority of the parents were identified through their middle-aged child. As refusal might be more common in cases of tense relationships or over-protection, these groups of parents may be relatively un(der)represented. Further, our findings represent the perspective of the parents; although they speculated about the feelings of their children, these data may not be considered to represent the children's views.

IMPLICATIONS FOR NURSING PRACTICE

Our findings provide valuable insight into parents' coping processes and related directions for practice to give recognition to the silent suffering of these parents, namely (a) narrative care and (b) a relational perspective both in oncological and geriatric settings.

Narrative care. It was striking in our study how a simple open question for many parents was sufficient to bring an elaborate story about themselves and their sick child. In this context, narrative care as a relational approach that helps persons in their search for meaning in the final and perhaps most challenging part of their life may be useful. It entails a comprehensive way of listening *to*, listening *for*, and listening *behind* stories (Randall, 2015) by means of reminiscence, life review, guided autobiography etc. Narrative care (Baldwin, 2015; Buckley , McCormack, & Ryan, 2014; Bohlmeijer et al., 2007; Clarke et al., 2003) seems a promising avenue to give recognition. Insights from the balancing acts however learn that narrative care should not be narrowed to ''force'' these parents to talk about their story. Narrative care implies a gentle invitation to voice what is going on in a climate of mutual trust and tolerance for a wide range of experiences over time.

A relational perspective in both oncological and geriatric settings. Our study points to the need of a shift in care from a focus on the individual experience of the patient and the spousal caregiver to a multigenerational family-sensitive perspective is favoured (Fletcher et al., 2012). In case of adult patients parents are often no longer considered as next of kin. Nurses should acknowledge that parent-child ties have a longer history than any other relationships and that a serious illness as cancer may require a redefinition of this relationship. Further, nurses should recognize how ingrained parenthood may be in the identity of older persons. Although the practical side of parenthood may not be as central as it was when children were young, this study shows that the psychological experience of being a parent continues to play an important role. Family meetings (Powazki et al., 2014), genograms and ecomaps (Wright and Leahey, 2013) may be useful tools for unravelling family dynamics and meaning making within families confronted with cancer.

IMPLICATIONS FOR FUTURE RESEARCH

Our data clearly portray that the way parents cope with the illness of their child is co-influenced by the space parents think they are allowed to take according to previous relationship patterns or current cultural norms on parenting. Hence, to further our understanding of the experience of older parents we need to give voice to the sick middle-aged children and analyze patients' experiences in tandem with their parents' experiences (Li and Loke, 2014). In addition, a prevalent issue in health care is the growing multicultural composition of patient groups. Yet, our sample was primarily Caucasian, leaving open how older parents in other cultures experience the illness of one of their children (Silverstein et al., 2010) and in particular in countries where rates of intergenerational co-residence are higher (Hank, 2007).

CONCLUSION

Our study makes older parents' roles and experiences during the cancer journey of their middle-aged child more transparent. This study showed that the world of the child, in-laws and grandchildren is so interwoven with the older parents' own world that every sign of suffering may influence their well-being. The parent and child relationship is still important at old age, and recognizing that is essential to effective care planning. For care by nurses to make a difference, attention must be directed to how older parents can be invigorated in their parenthood while respecting the child's autonomy. Narrative approaches may provide older parents with opportunities, if they so desire, to talk about their experiences and allowing them to feel their experience is worthy. Principles of family-centred care are suggested as a foundation for respecting the connectedness between patients and their older parents.

CONFLICT OF INTEREST

None declared.

FUNDING

This work was supported by the Flemish League against Cancer (VLK A11/TT/0756). The funding source had no involvement in the research conduct nor in the preparation of the manuscript.

ETHICAL APPROVAL

The Ethics Committee of the Ghent University Hospital (B670201112271).

ACKNOWLEDGEMENTS

The authors wish to thank the participants who were willing to share their experiences and insights.

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CHAPTER 4. SUFFERING IN SILENCE. A QUALITATIVE STUDY ON OLDER PARENTS WHOSE CHILD DIED OF CANCER.

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doi: 10.1080/07481187.2016.1198942

SUFFERING IN SILENCE: A QUALITATIVE STUDY ON OLDER PARENTS WHOSE CHILD DIED OF CANCER

ABSTRACT

As life expectancy grows, the death of a middle-aged child becomes a highly prevalent problem for older adults. The present study is based on 9 interviews and explores the experience of parents (≥70 years) outliving their child. The bereaved parents described some silencing processes constraining their expression of grief. When an adult dies, the social support system nearly automatically directs its care towards the bereaved nuclear family. Parental grief at old age is therefore often not recognized and/or acknowledged. Health care providers should be sensitive to the silent grief of older parents both in geriatric and oncology care settings.

Grief and its concomitant loneliness are common phenomena in the process of aging. Just as aging is often associated with desirable life events (Norris & Murrell, 1990) such as grandparenthood and retirement, it is also associated with undesirable life events, such as the loss of a loved one (d'Epinay, Cavalli, & Guillet, 2009; Newson, Boelen, Hek, Hofman, & Tiemeier, 2011; Shah & Meeks, 2012). In one study, over 70% of older adults above 65 years experienced the death of a close loved one in an 18-month observation period (Williams, Baker, Allman, & Roseman, 2007). Thanks to longevity, it is no longer uncommon for the so-called older age group to include both parents and children. This leads to the emergence of new emotional events, which challenge the life of older persons, but which are still remote from public imagination (Marengoni, 2010). One of these events is the pain of older parents when seeing their adult child seriously ill and dying (Cacace & Williamson, 1996; Marengoni, 2010; White & Beach, 2012). Generally, no less than 1 in 10 parents over the age of 60 have to deal with the death of a child (Audenaert & Vanderleyden, 2003). Taking into account the aging population and the rising prevalence of certain chronic diseases such as cancer (Eurostat, 2010; Ferlay et al., 2013b), this percentage will only increase.

That the death of a loved one can interfere with the life and functioning of next of kin is well known. Literature on grieving older widows attests to a worsening of health status (Buckley et al., 2012; Mostofsky et al., 2012; Stroebe, Schut, & Stroebe, 2007), increased risk for mortality (Shah et al., 2013) and emotional and psychosocial changes (Anderson & Dimond, 1995; Arbuckle & de Vries, 1995; Erlangsen, Jeune, Bille-Brahe, & Vaupel, 2004; McLaren, Gomez, Gill, & Chesler, 2015; Naef, Ward, Mahrer-Imhof, & Grande, 2013). The majority of grieving older adults are able to recover and return more or less to pre-loss functioning. Nevertheless, a minority may experience a more difficult grief course (Bonanno et al., 2002) exhibiting reactions that can be understood as prolonged or complicated grief (CG). Recent population studies found that nearly 5 to 7% of bereaved people developed CG (Kersting, Brahler, Glaesmer, & Wagner, 2011; Newson et al., 2011). These studies underscore the need for bereavement care in old age, and particularly for persons over 60 who have lost a child or partner due to cancer.

Qualitative bereavement care is grounded in an awareness of and insight in the lived experience of the bereaved person. Unfortunately, grief of older parents gets scant attention in society as well as in research and clinical practice. When a young child dies, there is almost immediately an outpouring of support for the young parents. The attitude of the environment can be totally different when a middle-aged child dies. Often less consideration is given to these parents, as if the normality of losing loved ones in old age makes one immune to the pain, the intrusiveness, and the need for care. The same tendency can be discerned in the research literature (Williams, Baker, & Allman, 2005). Only a few studies describe the experiences of older people whose adult child has cancer or has died of cancer and these are merely descriptive and give no concrete recommendations for health-care providers in daily practice (Van Humbeeck et al., 2013). This contrasts with the more developed literature on widowhood in old age (Carr, Nesse, & Wortman, 2006), on bereaved adult children (Umberson, 2003), and on the experience and impact of a serious illness or death of a young child for young parents (Harper, O'Connor, & O'Carroll, 2014; Klassen et al., 2007; Schweitzer, Griffiths, & Yates, 2012). The transferability of these findings to the group of older parents is questionable. Although there might be recognizable and similar themes, the specific context of older parents gives a particular resonance that is different from that of younger parents (Hooyman & Kramer, 2006; Parkes & Prigerson, 2010).

Overall, research and practice focussing on how the death of a middle-aged child is experienced by older parents remains limited. This lack of information leaves people in the social environment and health care providers (HCPs) empty-handed in acting adequately and appropriately. Knowledge and insight into the older parents’ experience is essential for the provision of tailored bereavement care. Therefore, the purpose of this study was to describe older parents’ own perspective on the experience of outliving their child and how they cope with this loss.

METHOD

DESIGN

A qualitative methodology with elements of constructivist grounded theory was used, as it allows for an in-depth exploration of how older parents experience the death of their child (Charmaz, 2014). The study protocol was approved by the Ethics Committee of the Ghent University Hospital (B670201112271).

PARTICIPANTS

Parents were recruited from the geriatric ward of the Ghent University Hospital, several Flemish nursing homes, and local health service agencies. Parents above 70 years whose middle-aged child had cancer or had died due to cancer were eligible for participation. Potential participants were approached by a trusted health care provider (physician and/or nurse). Only when permission was given contact information was passed on to the researcher (LVH). Major reasons for parents' refusal included being overwhelmed, lack of interest, and being too ill. The current study was exploratory in nature, and part of a larger project designed to examine the relationship dynamics between oncology patients and their older parents. Only the results of the parents' experience of being bereaved of a middle-aged child due to cancer will be presented in this article. The parents' experience of having a child with cancer will be reported elsewhere.

A purposive sample of 25 parents (20 mothers and 5 fathers) of 22 cancer patients was attained of whom 9 parents were confronted with the death of their child. We will further report on the experiences of these 9 grieving parents (1 father and 8 mothers). The majority of these parents (*N* = 8) were widowed. Three still lived at home, six lived at a nursing home. The children, aged 51-66 years, died on average 22 months after the cancer diagnosis (ranging from 1 to 72 months). All but one of the children died at the hospital; one child died at home. At the time of the interview the participants were on average 8 months bereaved (ranging from 1.5 to 30 months). The characteristics of the older parents and their deceased children are listed in Table 1.

Table 1. Demographic variables and disease-related characteristics of older parents and their deceased children

	Older Parent *N* = 9	Middle-aged child N = 9
Demographic characteristics		
Gender, *N* (%)		
Male	1 (11)	5 (56)
Female	8 (89)	4 (44)
Age (years), *N* (%)		
51 – 60		4 (44)
61 – 70		5 (56)
71 – 80	2 (22)	
81 – 90	6 (67)	
> 90	1 (11)	
M (SD); range	84.7 (5.5); 75 - 91	59.8 (5.2); 51-66
Partner status, *N* (%)		
Partner (married or living together)	1 (11)	6 (67)
No partner or divorced	0 (0)	3 (33)
Widowed	8 (89)	0 (0)
Living arrangement, *N* (%)		
Home	3 (33)	
Nursing home	6 (67)	
Disease characteristics		
Type of cancer		
Lung cancer		1 (11)
Throat cancer		3 (33)
Gynaecological cancer		2 (22)
Gastro-intestinal cancer		2 (22)
Bladder cancer		1 (11)

DATA COLLECTION

Individual one-time loosely structured interviews were conducted between December 2011 and March 2014. The researcher (LVH) was trained and coached by an experienced qualitative researcher (MG). She had no previous (therapeutic) relationship with the participants. An interview topic list was developed based on a literature review (Van Humbeeck et al., 2013) and input of clinical and academic experts. The interviews started with the open-ended question: ‘What has it been like for your since your son/daughter has been diagnosed with cancer?’. With this question, parents needed little encouragement to talk about their experiences, emotions and dilemmas. The interviews lasted between 21 and 149 minutes (82 minutes on average) and were held at the place of preference of the participants; for six it was at the nursing home, for three in their home. The interviews were audio-recorded and transcribed at verbatim with allocation of pseudonyms to the participants and removal of all identifiers to ensure anonymity. Validity of data collection was enhanced by peer review of the interview style. Field notes describing contextual elements about the interview were recorded by the first author.

DATA ANALYSIS

The iterative analytical process was inductive and followed the principles of the constructivist grounded theory approach (Charmaz, 2014). First, the all verbatim transcripts were read and coded by one researcher (LVH). By comparing interviews and coded fragments, concepts were developed that guided the next wave of data collection. Subsequently, the emerging concepts, categories, and relationships between categories were clarified by carrying out new interviews, and reanalyzing previous interviews. All data analyses were supported by the software program NVivo10 (QSR International). Several strategies were used to increase the trustworthiness of our data. For instance, three investigators (LD, RP, and MG) read and coded portions of interviews, but the principal investigator (LVH) read and coded all interviews. Emerging themes were also regularly discussed in an advisory group consisting of researchers and clinicians in the field of psychology, nursing, and medicine.

RESULTS

A common thread in participants' stories was their suffering in silence, their quest for a place at the funeral and in mourning rituals, their survivor's guilt, and their lasting bond with their deceased child.

THE ALONENESS AND LONELINESS OF GRIEF

Loneliness was described both as a feeling of being alone in their experience and as a physical solitude. Several parents described an *emotional loneliness* despite the presence of others because they had little or no opportunities to have a heart-to-heart talk. These parents attested to grieving and suffering in silence, while not necessarily being alone. They characterized this loneliness not primarily as a physical solitude, but as a deeper loneliness stemming from being alone in having these experiences, with no one else who could really understand their situation. The parents' grief was obfuscated by the experience of the nuclear family and remained largely unrecognized while "It's still your child. The dearest, the most precious" (Interview 2, 72-year-old mother and father of a 43-year-old son with lung cancer). In addition, parents sometimes struggled with the question whether they were entitled to grief for their deceased child. Typically, these parents took a back seat by deliberately placing themselves in the background. In an effort not to burden others around them, they chose to conceal their grief. Even more, they diverted the attention from their own grief making the environment completely focus on the remaining nuclear family. Therefore they refrained from expressing their own emotional upset till they were alone. As a consequence, their grief went underground, often resulting in family members and the wider environment assuming that the impact of the loss was not substantial and of great importance for the older person. This dynamic amplified the older parents' grieving in silence.

> I guess because I shelved a lot of it, people actually thought I was okay. So I created a world around me that people thought I was alright. Perhaps I created part of the situation myself, because people thought I was fine and had gotten over it. (Interview 13, 75 year old mother whose 48 year old son died of bladder cancer)

Related to the above dynamic, older parents often had the feeling that persons in their environment were not able to understand their experience. (Great)grandchildren, other children, and in-laws swiftly resumed the thread of life by giving in to appeals from work and leisure activities, while some older parents had few activities that could distract them from their loss and pain and that could invite them to move on with life. Older parents felt as if these differences thwarted others' ability to comprehend the depth of their loss. They noticed that friends and family steered conversations away from the deceased child, not wanting to upset them. These parents had lost their emotional connectedness with others and were convinced that especially in moments of severe emotional pain, no one could ever understand their experience. They had the feeling that it was not an option to openly articulate their genuine feelings and therefore felt being left in the lurch.

> But my daughter-in-law would be angry if she noticed that I often keep the obituary card close to me. She asserts that I'm dwelling upon my grief. (Interview 14, 87-year-old mother of a 65-year-old son deceased to throat cancer)

Other parents are faced with social isolation and experience an intense feeling of being alone with their grief (*physical solitude*). Most participants were alone due to a variety of reasons such as the death of their spouse and friends, infrequent contacts with (grand)children, no longer being the hub of the family. Some participants were dependent on the deceased child for being the main caregiver and provider of social contact (role reversal). For these older adults, the child may have been the primary social contact and shaped the older parent's sense of social embeddedness and well-being. As such the death of their child not only resulted in an intense grieving process but also in a cascade of secondary losses such as the loss of an important social contact and the loss of independent living at home. Even though these secondary losses had far-reaching consequences, they weren't recognized or acknowledged as meaningful by significant others.

A FEELING OF BEING INVISIBLE

A positional powerlessness can be observed in two areas, namely the process of saying goodbye and the funeral. The interview data depicted older parents as being “invisible” as they were disregarded in times of crisis and loss. Many participants were ill prepared because they had not been able to watch over their child’s deathbed, because of their physical condition, dependence on others or because others kept them away from the deathbed out of concern for the impact on their already vulnerable and frail state. Especially parents residing in a nursing home had little to no chance of a position at the deathbed, even when they yearned to stay at their child’s side. Others were very cautious, even doubting whether they had the right to claim a formal position. Some had to put up a struggle in order to pay their last respects to their deceased child.

> My family didn’t want me to go to the morgue. They didn’t want to go themselves. (…). Eventually I dared to approach my GP and the head nurse. (…). They were surprised by my request. (…). My visit to the morgue was prepared in secrecy. And so I took a cab with the chaplain of the nursing home. (…). I’m so glad that they’ve given me the opportunity to say farewell. (Interview 14, 87-year-old mother of a 65-year-old son deceased to throat cancer)

In addition, many parents spoke at length about getting no opportunity to be involved in and attend the funeral of their child. Due to medicalization of grief (i.e. the administration of sedatives based on the idea that this would reinforce/strengthen the parents’ coping) some older parent’s weren’t able to consciously experience the ceremony. Others couldn’t be present due to their health condition or the protective stance of family members. Either way, many parents expressed feelings of guilt and regret.

> It’s a pity that they gave me medication before the funeral. Thus, I don’t remember anything about the funeral itself. That’s really unfortunate. It’s much to my regret that I haven’t consciously experienced and taken part in the ceremony. (Interview 9, 87-year-old mother whose 62-year-old son died of throat cancer)

SURVIVOR'S GUILT

A feeling of injustice, which was already present during the illness trajectory of their child, continued after their child's death. Their child's death went against what they felt was the very logic of life and was seen as an unnatural event. Parents repeatedly voiced that children ought to be healthier and to live longer than their parents. Some parents shared that as being older persons they had already fully lived their lives. Parents were continually confronted with the idea "It should have been happening to me but for unknown reasons I'm still alive". Embedded in this idea was the confrontation with their own finitude and cumulated loss experiences. The narratives indicated the parents' need to come to terms with the asynchronous nature of their child's diagnosis and their disrupted expectations about their future.

> I am the one who's old. I am the one who should go. My son was young and still had a life ahead of him. (Interview 14, 87-year-old mother of a 65-year-old son deceased to throat cancer)

REMEMBERING AND MAINTAINING A CONNECTION

Several parents attested to a lasting bond with their deceased child. Although the way in which parents shaped this bond was very diverse, similar linking objects were discerned. Visiting and maintaining the child's grave and viewing pictures constituted important (silent) channels to remember and to initiate conversations about and with the deceased child.

Grave visit

Visiting the grave was often one of the last tangible links for the parents, which could be comforting and liberating at the same time. This was true in part because they could continue to care for their child by keeping the site tidy and laying flowers on the grave. However, care-dependent parents were no longer able to maintain the grave and had to rely on other children and/or grandchildren.

> The only thing that remains is the grave at the cemetery and the only thing I can do is putting flowers on his grave. I like having it nice and tidy. (Interview 1, 85-years-old mother whose 62-years-old son died of pancreatic cancer)

> I can go to the cemetery with my walker. Talk to him. Yeah, it’s comforting that I can go to the graveyard. (IV 9, 87-year-old mother whose 62-years-old son died of throat cancer)

The solace of memories and keepsakes

Parents indicated several times that they cherish the bond with their deceased child. Even though the physical appearance of their children was gone forever, they were never far from their thoughts. Even seemingly trivial events took on new meaning in light of the death of their child. Often it involved keepsakes that seemed quite commonplace at first glance, but which carried a deeper symbolic meaning and hidden personal story.

> And I’ve still got a little kitchen apron. It is very old, but he wore it when he was little. And it hangs on a coat rack. I have asked his wife for a keepsake and she gave me a scarf. This scarf is hanging with that kitchen apron on that coat rack. That means a lot to me... As it hangs there, yeah I always see it ... when I enter the room. And it reminds me of him. (Interview 9, 87-year-old mother whose 62-years-old son died of throat cancer)

> I sometimes talk to the obituary card of my son. If my daughter-in-law would know that ... He is with me at that moment. That is my greatest consolation. (IV 14, 87-year-old mother of a 65-years-old son deceased to throat cancer)

The various stories revealed great variety in how older parents were supported in shaping this continued bond with their child. As outlined in the quotes above, some parents were well supported, allowing recognition and a feeling of connectedness. Unfortunately, other parents felt a lack of understanding by others in their environment for their continued bond and an absence of treasured mementos. The latter may lead parents hide their linking objects and this intensified their suffering in silence and emotional loneliness. For these parents, their deceased child was the only soundboard for their grief.

Photos

Several parents asked the interviewer to go through photo albums. These photos proved to be powerful tools to build an inner representation of the deceased child and often they were given a prominent place on the wall, cabinet or the mantelpiece. On the one hand, they served as an object to have an internal dialogue *with* the deceased child and on the other hand served as a gateway or starting point for conversations with family members and others *about* the deceased child.

DISCUSSION

Grief due to the loss of a child, regardless of age, is described as one of the most complex emotional grief responses (Arnold, Gemma, & Cushman, 2005). With increasing life expectancy and medical advancement, the likelihood of older parents outliving their children increases. Older parents are watching their middle-aged children cope with and sometimes also die from serious life-threatening illness; frequently these adult children are the first line of support and care for their aging parents (Lottes, 2005). Our study showed three themes that should be taken into account if we want to tailor care towards the needs of these parents, namely (1) the phenomenon of silent grief, (2) the role of family, and (3) the importance of continuing bonds.

The bereaved parents described a number of silencing processes whereby their expression of grief was constrained--by themselves, their families and wider social networks-- which unwittingly reinforced the ‘silent’ nature of their grief. From the notion of ageism and disenfranchised grief, older parents may be likely to trivialize the intensity of their suffering, and attempt to exaggerate their strength and coping skills (Moss & Moss, 2012). Parents attested to struggling with the question whether or not they were entitled to grief for their child, which may have been linked with others' conviction that both the practical side and the psychological experience of parenthood are no longer of interest at this age (Antonucci, Akiyama, & Takahashi, 2004). Further, it was as if there were a sense of hierarchy or a pecking order of grief (Kastenbaum, 2008) that questioned the parents' entitlement to grief. In fact, older parents themselves may believe that others are suffering (even) more and hence that they were not on the first row when it comes to grief. This may lead to self-disenfranchisement and additional unnecessary suffering (Neimeyer & Jordan, 2002).

These silencing processes are intrinsically bound up with family roles. Our findings support and extend the assertion that families are frequently the most prominent "grief police" (Walter, 2000) as existing family dynamics and family norms can suppress grief talk (Breen & O'Connor, 2011). In essence, the participants believed that family members and friends did not grasp their loss and thus they were reluctant to express their feelings or tell their story (Smith, Nunley, Kerr, & Galligan, 2011). This may in turn inhibit the bereaved parents in such a way they were not able to tell their own story of grief, and in particular sharing the many memories and legacies of their child's life. This suggests that families promoting open communication may experience different grief reactions than families who cannot openly communicate with each other (Carmon, Western, Miller, Pearson, & Fowler, 2010). Older adults may feel pressured to look and act happy and move on with life whether or not an unspoken time limit is placed on how long an older person is allowed to mourn a loss. The parent's perception of family members dismissing their grief and underestimating the severity of their distress is in accordance with previous research (Ghesquiere, 2013; Owens, Lambert, Donovan, & Lloyd, 2005). Lastly, the interviews underscored the subtle power of mutual protection within families. Family members feel the urge to protect loved ones from pain and sadness; yet often this well-intended protection has a non-intended detrimental impact on the one who one wants to protect. This was evidenced in our study with regard to the space parents were allocated at the deathbed of their child or at the funeral, which is in line with Smith et al. (2011). Our data point further to the mutuality in this protection dynamic. Indeed, some parents were very cautious, uncertain about whether they had the right to claim a formal position. They often stepped back and gave space for comfort and involvement for the nuclear family. In sum, whether this lack of involvement in formal rituals was self-inflicted or other-inflicted, many parents described regret about not being fully involved. Such uninvolvement in rituals is known to potentially complicate the evolving grief trajectory (Wijngaards-De Meij et al., 2008).

Striking in our data was the importance of memories and tangible objects that served as symbols and witnesses of the bond parents had and still have with their deceased children (Neimeyer, Baldwin, & Gillies, 2006; Root & Exline, 2014). These linking objects (Klass, Silverman, & Nickman, 1996; Volkan, 1972) gave these parents solace, which they often couldn't find anywhere else. Yet the cherishing of such linking objects often happened in a hidden manner, as parents feared that other family members wouldn't understand. Although these linking objects had a protective nature, as they represent the continuing bond, the fact that accessing them was often a lonely activity showed how the continued bond in these parents could also include a danger. Indeed, for some parents there were no real life conversations that they considered valuable, and their only conversational partner was their deceased child. In other words, the oscillation between loss orientation and restoration as described in the Dual Process Model (Stroebe & Schut, 1999) was missing. Rather an exclusive focus on loss-orientated coping behaviors exists, which left parents more susceptible to complicated grief. In some cases, however, these linking objects, such as photographs, sometimes provided an important vehicle for conversations between surviving relatives and others about the deceased (Hastings, Musambira, & Hoover, 2007), on top of being an object of personal internal conversation with the deceased (Riches & Dawson, 1998). Here lies a great opportunity for the environment and HCPs in geriatric care to invite such stories and serve as an audience for them.

CLINICAL IMPLICATIONS

The narratives of these older parents showed how their grief processes lean towards disenfranchisement (Doka, 2008), making them vulnerable to more protracted and debilitating outcomes known as prolonged or complicated grief. Based on the narratives we can discern three potential routes of care that could help counter the parents' suffering in silence, namely: (1) narrative care, (2) the development of a supportive bereavement care policies for the older person, and (3) the integration of a multigenerational, family-sensitive perspective in bereavement services. Most of these routes of care pertain to all HCPs employed in an oncology, palliative or geriatric care context. Some routes of care are specifically oriented towards nurses and care assistants to assess the needs of an older person.

Narrative care

Many parents told how they felt as if they were another storyline from others in their environment. This left them lonely and feeling as if they could only talk with their deceased child. Remarkable in our study is how a simple open-ended question like, "How is it for you since your son or daughter was diagnosed with cancer?", asked with a sincere interest, was sufficient for parents to open up about their hidden thoughts, feelings and narratives about their deceased child.

Broadly defined, then, "narrative care" entails listening openly and respectfully to some portion or version of the story of a person's life, with the person being listened to experiencing an increased sense of insight, meaning, and empowerment, and thus a measure of emotional–spiritual healing. The therapeutic effects of narrative care have been described manifold elsewhere (Bohlmeijer, Roemer, Cuijpers, & Smit, 2007; Bohlmeijer, Smit, & Cuijpers, 2003; Holloway & Freshwater, 2007; Korte, Bohlmeijer, Cappeliez, Smit, & Westerhof, 2012). Narrative techniques may be beneficial in assisting bereaved parents, as they may communicate the longed-for recognition, as they may gently pull the bereaved from their isolation, and as they may facilitate meaning reconstruction (Bosticco & Thompson, 2005; Neimeyer & Sands, 2011). Telling their story in a safe climate may allow parents to embed their loss experience in their life story and to incorporate it bit by bit in their autobiographical memory, an important mechanism in healthy grieving according to the cognitive behavioral model of grief (Boelen, van den Hout, & van den Bout, 2006). Our study shows how narrative care need to not imply an extra intervention in an often already full care activities schedule. The ease of opening to parents stories by asking one simple question suggests is that good bereavement care need not require elaborate interventions but rather simply gentle, interested, and attentive listeners and compassionate witnesses (Weingarten, 2004).

Nurses and care assistants are often in a unique position to introduce such conversational remembering. Their curiosity about the deceased child and permission given to older parents to reminisce at their own pace may relieve their grieving symptoms. In our study photographs seemed important gateways to build up such a narrative stance. Photographs arising from their child's life can indeed be perceived as illustrations of a story that bit by bit is constructed, and in which previous and present relationships can be presented (Riches & Dawson, 1998). Photographs as 'objects of discourse' (Radley, 1990) allow parents to (1) remember their children's lives (as opposed to their deaths), (2) affirm their parental identity (often neglected or unseen in old age), (3) facilitate conversations by offering concrete records around which conversational remembering can take place, (4) give parents the ability to introduce 'lost' children to people who do not know them (and vice versa give HCPs tangible hooks to gently communicate interest in the one who is lost), and (5) normalize the continuing bond with their child (Riches & Dawson, 1998).

A supportive bereavement care policy for the older person

In our study, the ubiquitous silence and aloneness of these parents' grief, which was exacerbated in care-dependent parents, is striking. Yet, the importance of social support in grief is widely described (Norris & Murrell, 1990; Schwarzer, 1991; van der Houwen et al., 2010; Wilsey & Shear, 2007). Apart from commemorating and giving support in times of pain and loss, the environment can gently invite the mourners to temporarily step out their grief and oscillate to restoration orientation as described in the Dual Process Model (Stroebe & Schut, 1999). Yet, our study shows that this may not be the case for older parents. They often feel very lonely, either because their social network has tremendously shrunk during the years, or because they feel little connectedness with their environment. Therefore, we stress the importance of nurses and care assistants in geriatric wards and nursing homes being sensitive to the distressing effect of bereavement and losses that may take place in later life, and leave windows of opportunity open for communication (Chroinin et al., 2011; Tan, O'Connor, Howard, Workman, & O'Connor, 2013). However a caveat is in order as offering interventions for all grievers at old age is unnecessary, rather a stepped care model is indicated, with low-level psychological support or interventions and close monitoring to distinguish those older persons experiencing complicated grief from those with “normal” grief-related levels of distress (Glass, 2005; Nseir & Larkey, 2013). Indeed, several parents in our study attested to a need for care on a more basic level, namely on the plane of getting recognition by HCPs and their family members for their positional powerlessness. The stories we heard argue for the importance of searching together with the parents and their families for how they could get a place at the deathbed, how they could pay their last respects and how they could be involved in the funeral.

A multigenerational family-sensitive perspective in bereavement care

This study underscored the importance of seeing bereavement as a family affair and attending to the interplay of the parents’ grief with that of family dynamics (Hayslip & Page, 2013; Shapiro, 2001; Stroebe, Schut, & Finkenauer, 2013). The search for family meaning-making is intrinsically intertwined with our human reflex to protect our loved ones. Older parents want to protect their loved ones and demonstrate a certain solicitude for their next-of-kin, but this could separate them both physically and emotionally (Nadeau, 2008). Nevertheless, we want to register tolerance for unique coping styles as family members who share the same loss may have different experiences of grief. Nurses and care assistants can use these markers of difference to create conversations about the individuality of their experience. Furthermore, HCPs can normalize grief reactions, and encourage people to ask for what they need from others, and create opportunities to talk together as a family about individual and collective bereavement experiences (Moules, Simonson, Fleiszer, Prins, & Glasgow, 2007).

These lines of bereavement care can only take shape when nurses and care assistants are trained in loss and grief in order to increase awareness of the support needs of the bereaved person (Wass, 2004). Yet HCPs in general receive little training in bereavement care, and it is unclear whether they are equipped to be optimally helpful (Breen, Fernandez, O'Connor, & Pember, 2012). Our study also underscores that this does not include merely knowledge of normal and prolonged grief in older people, but also attitudes and competencies in active listening, presence, family meetings and caring communication. Therefore, appropriate supervision and support may be necessary for maintaining and enhancing bereavement care skills (Stephen et al., 2009; Wimpenny, Unwin, & Dempster, 2006). Taking this in consideration, a “Sherpa-like guidance” (Shear, Ghesquiere, & Glickman, 2013) by nurses and care assistants is crucial for these parents with enough knowledge to normalize, to intervene in case of prolonged grief and enough art to be humble. Such compassionate care requires an embeddedness in a care culture with attention to the person behind the patient, the resident, and the HCP. In addition, grief and death education should not solely be embedded in professional education but also from a preventive point of view in the wider community (e.g. seminars, workshops, television series to provide people with the basic knowledge and wisdom on death, grief and bereavement). So that bereaved individuals and families could better understand each other’s grief and the people in their social networks could better support them (Aoun, Breen, O'Connor, Rumbold, & Nordstrom, 2012; Breen, 2010).

LIMITATIONS AND FUTURE RESEARCH

This study comprises a first exploration of the experience of older parents outliving their middle-aged child. Some limitations of our findings should be underscored. First, all the interviews were held shortly after an experience of bereavement. The study therefore captures people's thinking at an early point, but does not explore how it may change over time. Second, the sample was relatively small and theoretical saturation was not fully achieved. One has to be cautious in generalizing these findings to all bereaved older parents, given the fact that participants were mostly female, thus the findings may not accurately reflect the views of fathers due to gender differences in adjustment to bereavement (e.g., Stroebe, Stroebe & Schut, 2001). Third, this study sheds light on the perspective of older parents and couldn't take into account the broader systemic (social or cultural) perspective. Nevertheless, we consider this study as a first exploration and a fruitful starting point for continued and future research efforts. Because older adults are the most frequently bereaved population group, examining the nature of late-life grief and non-spousal loss, and its possible complications, is clearly in order. More concretely, our research reveals the following domains for future research. First, it would be informative to get insight into the perceptions, attitudes, practices of HCPs towards bereaved older persons, and older parents in particular. Second, our study points towards the often hidden boundaries, expectations and ties within families that can hamper grief expression. Research on the subtle interaction patterns between family members and between generations in response to the death of a middle-aged child might fuel family oriented practice. Finally, action research could explore how bereavement care can be tailored to the needs of the older persons, their caretakers, their HCPs and the institutions in which they reside.

CONCLUSION

Our study was an initial exploration of an intricate and far-reaching phenomenon and provides a deeper understanding of the meaning of being an older person who has lost a child. Several ways forward for bereavement care were suggested. The main message is to bear in mind this silent grief of older parents both in geriatric and oncology care settings. These parents continually search (often furtively) for ways to stay emotionally connected by keeping belongings and cherishing the memories of the deceased child. A narrative approach offers one way for HCPs to give voice to the parents' suffering and offer a footing to find meaning, solace and connection in the oscillation between felt separation pain and memories. As many participants felt alone and unsupported in their grief experience, the importance of an family or contextual approach to bereavement care is suggested.

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PART II Experiences of middle-aged cancer patients

CHAPTER 5. SPIRALS OF PRECARIOUSNESS. A QUALITATIVE STUDY ON HOW CANCER PATIENTS EXPERIENCE THEIR ILLNESS TRAJECTORY VIS-À-VIS THEIR OLDER PARENTS

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SPIRALS OF PRECARIOUSNESS: A QUALITATIVE STUDY ON HOW CANCER PATIENTS EXPERIENCE THEIR ILLNESS TRAJECTORY VIS-À-VIS THEIR OLDER PARENTS

ABSTRACT

In 2011 in Belgium almost 25.000 new cancer cases were diagnosed in middle-aged adults (between 40 and 60 years old). With increasing life expectancy the chance augments that these patients still have older parents alive. This implies that care for these patients should also take into account the impact cancer may have on (the relationship with) their parents, an often neglected topic. This study wanted to gain insight in how these patients experience cancer vis-à-vis their parents (and environment). Loosely structured interviews were conducted with 11 cancer patients between 40 and 60 years old. Interview transcripts were analysed using the Qualitative Analysis Guide of Leuven (QUAGOL) method with support of NVivo 10 and was driven by multidisciplinary researcher triangulation. The data induced a fine-grained understanding of how middle-aged cancer patients relate to their parents. Depending on the situation, the time frame and the person the patient is talking about, they oscillate between three perspectives (I, They and We). The underlying processes discovered were togetherness-separateness, reticence-verbosity, and self-protection-other-protection. These findings highlight ways in which cancer patients limit as well as disclose information and emotions, and the role of apparently contradictory practices in enabling or hindering open communication. These insights challenge the often narrow interpretation of family-oriented care and openness in relationships.

Keywords: interaction; older parent; patient; qualitative study; cancer; relationship; process

INTRODUCTION

All relationships in a family are interactional and reciprocal; what affects one family member, affects the family as a whole (Black & Lobo 2008; Tomlinson & Astedt-Kurki 2008). At any point in time, disease can lead people to alter the way they relate to each other and to the world around them. When a person is diagnosed with cancer, it marks a critical life event for the entire family that can cause distress and significant challenges for all involved. With average life expectancies in developed nations exceeding 75 years, parents and their grown children have the potential to create close bonds that last for decades (Levitzki 2009). This worldwide ageing of the population gives rise to middle-aged cancer patients having older parents that are still alive.

Prior research in a cancer context has tended to shed light on a limited number of relational contexts and almost exclusively stems from parent-young child dyads (Sulkers *et al.* 2015) and patient-spouse dyads (Hendriksen *et al.* 2015; Senden *et al.* 2015); on the contrary the parent-adult child dyad received less attention (Van Humbeeck *et al.* 2013). Although some research exists on relationships between older parents and adult children, it either centers on older parents and children with mental illness, psychiatric conditions or developmental disability (Copeland & Heilemann 2011; Smith 2012; Johansson *et al.* 2015) or it analyzes the children’s perception when an older parent is diagnosed with cancer (Raveis & Pretter 2005; Kim *et al.* 2008; Fisher 2010; Caughlin *et al.* 2011).

Insight in the relationship between middle-aged cancer patients and their older parents is to date virtually non-existent (Fisher 2010). Cancer-related communication may be consequential to cancer coping (Badr et al. 2008) and patients and parents may be interdependent in their cancer coping. Of particular interest to this study are the possible changes in relationships between older parents and middle-aged children due to a cancer diagnosis. More specifically, this study sought to understand (1) how middle-aged cancer patients deal with their older parents during the illness trajectory and, (2) how the relationship and interaction was shaped during the illness trajectory.

METHODS

SETTING AND SAMPLE

The study was conducted at the Ghent University Hospital. Oncology patients between 40 and 60 years old were approached by a trusted health care provider (HCP). Selected patients were Dutch speaking, were able to provide informed consent and to complete an interview. Only when permission was given, contact information was passed on to the researcher. Initially, we used purposive sampling to include a range of characteristics, including age, sex, and cancer type of the patients to ensure a wide range of experience and views. In early interviews, strategizing and emotion management emerged as salient issues. The health condition of parents appeared to have an important influence upon the views and experiences of participants. Therefore, subsequent participants with a range of experiences were sought, including those (1) who had been confronted with cancer recurrence, (2) with different family structures, and (3) with different kinds of cohesion. Accordingly, we added questions to the interview schedule. Interviews were either conducted at the patient's home or in the hospital, as preferred by the patient. Participants were recruited and interviewed between February 2013 and March 2014.

DATA COLLECTION

The one-off, individual loosely structured interviews began with exploratory questions about their illness trajectory and their parent-child relationship. More in-depth questions were then asked to collect data on their perception of changes in the relationship with the parent(s) during the illness trajectory, the perceived communication with the parent(s), and the perceived support given by the parent(s). The study entailed concurrent data collection and analysis, enabling issues and themes identified in early interviews to iteratively inform the areas explored in later ones and also sampling. The issues and concerns raised in early interviews directed the course of subsequent interviews. Every interview was audio taped, transcribed verbatim and verified for transcription accuracy. Memos on the interview context and reflections on the interpretations of themes were made. This qualitative study was part of a larger project designed to examine the relationship dynamics between oncology patients and their older parents. Only the results of the middle-aged child's experience vis-à-vis their older parents are presented here. The findings concerning the parent's experience are reported elsewhere (Van Humbeeck *et al.* 2015).

DATA ANALYSIS

Analysis was based on the QUAGOL method (Dierckx de Casterle *et al.* 2012) and was inspired by the constant comparative method of the constructivist Grounded Theory Approach (Charmaz 2014). Not only does it enable the exploration of conceptual themes at play, but it also allows an explanation of relationship between these themes. Analysis was led by L.V.H. and L.D., who read and coded all transcripts. Findings were further refined during discussion sessions among all authors who read extracts of transcripts. To enhance the validity of the interpretations, researcher triangulation was used in all the phases of the study. We also used a peer debriefing strategy throughout the study by which the members of the research team discussed the emerging themes and their personal reactions to the material.To improve the quality of data collection, an experienced qualitative researcher (M.G) gave feedback on interview style, the codes and the data analysis. Preliminary findings were presented at meetings of nurses, psychologists, social workers of the Oncology Centre at the Ghent University Hospital always with an invitation to reflect on it from their daily practice.

ETHICAL CONSIDERATIONS

The study protocol was approved by the Ethics Committee of the Ghent University Hospital (B670201112271). All participants were given written and verbal information about the study and gave informed consent to participate. With the permission of the participants all interviews were audio recorded. All data have been anonymised. Names of people and places are pseudonyms (Saunders *et al.* 2015). Audio files were deleted at the end of the study. The COREQ (consolidated criteria for reporting qualitative research) checklist guided the preparation of this manuscript (Tong *et al.* 2007).

FINDINGS

Table 1. Sociodemographic and illness-related characteristics of participants (N = 11)

Sociodemographic characteristics		
Gender, *N* (%)		
Male	1	(9)
Female	10	(91)
Age (years), *N* (%)		
< 40	2	(18)
40 – 50	4	(36)
51 – 60	5	(46)
M; range	48.5	33 - 58
Marital Status, *N* (%)		
Married or living together	8	(73)
Partnership, not living together	1	(9)
Single	2	(18)
Contact with parents, *N* (%)		
Daily	6	(55)
Weekly	3	(27)
Monthly	1	(9)
According to necessity	1	(9)
Number of children		
0	1	(9)
1	2	(18)
2	3	(27)
3	4	(36)
4	1	(9)
Age (years) of children *M*; range	20.2	4 – 33
Parents alive, *N* (%)		
Only mother alive	4	(36)
Only father alive	1	(9)
Both parents alive	6	(55)
Marital status of parents, *N* (%)		
Widowed	4	(36)
Married	7	(64)
Living situation parents, *N* (%)		
Independent	10	(91)
Nursing home	1	(9)

Illness characteristics		
Type of cancer, *N* (%)		
Breast cancer	9	(82)
Bowel cancer	1	(9)
Haematological disease	1	(9)
First diagnosis or recurrence, *N* (%)		
First diagnosis	7	(64)
Recurrence	4	(36)

Interviews were conducted with 11 cancer patients between 33-58 years old. These participants were all women, with the exception of one man, and were in various stages of cancer with different treatment regimens as a result. There was a predominance of breast cancer patients: 9 out of 11 participants had a diagnosis of breast cancer, one had colon cancer and one haematological disease. The interviews took place between February 2013 and March 2014, and lasted on average 74 minutes (ranging from 36 to 152 minutes). The characteristics of the participants are listed in Table 1.

PARENTS AS NOT SELF-EVIDENT IN THE STORIES OF THE CANCER PATIENTS

As the participants described their communication with their environment and their coping with cancer, it became evident that the parents don’t play a leading part in the cancer patient’s stories (especially when being married). The shared aspects of the experience sometimes focused on the parent- child relationship but in other cases included larger family connections. They often refer to utilizing resources within the nuclear family (partner and children), if available, and as a consequence parents in that instance constitute secondary carers. The findings described in this article thus pertain to older parents and the wider environment of a middle-aged cancer patient. In following paragraphs we present a framework for understanding the older adult-middle-aged cancer patient relationship that uses the notion of continuum as its basis.

THE SPIRALS OF PRECARIOUSNESS AS TWO INTERTWINED HELICES

The dynamics between the cancer patient and the older parents can be symbolized as spirals of precariousness consisting of two intertwined helices (Fig. 1). The outer helix is constituted by three patterns of easily observable behaviour and communication: I, We and They (Fig. 2). In what follows, we start by outlining the elements pertaining the outer helix.

Figure 1. The spirals of precariousness consisting of two intertwined helices

The outer helix

Within the stories three perspectives (I, They and We) emerged with regard to how patients relate to their family members, and their older parents in particular. Figure 2. shows the three perspectives complemented with some main considerations (frames with dotted lines) grounding the pendulum between perspectives. The main characteristics of these perspectives are discussed below.

The I-perspective

These interview excerpts were characterized with the particular use of singular first-person pronouns (I, me, mine, my). The *I*-perspective originates from a patient's quest for recognition of his everyday struggle with cancer. Participants experienced disappointment, abandonment and anger when their environment’s reactions were perceived as insensitive, uncaring or unhelpful. Often participants felt silenced by others who either dismissed or trivialized their diagnosis or feeling state. Participants acknowledged that some individuals were unable to cope with the implications of the cancer diagnosis and they avoided contact with these people in an attempt to reduce their own distress. Equally difficult were excessive emotional reactions as these social interactions posed threats to the patient’s normalcy. In response to these social interactions, strategies included carrying on as usual, but also censoring conversations when necessary. They tried to manage conversations strategically in order to control their emotional displays and as an effort to cope with and adapt to the stress of cancer. Participants could become highly self-absorbed by means of turning inward, disengaging from their environment, and shutting down emotionally. This protective withdrawal is prompted by an urge of self-care and self-protection. As these patients didn’t want to cope with other people’s distress in addition to their own they tuned out and adopted an, at first sight, emotionally stoic attitude.

> It′s me who has got the illness and they can′t cope. (…) It′s quite a burden to have to be responsible for other people′s emotions.(…) To be honest I didn’t have the energy or the wherewithal to be able to tell any of my friends; and I didn’t want to have to deal with their feelings or face any repercussions. I could only focus on my husband and children. (Interview 10, 44-years old female breast cancer patient, married).
>
> In retrospect I talked about my behavior with my parents. I asked them to see it from my perspective. Because in the end they just watch it happen. I and only I needed to deal with it on a daily basis. So it’s also my decision when and how I talk about my diagnosis or feelings. (Interview 1, 56-years old female breast cancer patient, married).

These participants showed a peripheral way of empathy as the ability of others to cope was not the focus of their attention. This movement towards a greater sense of “I” or separateness is not necessarily damaging to the relationship’s maintenance provided that the environment is sufficiently forthcoming in tuning in on the cancer patient's communicative preferences and taking their lead.

The They-perspective

We noticed a specific use of third plural personal pronouns (they, them, their) in these excerpts. In the *They*-perspective the overall tendency of the patient is to protect the environment, in particular the older parents. This mind-set is typified by a noticeable lack of emotional expression and a withholding information, leaving both parties suffering in silence. Participants report wanting to disclose information in the best possible way without off-loading emotionally onto others. Even though participants were sure their parents knew how scared they were and how much they worried, they never gave voice to those feelings to avoid hurting or upsetting their parents.

> I just try to stay upbeat about it and that gives them (parents) hope and encouragement, so everybody can stay on the positive side. (…) It's really hard for me to stay upbeat. Occasionally it happened that I was crying during the car ride to my parents, but when I entered their house I carried on during that short period of time. So yeah I'm very cautious and wary in sharing information or displaying emotions to others. I don't tell them everything about all my emotional states. (Interview 11, 49-years old breast cancer patient, married).

> I have difficulty in seeing the sadness in their eyes. I can't stand that. It's really hard because when I'm down I feel that might bring them down to. It comes down to a feeling of guilt. I often feel guilty because I cause so much distress and sorrow. And I can't bear that. I just can't.(…) They've got enough to cope with. The bottom line is that you keep silent, become more guarded just in order to shield the others. To be considerate. (…) You just really try to shield them (parents) from bad things that are happening … there's sometimes no need to tell them. (Interview 1, 56-years old breast cancer patient, married).

Certain aspects like the possibility of recurrence and the fear about death were less likely to be a topic of conversation because of a sense of protectiveness. These participants strove to give a compromised version of the truth and conveyed a positive and hopeful perspective by “acting normal”. The situation of those told was often considered in order to contain emotions and anticipate their reactions. Participants indicate of strategizing about how to deliver the news of their diagnosis to family members and the broader social network.

> I don't think my parents have got any idea how bad it really is, to be quite honest. (…) They know, they know I’ve got cancer, but because I look reasonably healthy, they don't think – you know, you don't have to look all bent double and crippled. (Interview 4, 46-years old breast cancer patient, divorced).

The We-perspective

The use of first-person plural pronouns (we, us, our) was prominent in these fragments. The *We*-perspective is characterized by a high sense of closeness, mutuality, and a willingness of both actors to communicate about difficult topics with a sense of humour and pleasure. Such a way of relating led to feeling recognized as person and as patient. Some participants appraised cancer as a joint stressor which they ‘fought’ together “We are going to get through this”. Throughout the interviews, the participants talked about a “tell it all” style of communication marked by being seemingly open in discussing the experience without any attempts to hold back difficult information. Despite that these participants adamantly state that they could be honest and open about feelings and needs, they recount several instances in which they or other family members avoided topics that seem to contradict the claim of consistent, total and unequivocal openness.

> I feel very much that we are in this together, I feel that this is a crisis…or passage that we need to go through together. We’ve got a kind of sense that whatever, whatever happens that, you know, we'll be able to get through it, manage it, make it as good as we can. And we cry with each other when things seem hopeless. That is certainly

> possible, but not too much. We will not burden each other. And she (mother) will not always share the things that weigh on her mind and me neither. (Interview 9, 33 years old breast cancer patient, married).

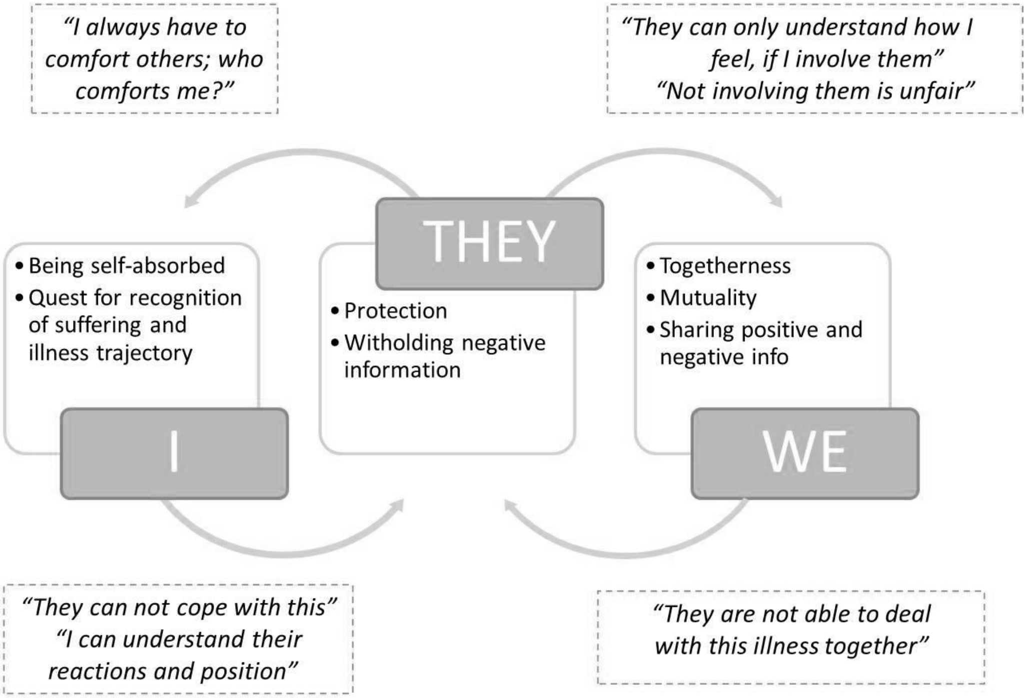

Figure 2. Shift in focus and priorities (fluctuations between a sense of "We", 'I' and "They" where identified throughout the cancer experience)

These three perspectives are not fixed, but malleable and should be seen as part of an iterative and transactional process which may change over time to meet the needs of the immediate situation. With I, We and They as anchors, the narratives showcase the possibility of perspective switches between them. These could be discrete instances or slowly evolving shifts and were discerned by means of a certain stance in participants' experience and the way in which they talked about the experience. We briefly describe considerations underlying these perspective switches (Fig. 2).

- A shift from the I-perspective to the They-perspective was often motivated by a certain clemency for the reactions of others. Previous comments or ways of relating that were first regarded as a lack of respect or recognition of their illness were now considered as evidence of an inability of the other to cope with the cancer diagnosis.

> And yeah she (mother) avoided me. And she never asked directly how I was doing, but always through the grapevine. Through my sister or brother. I blamed her for a lack of interest in my situation. After a while, and after several conversations with a psychologist I could put things in perspective. She presumably couldn't handle the situation. She denied it to herself and, you know, I distanced myself on purpose. (…) Eventually, I made efforts to come closer together as I realized that she didn't want to burden me with questions. (Interview 1, 56-years old breast cancer patient, married).

- A shift from a They-perspective to the We-perspective stems from a consideration that not involving the other is unfair because it deprives the other the opportunity to cope with the cancer diagnosis. Not disclosing felt like lying and being dishonest. This switch can also be indicated by the belief that the other can only have insight in their inner life and offer support accordingly if they don't shut others out of the experience.

> I originally tried to keep my distress private from friends and family to not worry them, but I soon found this unhelpful and subsequently shared with them. (Interview 2, 58 years old breast cancer patient, married).

- A shift from a They-perspective to the I-perspective arose in cancer patients who met with stigmatising responses in people they first tried to protect. This entailed a preference to be uncommunicative and detached.

> And you sort of think, where am I in all this? And so all of a sudden it was enough. I In the end it's me who's got the illness, who needs to survive and clearly my brother can't cope with it. He gave such hurtful comments. Practically denying my cancer diagnosis.

> In the beginning I tried to understand his reaction. I really love him, but he just drifted away. (Interview 5, 50-years old breast cancer patient, married).

- A shift from a We-perspective to a They-perspective was most noticeably seen in case of a poor prognosis and a transition to palliative care. This distancing was related to withholding their worries because of not wanting to further burden their already stressed family members.

> Then they said it was terminal. They can't help me anymore. The oncologist proposed an experimental chemotherapy regimen. But I said no to that. (…) This I can't share with her … this bad news I can't tell this to my mother. We share our joys and sorrows and I live with her since a couple of years. Normally I should take care of her and instead she is taking care of me while being in such poor health. I'm now preparing my funeral with my son, but I can't involve my mother in these arrangements. (Interview 6, 58-years old breast cancer patient, divorced).

A common denominator in all these perspectives is the suffering in silence. This observable pattern can be accounted for by understanding them in terms of a series of interrelated continua (inner helix) that are less manifest and obvious by nature.

The inner helix

Several ambivalences repeatedly emerge in the subtext of the interviews as phenomena that don't exist in isolation of one another. Although these contradictory experiences were not often openly discussed, its undercurrent was noticeably present. These are at the heart of the examined experience and demonstrate a complex interplay of several not so obviously displayed processes. The accompanying figure (Fig. 3) provides a pictorial representation of the complex interplay of these three contradictions as three crossing continua. These processes evoked the participants' aptitude for a certain perspective (I, They, We) and lie hidden "underneath" these different perspectives that drive cancer patients to display certain communication behaviours and ways of relating towards their parents (and wider environment). These processes could affirm or erode their employed behaviour and communicative practice.

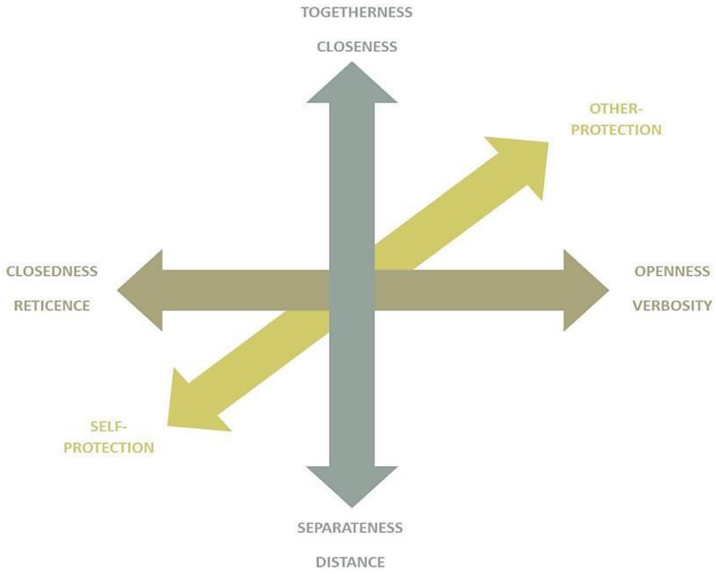

Figure 3. Three crossing continua: a complex interplay of several not so obviously displayed processes.

The first continuum takes place on a relational level and unfolds between togetherness (We-ness) and separateness (I-ness). This continuum is based on the extent of interaction and shared experience. Throughout the interviews, the participants talked about how their sense of cohesion underwent fluctuations. This attests of an undercurrent tension and often unconscious struggle between a need to maintain mutuality and partnership while also preserving a sense of autonomy. Sometimes the individual narratives revealed a relationship characterized by the experience of togetherness, in spite of feelings of loneliness and isolation because of a ‘guarded secret’. This demonstrated that contrasting versions are not necessarily indications of separateness, although it does show how the experience of togetherness might suffer as a result.

The second continuum is set on the informational level and deals with the notions of verbosity and reticence. This continuum involves expression of information and the concomitant desire to conceal. The participants used discernment when communicating to their parents and others, particularly by being selective and taking control over the interaction. They made decisions on what information they wanted to share with whom, how and when to do so and what they chose to withhold. We observed a presence of a more implicit avoidance in the We-perspective and rather a more explicit avoidance in the I- and They-perspective. The findings underpin that it is possible that relationally close, linked parents and cancer patients are simultaneously open and selectively avoidant. The participants attempted to decipher what information about their diagnosis and treatment their parents could and could not handle. The issue of what to reveal and conceal was compounded by an evaluation of emotional state, personality, and coping abilities of the other.

The third continuum takes place on the emotional level and represents a prevalent undercurrent of solicitude with regard to oneself (self-protection) at one end and solicitude with regard to others (other-protection) at the other end. This solicitude has a egocentric and altruistic cornerstone; avoidant strategies characteristic for the I-and They perspective were employed in order to preserve the self or the other. This focus on self-protection often stems from the anticipation that talking with others could be labour-intensive when conversations evoked fear and distress in other people and the self. Participants voiced the importance of being able to focus on self, but that it often was a conflicting factor in taking care of others. Participants were also driven by other-protection motivations when containing the impact of the illness for others trying not to burden family members with their own distress. Finally, with other protection, cancer patients were concerned that information would affect the dynamic of the family unit or would somehow hurt and burden their family members.

DISCUSSION

The current findings give insight in how interaction may unfold between a cancer patient and his older parents, what the seed-bed is for this communicative behaviour, and how an intricate balancing act between distance and closeness; openness and closedness; self-protection and other-protection may influence these communicative practices.

A significant finding is that parents were not self-evident in the stories of adult cancer patients, especially when they were married. There are several ways to explain this. First, in social convoy theory circles are used to separate people in terms of the closeness of their relationship with an individual. This theory states that there is an ebb and flow in the emotional importance of our relationships. So the composition and closeness of these circles changes as we journey through life (Kahn & Antonucci, 1980). Second, when a middle-aged child is married and has children, a culturally rooted tendency exists to emphasize the independence and integrity of this nuclear family. In the hierarchy of obligations (Ungerson, 1987), the partner is the primary carer and parents in that instance constitute the secondary carers. Third, Ketokivi (2012) showed how living with a partner generates “exclusive family intimacies” pushing other intimates such as parents further away. Those living without a partner often cite parents and/or siblings as intimates. Recent research (Rözer et al. 2016) shows that older parents play less of a prominent role as a sounding board compared to a spouse, children or siblings. It also appears that often a dichotomy is created between the family of procreation and the family of orientation. The members of the nuclear family and the family of orientation are not always assigned an equivalent position when being married.

This study showed that cancer patients find talking about their diagnosis to be challenging and complex (Turner *et al.* 2005; Selman *et al.* 2015). Other studies pointed out that cancer patients engaged in intricate communication work (Donovan-Kicken *et al.* 2012), thus supporting our observation of their struggle with how to talk- or not to talk- about the cancer, treatment and related concerns. With respect to participants’ careful considerations on sharing their cancer experience several studies in other disease contexts confirm our observations. For instance literature on HIV patients (Edwards *et al.* 2014) and couples dealing with a cardiac event (Goldsmith & Miller 2014) report on patients employing great selectivity regarding topics and depth of their talk.

Our study reveals that the cancer patient's avoidance of aspects and ramifications of the illness often created family silence (cf. I and They-perspective). Openness and avoidance as salient aspects of the cancer experience were previously described in couples' cancer-related communication (Miller 2014) and our findings confirm that this also applies to the older parent-child dyad. In several studies, patients have reported feelings of sorrow when witnessing the pain of loved ones, guilt for causing this upset, and worry that disclosure may result in emotional anguish for family members (Manne *et al.* 2007; Hilton *et al.* 2009; Yoo *et al.* 2010). To this extent, our participants' accounts are consistent with the broader literature, suggesting that different thought processes (e.g. avoidance of psychological distress, desire for mutual protection against harmful situations, and belief in positive thinking) may contribute to a phenomenon of silence (Zhang & Siminoff 2003; Edvardsson & Ahlström 2008). However, a previous study showed that the well-intended hiding of emotional reactions for their parents may in fact create the opposite of what these cancer patients are trying to achieve (Van Humbeeck et al., 2015).

The dynamics of the I-perspective resemble that of mothers with cancer being determined to "protect the rhythms of their lives and family routines" (Stiffler *et al.* 2008). The communicative behaviour of the I-perspective dovetails with findings that suppression of emotions can be adaptive, fulfilling important social functions, such as preventing escalation of negative emotions, and thereby benefiting both social partners and their relationship (Butler *et al.* 2003). Specifically, there is evidence that distancing occurs when an individual's desire to be valued by a relational partner is obstructed (McLaren & Solomon 2008). In our study, participants talked at length of negative or lacking support including avoidance, or minimization of the illness and its consequences. The experienced disconnect resulted in patients feeling rejected or abandoned (Hinnen *et al.* 2007). Our observation that the types of reactions people receive may impact on further disclosures is consistent with earlier research (Figueiredo *et al.* 2004). The identified They-perspective shares commonalities with other concepts such as empathic attunement (Hershberg 2006), and protective buffering (Kuijer *et al.* 2000; Manne *et al.* 2007; Langer *et al.* 2009). The current study found that the cancer patients' self-silencing, as a feature of the I- and They perspective, could stem from other- or self-protection and was either self-inflicted or other-inflicted. Recent research (Manne *et al.* 2014; Brandes *et al.* 2016) has shown that cancer patients' emotional attitudes (internal barrier) and perceived social norm (external barrier) were the most important determinants of their intention to express concerns. The pattern of being open while being selectively avoidant as a feature of the We-perspective was previously described in the context of lung cancer (Caughlin *et al.* 2011).

A number of studies make one or another end of the three continua (inner helix) salient without revealing the both-and relationship between them. The continuum of togetherness vs. separateness is in accordance with the existence of me-ness and we-ness as two aspects of identity when a family member has a life-threatening illness (Carlander *et al.* 2011). Our results converge with a study that focused on we-ness (Fergus 2011) as an interweaving of family identity and personal identity.

IMPLICATIONS FOR PRACTICE

The present findings have implications for supportive and psychological care of cancer patients. First, our findings underline the importance of looking beyond overt behaviour and to be aware of the caring and solicitude that can ground these behaviours. Acknowledging the underlying mechanism of solicitude (other-protection and self-protection) can make a big difference in how family and patient can interact with each other and with HCPs. Second, many HCPs advise families managing cancer to frequently engage in open, direct communication, expressing needs and emotions. Although there is general consensus that non-disclosure is detrimental (Traa *et al.* 2015), negative consequences of disclosure have been reported by patients with cancer (Gray *et al.* 2000; Yoo *et al.* 2010). Openness in interpersonal relationships may pertain different things for different persons (Goldsmith, 2014). There is the danger that openness and togetherness are regarded as a panacea or the 'ideal' stance to hold and to be facilitated in practice. This study underscores the importance of not imposing an expectation of total openness and togetherness on cancer patients. HCPs must also be educated to recognize that topic avoidance can be beneficial if satisfying both individual's information needs (Parks 2007). Parks (2007) explains that strategic nondisclosure can serve to provide relief in problematic interactions; thus, despite the HCPs priority of openness, topic avoidance may be a competent communicative choice. On that account, openness-enhancing interventions the family level shouldn't be put forward as ideal care practice. Thus it may be more relevant to facilitate family members' and patients' communication efficacy, rather than stating that all communication is good communication, and more communication equates with better communication. To that end, it may be important for patients and family members to negotiate ways to let each other know options for how to communicate (Magsamen-Conrad *et al.* 2015). Third, it is important to inform the patient's social network about the emotional barriers related to telling others about cancer-related concerns (Yoo *et al.* 2010). HCPs are well placed to support the on-going disclosure process of cancer patients by opening up opportunities for discussion at clinical appointments (Munro *et al.* 2015).

LIMITATIONS

In light of practical contributions of this study, we do recognize several limitations and directions for future research. Whilst restricted to one hospital, this study is considered to highlight a number of important issues linked to the views of cancer patients vis-à-vis their older parents and wider environment. An important limitation is that we attempt to evaluate what is a dynamic process between individuals from only the perspective of one individual or perceptions of one's own behaviour. Further, our findings mainly pertain to Dutch speaking, articulate, self-reflective breast cancer patients. The predominantly Caucasian sample limits transferability to other ethnic groups. Further research would benefit from broadening the descriptive scope to include different cultures, and different types of cancer or illness. Next, data saturation is unlikely to have been reached because of our small sample size. Research with a larger and more diverse sample is needed to extend knowledge of the perspectives: their development over time, the association of the middle-aged child, parent and social conditions with them and prediagnosis relationship quality. Another understudied feature is how patient and parent communication, both open and avoidant, affects both actors' well-being and relational outcomes.

CONCLUSION

This qualitative study adds to the literature by providing insight into how middle-aged cancer patients perceive the relationship with their parents. With the findings presented in this article, we extend the understanding of how a middle-aged child-older parent relationship develops in the context of a cancer diagnosis. Our findings extend the knowledge base of communication, tensions and the adult child-older parent relationship and offer promising avenues for future research in these areas. The findings of this study can help HCPs understand why cancer patients do not always openly communicate with their parents (and wider environment)

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PART III Experiences of nursing staff

CHAPTER 6. GRIEF AND LOSS IN OLDER PEOPLE RESIDING IN NURSING HOMES: (UN)DETECTED BY NURSES AND CARE-ASSISTANTS?

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Based on an article published in Journal of Advanced Nursing

doi: 10.1111/jan.13063

GRIEF AND LOSS IN OLDER PEOPLE RESIDING IN NURSING HOMES: (UN)DETECTED BY NURSES AND CARE-ASSISTANTS ?

ABSTRACT

Aim

To explore how nurses and care-assistants (nursing staff) working in six Flemish nursing homes experience and describe their involvement in grief care.

Background

Although grief in older people is widely described in literature, less is known about how nursing staff in nursing homes offer and perceive grief care.

Design

A qualitative research design with elements of constructivist grounded theory was used.

Methods

Loosely structured face-to-face interviews were done with fourteen nurses and care-assistants. Data were collected from October 2013 - March 2014. Interview transcripts were analysed using the Qualitative Analysis Guide of Leuven (QUAGOL) method with support of NVivo 10.

Findings

Grief care in nursing homes is characterized by a complex tension between two care dimensions: (1) being involved while keeping an appropriate distance; and (2) being while doing. Nursing staff described key enablers and influencing factors for grief care at the level of both the individual and the organizational context.

Conclusion

Findings suggest an established personal sensitivity for grief care considered from the nursing staff points of view. Nevertheless, a common denominator was the necessity to further develop a supportive and multidisciplinary grief care policy ingrained in the existing care culture. Suggested components of this grief care policy are: (a) centring attention on non-death-related loss and the cumulative nature of loss in residents; (b) building capacity by means of reflective practices; and (c) the importance of self-care strategies for nursing staff. Further, the findings from this study point towards a need for education and training.

Keywords: grief, older people, loss, nursing, nursing home, nurses, care-assistants

SUMMARY STATEMENT

WHY IS THIS RESEARCH NEEDED?

- Loss and bereavement are common among older people and an unfortunate minority may experience mental health disorders.
- Nursing staff (e.g. nurses and care-assistants) face challenges in meeting the loss-related needs of older people. Failing to fully understand the experience of loss and grief among older people risks disenfranchisement of these experiences.
- Little is known about the response of nursing staff and the current grief care practice in nursing homes.

WHAT ARE THE KEY FINDINGS?

- Grief care actions of nursing staff towards residents ensue from a careful balance artistry on two care dimensions: (1) being while doing and (2) being involved while keeping an appropriate distance.
- The balance nursing staff can attain between these two dimensions depends on a substructure made up by individual and organizational related factors.

HOW SHOULD THE FINDINGS BE USED TO INFLUENCE POLICY/PRACTICE/RESEARCH/EDUCATION?

- Supervisors should support nursing staff in developing opportunities and skills for emotionally sensitive resident care and grief care provision.
- Grief in nursing home residents should be approached creatively and responsively. Education should focus on helping nursing staff to be courageous enough to connect emotionally with residents. This requires change on a relational level as well as at the level of the caring environment.
- Future research should focus on the mutual grief of residents and nursing staff, the type of grief care actions that nursing staff undertake and what residents consider desirable.

INTRODUCTION

Grief and the pain of loss are universal human experiences that every person regardless of age is confronted with (Hooyman & Kramer 2006). Old age is typically characterized as a time of age-associated changes, major transitions and its attendant losses (Hansson & Stroebe 2007a). In Europe, the number of dependent older persons (65+) is expected to more than double, reaching 44.4 million by 2060 (Communities 2009). In Belgium, the projected number of older people (65+) in nursing homes will increase from 125.500 in 2010 to 166.000 in 2025, which is an increase by 32% (Van Den Bosch *et al.* 2011). The most important functions of Belgian nursing homes are long-term care and terminal care but other services such as respite care for residents' families and day care are also provided (Meijer *et al.* 2000). In Flemish nursing homes, the average age at admission is 82 years and the mean length of stay is three years (Vandenboer *et al.* 2006). Thirty-eight percent of nursing home staff are nurses and the majority (62%) are care-assistants (Zorginspectie 2012). Given the ageing population, particular concern for nursing staff (nurses and care-assistants) in nursing homes must be meeting the loss-related needs of older people which are regularly overlooked or quickly dismissed (Moss *et al.* 2001).

Grief in old age and its impact has been under study, but what is less researched are the care actions that nursing staff undertake in assisting older individuals and their families to navigate loss in general. Therefore, the goal of this study was to gain insight into the experiences and perceptions of nursing staff working in nursing homes concerning care actions focused on loss.

BACKGROUND

Types of losses and grief situations in old age

Loss and grief situations are pervasive universal phenomena affecting persons of all ages in a wide range of practice settings. It results in a deprivation of some kind when people no longer have someone or something that they used to have (Hooyman & Kramer 2006). Multiple losses are highly prevalent in old age and pose many emotional, physical and practical challenges (Clarke *et al.* 2008, Nicholson *et al.* 2012, Ebrahimi *et al.* 2015). Most individuals experience grief that gradually decreases in intensity over time. About 7% of older adults, however, will develop the mental health condition of complicated grief (Shear *et al.* 2013). In old age, multiple losses contribute significantly to the onset of physical and mental health problems (Roberts *et al.* 2011). Factors most strongly associated with major depression in old age being grief over loss of opportunities and abilities to take part in valued activities (Snowdon & Fleming 2008, Edelstein *et al.* 2010, Fried *et al.* 2015), lack of privacy, social isolation and loss of independence and autonomy (Cassie & Cassie 2012). Further, loss and grief seem to be risk factors for suicidal behaviour in later life (Agerbo 2005, Erlangsen *et al.* 2011).

Nursing home admission in particular is a major life adjustment (Brandburg *et al.* 2013, Ball *et al.* 2014) marked by loss of health, independence, privacy, activities, relationships or possessions (Pilkington 2005, Coughlan & Ward 2007, Djivre *et al.* 2012). Many of these non-death-related losses experienced by older persons are relatively invisible to the outside world, with no available means of acknowledging the loss and the associated grief (Roos 2002). Although grief is often envisioned as private and personal, the psycho-social consequences of loss are inextricably linked as it can entail losing family and friends thus affecting social resources (Ryan & Coughlan 2011). In late life, the importance of having a supportive environment increases (Hansson & Stroebe 2007b) and peripheral ties, such as nursing staff, are important for older persons' quality of life (Lagacé *et al.* 2012), self-image (Westin & Danielson 2007), resilience, coping and well-being (Fingerman 2009).

How is grief care addressed in current practice and literature?

Studies indicate that nursing staff in nursing homes are highly skilled in delivering physical care. Nursing staff in nursing homes are increasingly in contact with older people who experience loss, death and grief, but just few studies have attempted to examine specifically the aspects of nursing care that focus on emotional support (Bolton 2000, Freshwater & Stickley 2004). Grief care mostly stems from the interest and initiative of individual nursing staff, with few procedures in place to assess grief care needs and few nursing staff skilled to provide grief care (Montgomery & Campbell 2012). This minimal emphasis on loss experiences in old age in current practice can be extended to the scarcity of literature on grief care in nursing homes (Stephen *et al.* 2009). Current understandings on grief care derive mostly from primary care (Birtwistle *et al.* 2002, Nagraj & Barclay 2011), hospital care (Warren 2002), or hospices (Foliart *et al.* 2001, Field *et al.* 2004) and almost exclusively focus on death-related losses. Nursing staffs' pivotal role in interactions with residents, family and other health care professionals underlines their excellent position to provide grief care. Aforementioned gaps in both practice and literature emphasize the need for research on grief care in nursing home settings. The aim of this study was to explore and describe grief care in nursing homes from the perspective of nurses and care-assistants. The overarching research question was, 'What are nursing staff's experiences with and understandings about grief care in Flemish nursing homes?'.

THE STUDY

AIM

This study aimed to explore and describe: (1) how nursing staff perceive grief and loss in old age; (2) how nursing staff experience being confronted with loss in their facility; and (3) which barriers and facilitators to grief care nursing staff perceive. It was not the objective of the study to identify the perceptions of nursing staff regarding normal or complicated grief, but simply to understand nursing staff's experiences with residents' diverse grief reactions regardless of the type of loss.

DESIGN

Given the lack of research on grief care in nursing homes, a qualitative descriptive study design (Holloway & Wheeler 2010) was adopted. Loosely structured interviews were conducted with nursing staff working in six Flemish nursing homes.

PARTICIPANTS

The researchers sought the assistance of the head nurses of the wards of the six participating nursing homes. These head nurses identified nurses and care-assistants willing to participate. In recognition of the close working relationship and interdependence between nurses and care assistants in the care of residents, it was deemed appropriate to include them both in the study. A purposive sample was derived to achieve maximum variation in qualification, gender, age and years of experience. The researchers contacted potential participants to confirm voluntary participation, give further information on the study and to set a date for the interview. Such a balance between heterogeneity and homogeneity enables rich data with thick descriptions (Morse 2015). To become a nurse in Belgium, one can chose from two types of educational programs. Nurses with professional bachelor degrees graduated (i.e. graduate nurses) from a nursing program of three year duration at a college for higher education. Nurses with a certificate degree (i.e. certificate nurses) received nurse training in their fourth year of secondary school. Their training is largely based on practice and apprenticeship. Care-assistants assist nurses by performing general services (e.g. making beds, feeding, bathing and grooming residents etc.).

DATA COLLECTION

Data were collected from October 2013 to March 2014, using individual one-time loosely structured interviews. Interviews had a mean duration of 51 minutes (ranging from 28 to 80 minutes) and were held at the place of preference of the participants. Interviews were conducted by two student-investigators (JM and SM). The interview guide consisted of reflective and open-ended questions and was developed based on literature and input from clinical and academic experts in nursing, care of older people and grief (Table 1). We started the interview by asking the participants to describe the concept ‘grief’ and ‘grief care’ in their own words. Next, we asked to provide specific examples of situations where they provided grief care. The interview guide was refined throughout the research project.

Table 1. Example questions from the interview guide

What do you think of when you hear about grief and loss at old age?
What does grief care mean to you ? What is your understanding of this term ?
How do you deal with loss experiences of residents?
What barriers do you experience when delivering grief care?
To what extent are loss experiences of residents discussed within your nursing home?
How do you experience the confrontation with a grieving or emotionally distressed resident?

ETHICAL CONSIDERATIONS

All participants gave written informed consent. The study protocol was approved by the Ethics Committee of the Ghent University Hospital (B670201318263 and B670201318265).

DATA ANALYSIS

Each audio recorded interview was transcribed verbatim. Analysis was based on the QUAGOL method (Dierckx de Casterle *et al.* 2012) and was inspired by the constant comparative method of the constructivist Grounded Theory Approach (Charmaz 2014). The process of analysis consisted of two parts: (1) a thorough preparation of the coding process on paper; and (2) the actual coding process in NVivo 10 (QSR International). This analysis method was chosen as it is an interdisciplinary team approach that combines within-case and across-case analysis resulting in greater complexity and depth in understanding the research phenomenon (Ayres *et al.* 2003). After analysing each interview separately, the codes and emergent themes were discussed in the research team consisting of four members with expertise in the field of the care of older people, qualitative research and grief. Themes were then further analyzed and compared again across all interviews. The resulting nonhierarchical list of concepts was introduced as preliminary concepts into NVivo 10 (QSR International). Analyses proceeded in parallel to data collection and continued until data saturation was reached such that no new themes were arising from the data (Sandelowski 1995). We present the findings as if nursing staff are a homogenous group because both nurses and care-assistants provide personal care. The researchers did not compare the practices of nurses with those of care-assistants, so the interviews with staff were not stratified by qualification of the interviewee.

RIGOUR

Trustworthiness of data collection was enhanced by peer review of the interview style. Field notes were recorded and appended to the transcript. Researcher triangulation was used in all phases of the study. The research and interpretation process was written down by means of an audit trail (Charmaz 2014). Exemplifying quotes from the interviews are used in this paper to allow the reader to make judgements about interpretation. Pseudonyms are used to protect the identity of the participants.

FINDINGS

The purposive sample consisted of nine nurses and five care-assistants (13 women), with an average age of 40.6 years (range: 21-60 years) and an average of 18.9 years of work experience (range: 3-34 years) (see Table 2).

Table 2. Socio-demographic characteristics of participants.

Participant	Age (yrs.)	Work experience (yrs.)	Diploma
1. **Denise**	60	34	Graduate nurse
2. **Jenny**	48	27	Graduate nurse
3. **Anita**	44	22	Certificate nurse
4. **Kelly**	23	5	Care-assistant
5. **Michelle**	43	21	Certificate nurse
6. **Nicole**	44	22	Graduate nurse
7. **Fiona**	21	3	Care-assistant
8. **Susan**	47	25	Graduate nurse
9. **Charlotte**	47	26	Graduate nurse
10. **David**	26	5	Care-assistant
11. **Sophie**	52	27	Graduate nurse + pastoral assistant
12. **Elizabeth**	25	6	Care-assistant
13. **Lindsay**	51	30	Graduate nurse
14. **Julia**	38	12	Care-assistant

GRIEF CARE: AN AMBIGUOUS CONCEPT

The participating nurses and care-assistants had difficulty in defining grief care. The interviews revealed a variety of interpretations. Some nursing staff considered grief care as an essential part of daily emotional and relational care performed by nursing staff that could not be planned for. Others had a very restricted interpretation of grief care, more in line of specialist care performed by psychologists and chaplains by means of scheduled follow-up and visits. During the interviews, we noted that the participating nursing staff became increasingly aware of the meaning of grief and grief care:

> The questions stimulate you to think; normally you don’t realize it. When the question is asked, you start thinking and then you see the concept a lot larger. I thought that I could not tell you a lot, but suddenly I realized I could give many examples. (Kelly, care-assistant)

THE SUBSTRUCTURE OF GRIEF CARE ACTIONS: A COMBINATION OF ENABLERS AND INFLUENCING FACTORS

Participants gave a rich account of their perceptions on and experiences with grief care in nursing homes. Participants described factors that could either aid or hinder grief care in a nursing home. These factors relate to: (1) the organisational culture; and (2) individual characteristics of nursing staff. Figure 1. depicts a schematic representation of the dynamic interplay between individual and organizational factors and two care dimensions at the heart of grief care in nursing homes. This schematic representation should be seen as a dynamic, context-specific process rather than a rigid framework.

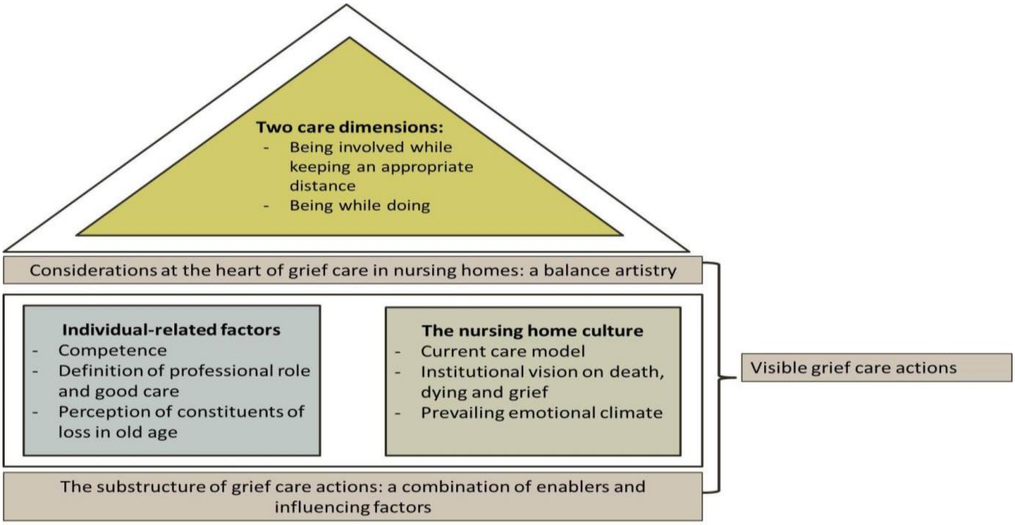

Figure 1. Grief care: a dynamic interplay between individual, organizational factors and two care dimensions

The nursing home culture

Themes relating to the organisational culture were: (1) the current care model; (2) the institutional vision on death, dying and grief; and (3) the prevailing emotional climate.

First, nursing staff highlighted that the more a nursing home adhered to a lean managerial care model, as evidenced by a routinized and task-oriented work environment, the more grief care was impeded. Relationship building and compassionate care were seen as vital prerequisites of touching on grief issues. Indeed, some participants worked in a care model that stressed non-involvement and physical labour. In such a climate nursing staff found it hard to get to know residents as people with unique life stories. As such many nursing staff experienced feelings of helplessness, personal inadequacy and discomfort with the 'rules' imposed on them:

> When you are confronted with a tearful resident having a distressed moment then you should weigh up the pros and cons of staying ten or fifteen minutes longer in that

> room. Because that is at the expense of another resident’s time with you. (…) I will brief my co-workers that I was delayed due to that resident having a hard time. You should always justify yourself when deviating from the set time schedule. You have to justify how you manage your time toward the management. They only focus on the physical aspects of care, but care should include more than that. (Anita, certificate nurse)

Second, the vision in the nursing home regarding how to deal with death, loss and grief in general was regarded as influencing grief care. In some nursing homes it was the norm to silently cover up death and loss, out of consideration for the vulnerability of the residents, or out of awkwardness. Participants mentioned a form of gatekeeping to shield residents from emotionally loaded situations:

> And that resident was sitting upright, but with a far-away look. When I touched him … And I thought oh no it’s not going to be true … I didn’t say anything to the rest because other residents were present in that living room. And yeah everyone … Everyone is watching so … I just called one of my colleagues and asked for help. And we quietly wheel chaired that deceased resident out of the living room. (Kelly, care-assistant)

> When a resident has passed away then other residents are sometimes waiting in the corridor. We encourage them to express their condolences to the family and pay their last respects. We give them the opportunity to say goodbyes. Because often the residents have long-lasting relationships that should not be underestimated. (…) We also have a memorial corner. (Fiona, care-assistant)

Lastly, participants described the prevailing emotional climate as an important factor. In each team emotional display rules were interwoven into daily routines and care activities. For example, some participants described the norm of keeping a stiff upper lip, where the overt display of emotions was considered as a personal weakness. An unappreciative attitude towards expressed emotion and the corresponding lack of opportunity to talk openly hampered their personal grief:

> I didn't speak up because it is difficult to say such things in the group. And sometimes you really need time to vent and talk things over with a colleague. (…) But we don't really look out for each other. (Elizabeth, care-assistant)

Individual-related factors

Participants discerned three individual-related facets that may interact with the institutional culture to ground grief care, namely: (1) competence; (2) personal definition of professional role and orientation of care; and (3) perceptions of constituents of loss in old age.

First, participants identified two distinct aspects of competence related to grief care: instrumental competence and emotional sensitivity. Instrumental competence referred to the necessity of possessing accurate knowledge and skills essential for grief care. Emotional sensitivity concerns an aptitude (e.g. a natural talent) that is externalised in personal traits and which seems harder to acquire by knowledge acquisition. Participants talked about it as being a less tangible behaviour and in terms of 'having it or not'. For example, some nursing staff seemed more confident in the presence of intense emotions and were able to tolerate the openness of grief encounters, where there is sometimes literally nothing to be done except being present with someone in sorrow:

> Sometimes a resident just needs to talk. They just want someone to listen to them. So you need to delay all the clinical stuff. For me the emotional stuff is just as important. And that is not the case for all the team members. They don't give it a moment's of thought. Or they just flee the room because they don't feel comfortable and safe in the interaction. (Michelle, certificate nurse)

Second, the way nursing staff could integrate grief care was influenced by how they perceived their professional role and ascribed importance to several aspects of care. When nursing staff saw it as a privilege to work with older persons, they valued personal encounters more and were more inclined to give primacy to 'stolen encounters' (Nicole, graduate nurse) rather than technical acts. Several nursing staff considered the intrinsic properties of their work as an amenity for themselves: for them grief care entailed 'doing more than what you're told to do' (Susan, graduate nurse) or 'being able to stay after work' (Fiona, care-assistant). Others described how their priorities were shaped by the team's expectation of not overburdening colleagues with unfinished work leaving out emotional support of residents. Participants indicated that this work behaviour often impeded grief care:

> I have always put my heart and soul into resident's care. Helping others and working closely with older people is important for me. But the younger team members … I shouldn't generalize my observations to everyone. They're not all like that. (…) I see it as a privilege of taking care of these residents. But there are people that take care of the residents and don't genuinely care about them. For them it doesn't entail heart-to-heart talk about feelings or losses. They come into a resident's room and automatically turn on the radio hindering the resident to communicate with them. That bothers me a lot. (Susan, graduate nurse)

The last individual-related facet relates to whether nursing staff confined grief issues to death-related loss or also considered non-death related losses as relevant. Most of the participants recounted residents' experiences of loss as a result of death and just few identified the multifaceted nature of residents' losses. According to the participants a narrow focus on grief risks perpetuating the notion that death-related loss has greater impact than non-death related losses. Indirectly, this train of thought may influence the level of receptivity for loss and the primary focus of grief care actions by nursing staff:

> Recently we had a new resident who was constantly crying. Her kids had bought her brand new furniture and clothes but in fact that wasn't what she wanted. She wanted to furnish her room with her old belongings and mementos like vases, photos and statues. (…) For her children all this furniture was considered as worn and outdated

> and they had called a wholesale buyer to clear out her house. But she had a really difficult time in leaving them behind. We watched her pine away from grief. (Nicole, graduate nurse)

TWO CARE DIMENSIONS AT THE HEART OF GRIEF CARE IN NURSING HOMES: A BALANCE ARTISTRY

The combination of foregoing elements form the backdrop for the trade-offs that nursing staff need to make between two care dimensions: (1) being involved while keeping an appropriate distance; and (2) being while doing. Rather than dichotomies, these two care dimensions should be viewed as mutually enriching positions in a tense but constitutive relationship of each other.

Being involved while keeping an appropriate distance

Participants found themselves balancing in the establishment of appropriate levels of involvement in emotional encounters. Participants used a variety of metaphors like ‘switching on and off … drawing the line … keeping a bit of a barrier up, standing back’ to capture their ways to safeguard their own emotional health. The importance of self-care and self-protection was pointed out as an important reason for not being excessively compassionate in their daily work. Some could vent their emotions by discussing with fellow co-workers or family members while others bore and endured them by themselves:

> I take with me a lot of people’s journey and feelings and that stays kind of inbred in me. But it is not an easy thing to do day in day out. And sometimes this means giving oneself away and for me that’s not a bad thing. (…) At the end of the day, if you don’t feel emotional you don’t care and then you’re not a carer. But that’s my perspective. (Fiona, care-assistant)

The majority, while espousing engagement as a desirable end, also acknowledge that too much emotional engagement may render nursing staff incapable of doing the job. Staff did not always make themselves accessible to bond with residents even when there was an opportunity to do so or stated that is was not up to them to get emotionally involved:

> And I feel that I have, during some years gotten used to it, I don't relate to myself in different situations. (…) It doesn't upset me anymore. You have to learn to keep a distance; otherwise you don't have the strength to keep on working. (…) It's only a job and when I take of my uniform after my shift all these problems and emotions just vanish. I never ruminate and think of residents while I'm at home. (Jenny, graduate nurse)

Some participants described how their feelings evolved over the years, learning to distance themselves as sort of a natural way:

> Working in a nursing home can be a great emotional strain, in the beginning I felt quite empty when I came home, completely drained. Mentally and physically. (…) So now I don't probe further when a resident seems emotionally distressed. I try to cheer up the resident, because I know that I can't resolve their emotional issues. (…) That's beyond your control. (…) Such things will leave a mark on you if you don't emotionally disconnect yourself. (Charlotte, graduate nurse)

Participants indicated deflecting resident's questions with humor or intentionally avoiding these tearful residents. This could give rise to a particular proclivity for ignoring residents' emotional cues as this was less stressful than handling them:

> I'm not good at that. I really feel powerless because I do not have clear-cut answers. (…) I already know that is my weakness. (…) I really try to skirt around these issues and then I tend to leave the resident's room as fast as possible. (Kelly, care-assistant)

Being while doing

A second balancing act was noticed between meeting the emotional needs of residents (being with) as well as the physical needs (doing for). Nursing staff often felt as if these needs were at odds with each other and recognized not being able to provide basic grief care. They were aware of residents' loss experiences in theory, yet the day-to-day reality of the nursing home hindered opportunities to demonstrate this awareness in any empathetic form. Participants indicated that although grief care is not limited in time or space they were consciously creating closure in time and space during care. In contrast to the abovementioned practice of withdrawal, several examples of being while doing were also evident in the interviews. Key dimensions of these acts included noticing emotional clues, being courageous and connecting emotionally:

> I washed a resident whose brother recently passed away. While I washed her, I let her reminisce about her brother. It's not much effort to do this and afterwards the resident stated that she has never been taken care of like this. Just by giving it a moments of thought and hearing her story. It was no trouble for me to let her vent while continuing taking care of her. (…) But you need to have the courage to broach the subject, to notice subtle things and pursue it in greater depth. (Sophie, graduate nurse and pastoral assistant)

DISCUSSION

This is the first study that provides insight into the challenges encountered by nursing staff when providing grief care in a nursing home context. Apart from organizational aspects and the evident physical component, participants recognised grief in residents and saw grief care as a substantial component of nursing care. We noticed a discrepancy between the expressed views of nursing staff that more attention should be paid to the emotional needs of residents and the focus of nursing staff on physical problems and the technical side of their work in reality. This discrepancy has particular meaning for nurses as they perceive that emotional support pertains to the nursing domain. Participants attested of struggling to maintain a dynamic balance between detachment and concern, task and talk (thoroughly enmeshed together). Further, this study highlights a twofold challenge at both individual and organizational level to enable adequate delivery of grief care.

Our findings demonstrate a challenge of providing grief care in terms of the need to justify time when talking to a resident. When collective normative care routines (e.g. not talking to residents to complete tasks by the end of the shift) predominate, a nursing home culture based on a ‘tyranny of busyness’ (Manias & Street 2000, p. 378) rather than on the resident’s needs arises (Smith 2012, Jones *et al.* 2015, Zuniga *et al.* 2015). This in turn creates ‘a culture of self-regulatory practices and performances prohibitive against signs of sadness and longing’ (Gibson 2014, p. 228). In line with previous research, many participants indicated opportunistically creating time for communication with residents during procedural care (Chan *et al.* 2013). Our findings lend weight to the idea that physical care (e.g. bathing or dressing a resident) can be performed in a way that simultaneously expresses emotional care (‘being while doing’). As such the action/procedural focus (‘doing’) acts as an undercurrent within which the relational focus (‘being’) can take place (Denier *et al.* 2009). The issue therefore becomes not whether ‘being’ overrules ‘doing’, but how these two care dimensions may operate on equal footing to enhance grief care (Zisberg *et al.* 2007). Hence, grief care is enhanced not only by more time in care, but also by continuously adjusting to the residents’ needs and hopes in caring interactions by means of the framework person-centred care. (McCormack & McCance, 2006; McCormack & McCance, 2016). Being person-centred relies on knowing the older person and seeing beyond immediate needs. This framework appears to offer a promising way of regenerating grief care practice in nursing homes.

The verbal silence and reticence about death, loss and grief mentioned by our participants was echoed in established findings (Costello 2006, Dwyer *et al.* 2011, Osterlind *et al.* 2011, Ball *et al.* 2014, Rivolta *et al.* 2014). In this regard, several studies point to the development of avoidance behaviours (Wadensten *et al.* 2007, Tan *et al.* 2013). In light of this, it might be a sensible coping strategy for nurses to let the procedural focus dominate their practice as a form of self-protection (Sandgren *et al.* 2006, Bryon *et al.* 2012).

Grief care as emotion-oriented care is counteracted by the growing emphasis on instrumental competence and a nursing home environment that leaves little room for narrative space

(Grandey *et al.* 2007). In addition, participants struggle to find a balance between proximity and distance (Allan & Barber 2005, Martinsson *et al.* 2011). As loss-related needs of residents actualize nursing staffs' vulnerability, an exercise of courage is needed to engage in grief care (Stenbock-Hult & Sarvimaki 2011, Thorup *et al.* 2012). This courage is particularly important when efficiency and rationality gain the upper hand in contemporary care (Hawkins & Morse 2014).

LIMITATIONS

The strengths of this study are the data analysis method and researcher triangulation. However, this study also has some limitations. First, the study relied on nursing staffs' verbal accounts and no observation of their actual practices was done (data triangulation). Second, despite trying to ensure gender balance, only one male participated in this study. It may be that other themes would have emerged if more males were included in the study. Third, although data saturation was considered to have been achieved with the current participants, a larger number of participants from different backgrounds might have been more representative of the broader public. Fourth, recruitment was based on all nursing staff who may interact from time to time with grieving residents. However, approached head nurses tended to assume that participants should have a special interest in grief, loss and bereavement which may reduce transferability of the findings.

CONCLUSION

Our study provides insight into what grief care means for nursing staff, given that a nursing home is often under-resourced with staff and more conducive to tasks rather than relationship-based care. Results indicate that nursing staff experience a sense of responsibility for grief care, but that this is often overshadowed by several environmental and individual factors.

To begin with, if grief care is to flourish it has to be accorded value and status in care routines. Institutional policies and staff development initiatives need to reflect philosophies that promote grief care and relational practices. An appreciative inquiry approach (Dewar et al., 2013) at the organizational level could be adopted to build capacity in grief care. Workload management and collaborative working are key elements of a nursing home culture that fosters grief care. Furthermore, a grief care policy should include attention to self-awareness and self-care as a shared responsibility of the individual nurse/care-assistant, immediate colleagues, head nurses and management of a nursing home (McCormack & McCance 2006, Tehrani 2010). Finally, grief care should be integrated in both (under)graduate level curricula (Wass 2004) and 'on-the-job' experiential learning (O'Connor & Breen 2014). Reflective journaling (Harrison & Fopma-Loy 2010) and video interaction analysis (Caris-Verhallen *et al.* 2000) are possible vehicles to prompt insight in individual-related facets of grief care.

Last, this study opens up new questions for further research focussing on how residents and staff mutually grieve the loss of another resident, the dynamics of concealment of loss in nursing homes, the perspectives of residents regarding grief care, the development of open environments where residents and nursing staff can communicate their needs and finally the potential of peer support between residents in the context of loss and grief (Perkins *et al.* 2013, Sandhu *et al.* 2013).

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria by the ICMJE (http://www.icmje.org/ethical_1author.html):

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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CHAPTER 7. GENERAL DISCUSSION

Draden van verbondenheid

“De draad van de liefde
verbindt mij met jou.
De draad van het gemis
verbindt mij met jou.
Zoveel draden verbinden mij
met zoveel mensen.
Maar altijd is er die draad met jou,
zij doorkruist alle andere draden.
Ze geeft betekenis aan alle levensdraden.
De draad van de liefde
verbindt ons voor altijd,
en de draad van ’t gemis
verweeft zich met die van de liefde.”

Marinus Van den Berg

1. INTRODUCTION

This dissertation addressed how older parents and their middle-aged children experience their life when characterized by the presence of a demanding health-related condition such as cancer. In addition, the nursing staffs' (nurses and care-assistants) experience in dealing with grief and loss in residents of a nursing home was explored.

In this chapter we will discuss the main findings of the separate studies and consider the core concept of balance artistry in a broader perspective. The discussions and conclusions from preceding chapters are not touched upon so that duplication is avoided. Several challenges for contemporary health care practice will be discussed. Then a reflection on some methodological issues will be given. Future directions for research will complete this chapter.

2. SUMMARY OF MAIN FINDINGS

2.1. PART I. THE PERSPECTIVE OF OLDER PARENTS

In part I we started with summarizing the current knowledge on the experiences of older parents regarding their position (i.e. status) and role (i.e. prescribed or expected behaviour) as a parent of a middle-aged child with a serious illness (Chapter 2). Secondly, we wanted to gain insight in older parents' experiences, concerns, and dilemmas regarding their position and role as a parent of a middle-aged child with cancer (Chapter 3). Thirdly, we investigated the experiences of older parents with regard to the death of their middle-aged child due to cancer (Chapter 4). We formulated the following research questions:

RQ1: What is the current state of knowledge on older parents having an adultchild with a serious illness ?

RQ2: What does it mean to a parent to care for a middle-aged child with cancer and how do parents give meaning to their parental role throughout their child's illness trajectory ?

RQ3: What is the experience of older parents outliving a middle-aged child who died of cancer ?

An overview of current literature (Chapter 2) on how older parents cope with a serious illness and/or death of their child showed that:

- The included studies were limited by small samples, a limited range of outcome variables and cross-sectional designs.
- The contiguous fields, such as the experience of young parents with children with cancer or the experiences of family members (often restricted to spouses), are evolving more rapidly.
- The field of older parents' experiences of having an adult child with cancer is receiving considerably less attention. Several questions remain unanswered and it seems that a thorough understanding of the parents' experiences is lacking.

Interviews with older parents (Chapter 3) revealed that:

- Older parents are facing energy-consuming and delicate balancing acts in three areas (1) shielding while being shielded, (2) between being involved while keeping an adequate distance, and (3) shifting attentional priorities between their child, themselves, and others.
- The participants seemed to conceptualize their parental role as one of negotiating contradictory attitudes, motivations, and forces. They constantly juggled their commitment by searching their place and tuning in on boundaries set by their child.
- Even when the practical side of parenthood is relinquished at old age, the psychological experience is not. Older parents wanted to be supported in whatever role they could adopt. The degree of parental involvement was conditioned by the degree of perceived understanding and agreement between themselves, their child, and their child’s spouse, the former relationship with their child, their own capacity to provide help, and the match of coping styles.
- Older parents often shouldered the bulk of the caregiving when their child was divorced or widowed. Otherwise, caregiving duties fell primarily to the nuclear family.
- Few parents reported feeling aggrieved, as they believed they had a valuable and useful contribution to make in their sick child’s life and their ability to intervene was limited as the child’s mate’s preferences had to be considered.

Interviews with older parents outliving a middle-aged child due to cancer (Chapter 4) accentuate that:

- Older parents are struggling with the question whether or not they are entitled to show grief for their middle-aged child. When an adult dies, the social support system nearly automatically directs its care towards the bereaved nuclear family. Parental grief at old age is therefore often not recognized and/or acknowledged.

- A feeling of injustice, which was already present during the illness trajectory of their child, continued after their child's death.
- These parents continually search (often in a hidden manner) for ways to stay emotionally connected by keeping belongings and cherishing the memories of the deceased child.

2.2. PART II. THE PERSPECTIVE OF MIDDLE-AGED CANCER PATIENTS

In part II of this dissertation we further investigated the experience of middle-aged cancer patients For that purpose we formulated the following research question:

RQ4: How do middle-aged cancer patients experience cancer vis-à-vis their parents (and wider environment) ?

The interviews with middle-aged cancer patients (Chapter 5) indicate:

- Three perspectives (I, They and We) with regard to how they relate to their family members, and their older parents in particular. These perspectives represent the cancer patient's employed behaviour and communicative practice.
- A complex interplay of three interrelated processes that are less manifest and obvious by nature (e.g. togetherness-separateness, reticence-verbosity, and self-protection-other-protection) on which participants array their relationships inside and outside their nuclear family.

2.3. PART III. THE PERSPECTIVE OF NURSING STAFF REGARDING LOSS IN OLD AGE

RQ5: What are the experiences and perceptions of nursing staff working in nursing homes in Flanders concerning care actions focused on loss ?

Based on the interviews with nursing staff (Chapter 6), we found that:

- Grief care in nursing homes is characterized by a complex balancing act between two care dimensions: (1) being involved while keeping an appropriate distance, and (2) being while doing.

- Nursing staff in nursing homes share an aspiration for grief care, but the organisational setting and nursing staffs’ personal characteristics can strongly influence their capacity for grief care.
- Nursing staff need education in grief care, more time to listen, and more opportunities to reflect, to share experiences, and to support each other.

3. BALANCE ARTISTRY AS A FUNDAMENTAL ASPECT

While some themes fell primarily to only middle-aged children or primarily to parents or nursing staff, we found that striking a balance as a theme was shared by all three parties. This balancing is present, yet with a different meaning, in both the parent-child relationship as the resident-health care provider relationship and was performed both on relational and emotional levels.

3.1. BALANCE ARTISTRY IN THE MIDDLE-AGED CHILD-OLDER PARENT RELATIONSHIP

Uncertain boundaries and changing connections

This dissertation underpins the assertion that a cancer diagnosis does substantially alter the middle-aged child-older parent relationship ranging from relationships with enhanced closeness to ambiguous, distanced, or subsided relationships (Chapter 3). The cancer diagnosis required renegotiation of the parent-child relationship and resulted in a delicate interplay between what older parents think is suited, are willing and able to do for their adult child and his/her nuclear family. As a result, three patterns of parenting were displayed: involved parenting, bystander parenting and helpless parenting. The pattern of involved parenting is reflected in earlier research on role continuity of mothers of adult traumatic brain injury survivors (Wongvatunyu & Porter, 2008). Our findings on the older parent's caregiver strain and the tensions surrounding the balance between dependence and independence corroborated with other studies in the field of clinical rehabilitation (Jones & Morris, 2013; Knox, Douglas, & Bigby, 2016).

Older parents attested of an uncertain boundary between carer and parent and of being careful to balance the caregiving and parental role. This often meant running the fine line between trying not to be patronising and trying not to be dominating, trying not to butt in, trying not to give unsolicited advice, and trying not to undertake uncalled-for action. The challenge of negotiating the appropriate extent of parental involvement is also seen in transitional care programs when young adults with congenital disease, mental illness and chronic conditions age out of child-focused programs (Clarizia et al., 2009; Fredericks et al., 2011; Lindgren, Soderberg, & Skar, 2016; McDonagh, 2005). However, these programs regard dealing with parenting issues and inclusion of family as an integral component. It is even so that a complete removal or abdication of parental responsibility is not advocated in these young adults in order to promote positive health outcomes. This contrasts with the acute onset of a middle-aged child's cancer diagnosis that may be conceptualized as disrupting the existing family life cycle (Carter & McGoldrick, 1999). As such, being cared of by older parents and the parental overprotectiveness is not experienced as congruent with their attained independence as an adult, but rather seen as a regressive step to childhood.

To end, we should highlight that the reemphasis of a fulfilling and meaningful pragmatic role for older parents in relation to their children could potentially help prevent or reduce mental health problems. Several studies showed that parents who provide functional support to their adult children experience fewer depressive symptoms over time than parents who do not provide help to their adult children (Byers, Levy, Allore, Bruce, & Kasl, 2008; Marshall & Lambert, 2006). Apparently, providing support to adult children can enhance the self-esteem of older adults and contribute to feelings of independence, which in turn can affect life satisfaction (Lowenstein, Katz, & Gur-Yaish, 2007).

A discourse of silence in the stories of both older parents and middle-aged cancer patients

Part of managing a chronic illness is managing information surrounding the condition such as sharing health information with others. Within many families, the patient was the central gatekeeper of information, and their wishes regarding what should be discussed influenced communication with clinicians and within the family (Foster et al., 2015). This dissertation breaks new ground by shedding light on how the discourse of silence is linked to both older parents' and middle-aged cancer patients' stories. Both, from their point of view, reported that there were significant changes in their patterns of communication, the most notable being self-renunciation of needs and concerns. They both were subjected to a number of silencing processes whereby their expression of distress and grief was constrained - by themselves, their families and social networks (Chapters 3, 4 and 5). This self-silencing could stem from other- or self-protection and was either self-inflicted or other-inflicted (Chapter 5). Notably, both parents and cancer patients experienced conflicting perceptions regarding talking versus not talking. Either of them implicitly recognized the value of communication (e.g. sharing concerns and distress), but simultaneously acknowledged the risks (e.g. increase of burden and uncertainty in the other party).

As a result both parties subjugate themselves because it was believed that if they exposed their concerns and distress it would interfere with the other's coping efforts. The communicative behaviour of both parents and children is in response to the best interest of the other party and the fulfilment of one's own needs. However, the unintended consequence is that family and friends underestimate the extent of emotion work, making the older parents' and cancer patients' efforts invisible in the social arena. This well-intended communicative cancer patient's behavior aimed at facilitating the older parents' coping may actually impede their coping. Many parents reported not knowing why their child was uncommunicative, and described this as a source of frustration and emotional toil (Chapter 3).

This discourse of silence is also echoed in research concerning parents of a young child with cancer (Dunn et al., 2011; Hildenbrand et al., 2011; Kars et al., 2008) and the cancer patient-partner dyad (Lindholm, 2002; Song, 2012). Hence, we note that the mechanisms of mutual protection and emotional attunement exist regardless of the age of the patient at time of diagnosis and regardless of the relationship type. The main difference is located in the opportunity that young parents and partners have to obtain first-hand information and to be physically close to the patient. Young parents are able to manage the demands of their child's illness in various ways which include continual visits to the hospital, closely observing and monitoring their child's progress (Schweitzer, Griffiths, & Yates, 2012). Parents of younger children seek information in order to be advocates for their child, but in our study the child was his or her own advocate (Chapter 3). These changes in family dynamics were most clearly seen when the child is married (Chapter 5). Parents fade from importance in decision making at all levels and no longer have primacy in adult child healthcare decision making.

Our findings are in line with the communication privacy management theory (Petronio, 2002) which posits that individuals purposely select what information to share or withhold from others and as such claim ownership of their information. Our findings clearly underpin the construction of boundaries relating to who is privy to certain information (Chapter 5). The pursuant suffering in silence seems to fit with the lack of openness between parents and young children diagnosed with cancer (Veldhuizen & Last, 1988). Veldhuizen and Last (1988) formulated the 'law of double protection', meaning parents influence their child's emotional word, not only from an empathetic perspective but also as a way to protect themselves. In this dissertation this was not only seen among older parents but in middle-aged children too. The middle-aged children preserved normalcy by not showing their emotions and thus preventing their older parents from becoming distressed.

3.2. BALANCE ARTISTRY IN THE RESIDENT-HEALTH CARE PROVIDER RELATIONSHIP

Being while doing

A first balancing act was noticed between meeting the emotional needs of residents (being with) as well as the physical needs (doing for). They often felt as if these needs were at odds with each other and recognized not being able to provide basic grief care (Chapter 6). The participants' feeling of being forced into choosing between differing but equally important needs, resulted in giving lower priority to communicational, social, psychological, and relational needs, compared well with previous studies (Slettebo et al., 2010; Vryonides, Papastavrou, Charalambous, Andreou, & Merkouris, 2015). Recent research conducted in a hospice setting also highlighted the embedded and taken-for-granted rules and behaviours of nursing staff (Haraldsdottir, 2011). In this specific study nursing staff were very attentive in assuring residents' physical comfort, but felt rather uncomfortable if tasks were not completed. It was even noticeable that they didn't want to engage with patients unless a physical task required them to enter the room. In our study, nursing staff considered interpersonal relationships and paying attention to residents' grief as important aspects of the resident-health care provider relationship (Munyisia, Yu, & Hailey, 2011), and yet they found it difficult to achieve this. Despite the fact that they knew what was ''the right thing to do'', various organizational barriers made them unable to implement this course of action. The nursing staff's experience of pressure is about not finding opportunities to engage in true encounters where the opportunity is created for a resident to talk more deeply about concerns, loss and grief. When nursing staff easily get ''need-orientated'' this is at the expense of sensibility and focus on the situation (Delmar, 2006). When time pressure pushed nursing staff out of balance and when the caring becomes purely ''doing'', nursing staff felt dissatisfied (Ranheim, 2009).

The precarious balancing of emotions in care encounters

Building a close relationship, whilst maintaining professional boundaries is challenging during highly sensitive, and emotionally charged moments. Taking care of vulnerable, grieving older persons is an important part of nursing staff's care and holds significant potential for interpersonal and emotional complexities. Our findings (Chapter 6) underscore the nursing staffs' balancing in the establishment of appropriate levels of involvement in emotional encounters. This balancing act between being involved while keeping an appropriate distance was essential in the experiences of both older parents and HCPs. However, we note one crucial difference: HCPs can take control of the resulting interaction and relationship. The direction in which the parental role is defined depends largely on the boundaries set by their child.

Essentially, two opposing logics of care govern emotions in health care: bureaucratic models, where efficiency is emphasised, and personalized models, where empathy and emotions are prioritised (King, 2012). Our findings make clear that managing emotional labour is essential for nursing staff to develop the ability to manage the boundaries of intimacy and distance (Bailey, Murphy, & Porock, 2011). Emotions, as they emerged within the interviews, were concurrently viewed as an asset, aptitude, and impediment within their daily work. Our findings underpin that grief care consists of different skills: (1) understanding and interpreting the emotional needs of others, (2) providing a personal response to these needs, (3) pacing the work and taking into account other responsibilities . Nursing staff not able to manage emotional labour associated with grieving residents frequently mentioned using distancing strategies. The creation of a light-hearted and upbeat atmosphere was not only intended to protect the resident from having to face difficult emotional issues, but was also important in helping the nursing staff cope. We noticed that this coping mechanism was developed by individual team members and on an organizational level. Further, we noticed that this ability to sense and understand a resident's emotions and react appropriately was surprisingly not related to the years of experience. We contend that it requires attentiveness and enough personal courage to handle own feelings and resident's feelings related to vulnerability and uncertainty and to bear witness.

4. OPPORTUNITIES AND CHALLENGES FOR HEALTH CARE PRACTICE

In this section of the chapter, we draw attention to important challenges and issues for HCPs, and organizational leaders. Some challenges are oriented towards nurses and care assistants as they are often the most accessible care provider on the care team, privy to family conversations and on-going family communication throughout the illness trajectory. Other challenges pertain to different health care providers (HCPs) employed in an oncology, palliative, geriatric or primary care context as they go beyond the sole responsibility of nurses; and rely on effective collaboration and joined-up working across professional boundaries. Further, we raise several ways ahead to make use of education and training in order to obtain the needed skills and knowledge.

4.1. RECOGNITION AND CONSIDERATION OF THE MIDDLE-AGED CHILD-OLDER PARENT RELATIONSHIP IN LIGHT OF A CANCER DIAGNOSIS

One of the main principles to guide oncology and geriatric care is that of patient- and family-centred care (PFCC), defined by the Institute for Patient- and Family-Centred Care as, an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and HCPs. It is founded on the understanding that the family plays a vital role in ensuring the health and wellbeing of patients of all ages. We reason that a multigenerational family-sensitive practice in both oncology and geriatric care contexts is much needed. Interventions such as whole family approaches could be formulated to adapt a more individualized definition of family caregiving, without presupposing a predefined standardized experience of family life (Illingworth, Forbat, Hubbard, & Kearney, 2010). When we think of families, we tend to concentrate on the nuclear family, that is, parents and their children living together in one home (Connidis, 2009). In PFCC, the patient provides the definition of family along with the extent of the family's involvement in their care. PFCC is not intended, however, to take decision-making control away from the patient or transfer it to the family. Patients continue to make decisions about their care as long as they are competent to do so. Hence, the need exists to recognize diversity by going beyond the nuclear family and beyond the household to include non-resident kin and those who are considered family by virtue of assumed obligations and the support that is extended and received (Scanzoni & Marsiglio, 1993).

This dissertation underscores that the parent and child relationship may be important at any age, and recognizing that is essential to effective psychosocial care in oncology (Oncology Nursing Society, 2012). Our findings depicted the older parents as invisible for HCPs in oncology settings because they were no longer considered as next of kin or an important support system (White & Beach, 2012). Hence, there was a disjuncture between the formal change in the parent-child relationship as viewed by HCPs, and the informal adaptation of the parents' perception of their continued parental responsibility to care. In spite of older parents feeling responsible for their child's care, they were often unable to take on this responsibility as their child attained the status of an adult (Koropeckyj-Cox, 2002). Although the practical side of parenthood may not be as central as it was when children were young, our findings show that the psychological experience of being a parent continues to play an important role (Esbensen, Swane, Hallberg, & Thome, 2008). Findings indicated that there may be feasible ways of providing support, even by older parents who are in need of support themselves (Boerner & Reinhardt, 2003). Older parents occupy, just as partners, a dual role: as provider of support to the cancer patient and as a family member who needs support in relating to this experience.

It is critical for nurses, psychologists and social workers in oncology care to develop skills to understand the cancer patients' frame of reference and context. First of all, the focus should specifically be on questioning cancer patients about their next-of-kin by means of genograms and ecomaps (Wright & Leahey, 2013), and in particular gaining insight into older parents being alive. The construction of a visual depiction should not be an end in itself, but rather a means toward a process of engagement. In addition, these genograms and ecomaps should be viewed as dynamic tools that should be updated or re-created over time. If parents are alive HCPs should aim to obtain a comprehensive picture of the quality of the relationship, level of connectedness, level and nature of support provided, and potential areas of stress. Of particular relevance for HCPs is the finding that there was more than one model of involvement, as different approaches to defining the parenting roles worked for different parent-child relationships. Engaging with the different types of involvement, while also bearing in mind that this involvement may fluctuate over time, seems key when developing successful oncology care. HCPs might be at risk of upsetting a delicate balance within parent-child relationship and family if they take an approach that is too directive and/or they prematurely suggest a different role or level of involvement for an individual parent without a grasp of the overall relationship.

In addition, older parents should be approached as embedded within a web of family affiliations while occupying several roles simultaneously (e.g. parent of a sick adult child, spouse, grandparent of a young grandchild). Our findings underscore that older parents of middle-aged children with cancer may experience a substantial deficit in practical assistance when they face their own health events. Such an imbalanced flow of support may place these parents at greater risk for negative health outcomes. Although not all older parents need professional help, knowing where to turn for practical and emotional support in case difficulties arise is of paramount importance. The primary care setting is well situated for the identification of these older parents in need of support, as many older adults frequently consult their general practitioner (GP). A GP has often long-term relationships with patients and is as such an important stakeholder in supporting these (bereaved) older parents by means of listening to their stories, normalizing their grief experiences and referring if necessary. Additionally, we need to enhance communication between GPs and mental HCPs and provide easily accessible and useable resources in order to facilitate referral processes and ensure that patients who need extra clinical intervention are able to access appropriate supports. Finally, we need to clarify the processes involved in referring a patient to a mental health professional and also ensure that reimbursement of GPs’ time is adequate in order to optimise grief care and emotion-oriented care.

HCPs in both oncology care and geriatric care can help the middle-aged child and the parents individually to enhance and develop strategies to negotiate their desired level of involvement. Subsequently, HCPs' recognition of parents' emotion work, positional powerlessness, endured suffering, and emotional interconnectedness with their middle-aged child may provide essential emotional support. In conclusion, becoming more 'older parents aware' and recognizing, valuing and supporting older parents could be a keystone to progress family-oriented care. Older parents should be seen as a potential resource, having needs in their own right, instead of being part of the taken for granted background of family care (C. M. Burns, Abernethy, Dal Grande, & Currow, 2013).

4.2. RECOGNITION OF THE UNDERLYING CORE MECHANISM OF SOLICITUDE AS THE BACKBONE OF CANCER PATIENTS' AND OLDER PARENTS' COMMUNICATIVE BEHAVIOUR

In meeting both the cancer patient and the older parent, HCPs need to be aware of their conflicting needs (i.e. not add to the burden of others and at the same time lean on others for support). HCPs in oncology care should be aware of the burden on cancer patients to balance both their own feelings and suffering and the feelings of uncertainty of family members. Relying exclusively on screening for distress to identify patients and family members in need for services is less efficient. Furthermore, we are arguing for evaluating distress screening in terms of whether it succeeds in linking patients and their family members with services that they would otherwise not receive.

This dissertation reinforces the need for HCPs to understand the varying approaches to information sharing, that might be 'discordant, complementary, or in agreement' (Kelly, Pyke-Grimm, Stewart, & Hinds, 2014). According to our findings, HCPs' strategies must be designed not to harm the existing mechanism of solicitude and the diligent management of the patients' relationship with their parents. Hence, HCPs in oncology care should not only focus on the destructiveness of secrecy but, in addition, also make room for an appreciation of the cautious way in which both cancer patients and older parents deal with sensitive issues (Rober, Walravens, & Versteynen, 2012). The best clinical approach is thus to follow the cancer patients' lead rather than trying to facilitate the expression of emotions. HCPs have to walk a thin line, reconciling the child's with the parents' needs and at the same time supporting the child's leading role.

These complexities can seem impenetrable for nurses and health care teams pursuing the best care and goal planning for oncology patients. Specifically onco-psychologists should consider the often hidden complexity of giving information and talking about feelings; including the various contextual factors and considerations that may influence the timing and desirability (cf. switches between perspectives). A valid starting point for onco-psychologists is supporting cancer patients in making explicit why they are not talking which in turn may facilitate a shared understanding of why certain topics are not frequently discussed. Consequently having a discussion may help frame the meaning of communicative avoidance and unravels the essence of thoughtfulness and solicitude behind what, at firsts sight, appears a seemingly innocuous stoic stance (cf. I and They perspective). Conversations about functionality of avoiding certain topics and the impetus behind their communicative patterns should be put forward instead of consensually advising open communication.

4.3. NARRATIVE CARE AS CORE CARE IN NURSING HOMES

Our findings show that HCPs should not consider older parents as a homogenous group that unanimously experience the enactment of their parental role as finished at old age. One should not make assumptions about their experiences as the meaning of being a parent of a sick middle-aged child can only be recognized by asking the older parents. Our interviews show that one question ("What has it been like for you since your son/daughter has been diagnosed with cancer?'') may give access to a whole narrative at least if the parents are allowed to tell their story. Narrative care may bring meaning to their experience. We see narrative care as a relational approach that helps older persons in their search for meaning in the final and perhaps most challenging part of their life. Narrative care is a humane way of caring for people, that can also be incorporated in an effective health care. It does not espouse one method in particular what is reflected in different examples of such care:

reminiscence groups, life story telling, life-review therapy etc. All these approaches see narratives as (1) bringing meaning to experience, (2) unique, (3) relational, (4) unstable, and (5) a form of character development. Broadly defined, then, “narrative care” entails listening openly and respectfully to some portion or version of the story of a person's life, with the person being listened to experiencing an increased sense of insight, meaning, and empowerment, and thus a measure of emotional–spiritual healing (Baldwin, 2015).

We see narrative care as core care, a fundamental element in attending to another person’s needs. Not simply an adjunct to care but a defining aspect of that care. HCPs themselves can play a vital role in encouraging autobiographical learning. It need not to be costly care. Much of the listening that happens in a health care context has to happen while carrying out specific tasks. Ultimately, it’s not about the quantity of time but about the quality of the connection. Such encounters can consume mere minutes of a HCP’s time but amid these moments rich pictures of the residents can be gained. Narrative care requires a combination of a narrative environment and a narrative attitude. You need a sensitive listener who can ask those gentle, probing questions that invite the person to go a little deeper, more extensively and more expansively. In addition, listening should be recognised by policy makers and managers as a real intervention and be awarded the necessary value.

4.4. CREATION OF AN ORGANIZATIONAL CULTURE IN WHICH RELATIONAL CARE, NARRATIVE CARE AND GRIEF CARE ARE GIVEN LEEWAY

Long-term care settings, in particular, have been described as “a world of emotions” and critical to residents’ well-being is their emotional relationship with the HCPs who care for them (Ruckdeschel & Van Haitsma, 2004). However, the complexity of staff experiences working in long-term care are often unacknowledged. The relationships between staff and residents should be viewed as complex, multidimensional, and situational. Often these relationships evolve to the level of fictive kin (Brasade & O’Neill, 2014) and this emotional component of caregiving provides meaning to nursing staff through the satisfaction inherent in relationships per se (Ball et al., 2009).

Nursing staff indicated a difficulty to work with accumulated loss in ageing and our findings point to the significance of choosing to see rather than avoid an older person's vulnerability and suffering (Chapter 6). Nursing staff experienced a sense of insecurity fuelled by feelings of incompetence and inadequacy. Our findings highlight the importance of the nurse attribute, authentic presence (Newman, 2008), that may encourage residents to openly share their feelings of loss with staff members. However, the expression of compassion isn't enough to achieve this. It requires of HCPs to bear witness and have enough courage to engage in conversations characterized with feelings of vulnerability and uncertainty. In addition, this courage assumes HCPs giving permission to residents to have some breathing space and attentive listening to both enjoyable and compelling stories.

Finding deeper meaning about residents' various losses in nursing homes is more likely to occur when residents share their feelings and stories with nursing staff during synchronous relationships (Newman, 2008). Such synchronous relationships can only be maintained if subtle shifts between task-centred and person-centred communicative practices are enhanced (Westerhof, van Vuuren, Brummans, & Custers, 2014). "Being" and "doing" should presuppose each other as figure and background. Caring as "doing" should be empowered by caring as "being" and vice versa (Ranheim, 2009). As such these moments must be increased to become an everyday cultural pattern or norm for all.

An important starting point for nursing staff is validating the parent's position in the hierarchy of loss (Robson & Walter, 2012). In acknowledging the legitimacy of the parents' experience and privileging their position in the hierarchy of loss, HCPs may reduce the parental experience of disenfranchisement (Doka, 2008). An intentional openness as a personal attitude should be the core of care environments where older persons feel welcome to open their hearts and share their losses with nursing staff. We argue that enough people and the right people should recognize their loss and their grief by means of legitimization of their grief and an enfranchising approach. To this end, it could be helpful to ask older parents who in their social network recognises and who does not recognise their loss, to explore the hierarchies underlying their own experience of disenfranchisement (Robson & Walter, 2012). Furthermore, we want to encourage HCPs of being attentive for the “shadow stories” that can lie below the surface of what older people share about their lives by means of narrative care. This way HCPs may learn about losses that would otherwise have gone unspoken (de Medeiros & Rubinstein, 2015). HCPs could provide bereaved parents an opportunity to narrate by means of photographs and mementos, enabling them to construct their narrative through reminiscences (Neimeyer & Sands, 2011). In order to realize this listening should be recognised by policy makers and managers as a real intervention and be awarded the necessary value. We should build on the ideas of person-centred care, which recognises the needs of those giving care as well as those receiving care. This development requires not a one-time event, but a sustained commitment both in clinical teams and across organizations.

In light of this, we suggest a balanced approach that blends strategies to help HCPs to build their own grief care actions and relationships whilst implementing change in the workplace culture that are known to enhance grief care, narrative care and relational care. Fundamentally, these envisioned changes are one of the heart, and the investment that is required is both financial and attitudinal (Baker, 2007). It is desirable that HCPs are provided structured time for grief care independently of care tasks, but this preserved time is not meaningful when a compassionate attitude is lacking. We believe nurses need to develop the “head, hand and heart” approach, which integrates practical know-how with empathic understanding and technical knowledge (Galvin & Todres, 2012) to provide humane and sensitive care. This attentiveness should not only be deployed when having extra time, but should be regarded as an essential part of good care (Klaver & Baart, 2011). Both nursing staff and their leaders need to think of bodily care as a space and time set aside for recognising and supporting the expression of the resident’s emotions. The starting point is that emotions need to be seen as fruitful for everyday practice. Assuming that HCPs should learn to manage emotions (i.e. being aware of emotions and facing them) which is something completely different than positing that emotion should be contained (i.e. holding back and locked up inside). Hence, leaders in the long-term-care settings must ask themselves what work conditions, structures and processes increase the chances that nursing staff will deploy affective care for residents. The key goal in the development of this organizational culture is to recognize and overcome individual, group and organizational barriers in order to move towards “person-centred moments” (McCormack, Dewing, & McCance, 2011). Nurse managers and nurse leaders need to be open to create a care context focussed less on pre-set tasks and permit nursing staff to provide care in a flexible manner so that they have the ability to tune into residents’ individual moods when needed and adjust to the individual rhythm of the resident (Dalgaard & Delmar, 2008).

4.5. MISSING LINKS IN CONTEMPORARY EDUCATION

Simply giving HCPs protocols and guidelines to follow is not enough to change patterns of interaction with cancer patients or older parents, and to change grief care actions. There is a need to develop multilevel education that contains cognitive and behavioral components (McGilton et al., 2009). These targeted educational activities need to extend beyond knowledge and skills (i.e. traditional training approaches) and address a wider range of issues, especially attitudes and perceptions (i.e. tacit and intuitive forms of learning) of a wide range of HCPs (i.e. all grades of staff, both qualified and unqualified, across a range of professional disciplines must be included) (Fraser & Greenhalgh, 2001). We think that the demand on contemporary health practice today extends beyond the more traditional skills of care and caring. We argue that education needs to invest in methods that impact the tenderness of everyday care and improves the confidence in dealing with highly charged emotional situations (Warelow & Edward, 2007). We posit a suggestion to take action during various key moments in both vocational training and the further professional career of HCPs. Below we formulate some recommendations to achieve abovementioned objectives:

- There may be mileage in providing future HCPs with some form of coping skills training and identity building. In this way students may develop emotional insight in their own risk and protective factors, and attributes needed to build supportive relationships with cancer patients and older persons in stressful times (McAllister & McKinnon, 2009).

- Future HCPs should be provided with basic communication skills and knowledge in grief care. This may include a greater sensitivity to and recognition of the diversity of experiences and needs of grieving older persons.
- (Future) HCPs should receive education with particular attention to reflection (Howatson-Jones, 2016). This may well initiate the process of raising individual awareness and may well serve as a useful starting point for further development in the actual work context. It may help HCPs reflect on the norms, values and assumptions that underpin their practice and how they themselves have an influence on the type of care they think is (im)possible. The supportive and communicative aspects of these interdisciplinary reflection groups may help staff feel valued for what they do.
- Informal mentoring through access to positive role models can inspire and build staff confidence, particularly for students and new graduates (Mealer et al., 2012). It is important to reduce exposure to negative role models as their attitudes and behaviours can easily be imitated by new staff and students, and can be difficult to reverse (English, 1993).
- Another approach to respond to this challenge is to stimulate (interprofessional) workplace learning (Eraut, 2007) in order to attain emotional abilities associated with understanding, supporting and caring for older persons facing or coping with loss and death.
- It needs to be acknowledged that engaging with grieving older persons may be painful and stressful for HCPs. The organization of adequate support systems (e.g. peer support networks, reflective debriefing, work discussion groups or Schwartz rounds) for those who deal with grief and bereavement as parts of their professional lives may give them opportunities for sharing emotional

knowledge (Davis, 2011; Hartley & Kennard, 2009; Thompson, 2013). It may be helpful for HCPs to reflect on the assumption that underpin their care practice and how they influence the type of care they think is possible. Elucidating these personal stories may enhance emotional resilience and the HCP’s ability to engage, maintain and sustain rapport with grieving (older) persons.

- The stories collected in this dissertation might be as a powerful communicative tool in vocational training and continuing learning (Moon, 2010). Excerpts from interviews can be used to create multiple narratives of older parent’s and middle-aged children’s experiences to better appreciate the diversity in experience and the underlying dynamics.

5. METHODOLOGICAL CONSIDERATIONS

5.1. STRENGTHS OF THIS DISSERTATION

The use of qualitative methodology privileged the experiences of both parents, children and HCPs and enabled the researcher to articulate the commonalties (intersubjectivities) and differences between both groups (Fischer, 2006). The constructivist grounded theory approach (Charmaz, 2014) of this study added to the ability to draw upon and apply an interdisciplinary approach. Hence, we sought the input of a team of researchers and clinicians with different disciplinary backgrounds (e.g. qualitative research, grief, care for older people etc.). This enhanced auditability of this dissertation and offered the opportunity to find support for our analytical insights.

The recruitment of the older parents, frail older people, was quite complex (Harris & Dyson, 2001). Challenges included taking informed consent, finding opportunities to conduct the interviews, involvement of nursing home staff and trying to maintain privacy during the interviews. By setting up a comprehensive recruitment strategy (Zermansky, Alldred, Petty, & Raynor, 2007) and by continually refining this recruitment strategy we maximised the involvement of older parents. Through collaboration and a flexible approach, we could, however, gain access to our target population. Hence, we were able to include parental carers at different stages ranging in the journey from parenting a recently diagnosed child, to providing on-going care, to reflecting on their experiences in the past. Another strength of this dissertation derives from the fact that older parents and middle-aged cancer patients were interviewed by different interviewers. Two interviewers (a nurse and a psychologist) conducted the interviews, with one interviewing the older parents and the other one interviewing the middle-aged cancer patients. No specific information related to the case was shared beforehand between the interviewers. The strength of this approach was to be found in the fact that the participants had to sketch the situation from his/her perspective as the interviewer was not guided by preconceived ideas instilled by reading the transcribed interview with the other party beforehand. It also avoided the participants themselves fishing for what the other had said. Only after both interviews were conducted they were subject to a coding process by the two interviewers.

The interviewer tried to build a trusting relationship by being open and authentic. Honouring the participants' chosen location, time, and place in their (nursing) home were essential for instilling a trusting relationship. We took great care to ensure that participants set the tone and pace of the interview. Next, we embraced each interview as a social interaction allowing this often unheard group to express their views. In several occasions nursing home staff moved the participants to the dining room where there was little to no privacy. We tried to maintain privacy during interviews in nursing homes by moving the participant to their room, shutting the door of their room, and by putting up an interview in progress sign on the door. All this measures, however, couldn't avoid staff/visitors to enter the room during the course of the interview (Hall, Longhurst, & Higginson, 2009).

The interview guide was varied, ranging from general- 'tell me the overall story of being a parent of a child with cancer'- to specific questions- 'how do/did you deal with the emotional side of being a parent?'. The parent's interviews opened with a single question and then we allowed the participants dictate the interaction. Often this first question sufficed because the stories tumbled out. Older parents often felt isolated and yearned for an opportunity to talk with others about their experiences. We allowed participants to take the lead role in explaining their perspectives on their life experiences. The order of questions was changed throughout the data collection process. The interviews with the cancer patients and the HCPs were more structured in nature. In all studies, the emphasis was on participants' own descriptions of their experiences, with the interviewer merely "ensuring that each experience is discussed in detail and seeking clarification for any statement not fully understood" (Thomas & Pollio, 2002). We formulated questions in such a way that they instilled encouragement, acceptance and interest. During and immediately following interviews, the researcher recorded field notes paying particular attention to topics discussed, nonverbal behaviours and periods of silence during the interviews.

The researcher reflected on her own actions, feelings and conflicts experienced during research (Holloway & Wheeler, 2010). A self-critical stance to the study, the participants, their role, relationships and assumptions was adopted. The researcher wrote down any feelings, preconceptions and assumptions about the study (N. Burns & Grove, 2011). This process of memo writing provided the researcher with the opportunity to remember, question and make meaning about the time spent with participants and the data that were generated together (Mills, Bonner, & Francis, 2006).

5.2. LIMITATIONS OF THIS DISSERTATION

There are several methodological limitations to each study, which have already been discussed in the previous chapters. Some more general limitations that touch upon more studies are discussed below.

A first limitation is that the participating older parents (Chapters 3 and 4) are part of a purposive sample selected via family members and HCPs. Family members can play an important gatekeeper role when trying to engage older people in research. We found that cancer patients or their close family members were sometimes protective and tried to override the participant's decision to participate (Davies et al., 2010).

Second, our sample did not represent parents who had positive and negative precancer relationships (Chapters 3 and 4). Our study’s sample population consisted of parents with predominantly positive precancer relationships with their middle-aged children. As a result, this overrepresentation might have limited our ability to capture important changes in the parent–child relationship in initially poor relationships. Furthermore, we were not able to rigorously probe the possible enhancements or shifts in the parent–child relationship that take place when the relationship is initially poor.

A third issue is that both parents and their children were interviewed only one time, making it difficult to ascertain how the strategies they used changed over time (Chapters 3, 4 and 5). We could only rely on their rendering of these.

An additional alert is required as our findings mainly pertain to Caucasian, Dutch speaking, articulate, self-reflective older parents and middle-aged cancer patients. In addition, we excluded specific groups such as patients and parents who are not able to speak Dutch (probably excluding in this way some immigrants). Furthermore, the data reported here refer to mainly mothers of middle-aged daughters with breast cancer. However, differences in longevity indicate that midlife adults are three times more likely to have a sole-surviving mother than a sole-surviving father (Marks, L., & Jun, 2004). The longer life expectancy of women makes them more likely than men to outlive at least one of their children, particularly among women who had their children at relatively young ages and among those who have sons (Connidis, 2009).

It can be debated if our studies are grounded theory (GT) studies. We brought to the fore several elements that characterize a grounded theory study: theoretical sensitivity, theoretical sampling, constant comperative methods, coding and memoing. It has been an on-going search how to correctly name the underpinning methodology of the separate studies. According to Dey (2004, p.173) "there is no agreement on what constitutes a grounded theory, only varying interpretations which bear a family resemblance". We used a constructivist grounded theory (CGT) approach (Charmaz, 2014) which differs from the Glaserian and Strassian schools of GT. CGT moves away from the positivism and instead of underpinning the development of a core category with clear dimensions and properties CGT puts the uncovering of implicit processes and interpretation more on the foreground. For Charmaz, grounded theory is not prescriptive and rigid, and she advocates against what she describes as "methodological rules and recipes" (2006, p.9). Rather, she sees grounded theory methods as principles and practices that should be used flexibly. This is in direct contrast to Glaser (1998) however, who suggests that grounded theory is only grounded theory when it follows a specific set of methodological guidelines.

Theorising is the professed purpose of grounded theory research. This research has resulted in my own theorising of the studied experience. According to Charmaz (2009), the constructivist approach challenges the assumptions of creating general abstract theories and leads us to ‘situated knowledges’ (p.136). In CGT the concepts and theory are rendered in a more narrative way, as is the case in my dissertation. The present work is only in early development and needs further elaboration by means of further research.

Explaining data saturation or sufficiency as something I felt had occurred, due to there being no new insights in the data, perhaps does not provide sufficient rigor methodologically. However, I was seeing theoretical meaning in the data, it was convincing and plausible and felt like a story being told that gave meaning to participants’ experiences. Charmaz (2014) advocated in-depth knowledge over exhaustive completion of analysis, I remain confident justice has been given to the analysis of the data and more importantly to the participants.

6. FUTURE RESEARCH TOPICS

Areas for further research will be considered based on the limitations and the findings. Future research could address these limitations to provide a more in-depth and holistic understanding of the parent–child relationship and to inform care and interventions that are tailored to both middle-aged children and older parents.

6.1. THE INTERRELATEDNESS BETWEEN MIDDLE-AGED CHILDREN AND OLDER PARENTS

Despite extensive attention to the implications of caregiving for caregiver's mental health and well-being, little is known regarding the impact of the relationship of the caregiver to care receiver (Litwin, Stoeckel, & Roll, 2014; Penning & Wu, 2015). Gaps still remain in our understanding of the interrelatedness of middle-aged cancer patients and their older parents. Consequently, the implications of parental caregiving compared with those associated with caregiving to a spouse/partner or to others, remain unclear. Future (longitudinal) quantitative studies could investigate how cancer patients and older parents mutually influence each other over time (e.g. mental health and physical health). Future quantitative research may incorporate several individual and social structural characteristics of both the sick child and the parents (e.g. age, gender, marital status, number of adult children, geographic proximity, family structure, frequency and type of contact, emotional closeness, quality of parent-child communication, coresidential status). We need to conduct research examining the impact of family dynamics on individuals and vice versa, in the caregiving phase, as well as how these evolve during bereavement (Carolan, Smith, & Forbat, 2015).

Our findings suggest that the parental role holds much importance for well-being during an individual's later years. Future research could address the positive effects on older adults of giving support to others and mechanisms that explain this phenomenon. From a gerontological perspective, an important question is how the stress of parenthood may persist later in life when children grow up and do not require time- and labor-intensive parental care anymore. Parental mattering may become particularly important for older parents' psychological well-being because older adults tend to relinquish other salient roles, particularly, due to retirement and widowhood. Longitudinal studies with measures that tap into various dimensions of well-being may contribute to an understanding of parenting in old age as well as help to explain the specific mechanisms by which negative life events in middle-aged children impact older parents' well-being. These studies could include multiple-item measures focusing on burden as well as other aspects of mental health (both self-assessed and behavioral). Future quantitative research could particularly focus on older persons attaining the helpless parenting-pattern (Chapter 3) and how this effects on their well-being.

6.2. THE DYNAMIC NATURE OF THE OLDER PARENT-CANCER PATIENT RELATIONSHIP

The replication and extension of our analysis using a longitudinal design would provide a more dynamic picture of the middle-aged child-older parent relationship during the illness trajectory. These longitudinal studies are recommended to follow through older parents' experiences at different points in the disease trajectory of their child to enhance understanding of the transformational process of their role and position in facing a middle-aged child with cancer. Future qualitative research could use serial interviews that allows narratives to unfold in order to reveal the complexity of individual situations and the dynamic nature of parental grief (Murray et al., 2009). The foregrounding of dyadic analysis highlights the contextual nature of care practice and allows for the different perspectives and voices to be heard (Bjørnholt & Farstad, 2012). Interviewing middle-aged children and older parents jointly and individually may help highlight any discrepancies between individual and shared accounts and tease out individual experiences from collective ones. Mutual influence of communication avoidance as perceived by both patients and parents on each other's outcome may be examined as family communication perceived by patients may differ from patient communication perceived by family members. This means that openness of family communication during a cancer trajectory could be evaluated from the perspective of both patients and caregivers in order to better understand the dyadic interaction (Shin et al., 2016).

Additional qualitative studies could focus on other patient groups (e.g. other cancer types and other diseases with a limited life expectancy) and could include cohabiting older parents. Furthermore, there is a clear need for more research that examines different populations within Western cultures as well as cross-cultural research. Further, the study of a population where the transition of roles (e.g., losing the practical fulfillment of the parental role through the parent's increased disability and increased reliance on his or her child and others) is more highlighted, would be desirable.

6.3. (PARENTAL) GRIEF IN OLD AGE

Because older adults are the most frequently bereaved population group, examining the nature of late-life grief and non-spousal loss, and its possible complications, is clearly in order. More research is needed to explore what factors favor resilience and adaption to bereavement in later life. Many areas are yet to be explored about bereaved older parents: the meaning and impact of multiple, sequential deaths, and the effect on the multiple generations in the family. Research on the subtle interaction patterns between family members and between generations in response to the death of a middle-aged child might fuel family-oriented practice. Further research may provide a reliable indication of those older persons who may be significantly vulnerable in their grief and therefore most in need of (therapeutic) support (Sim, Machin, & Bartlam, 2014).

6.4. EMOTION-ORIENTED CARE IN LONG-TERM CARE SETTINGS

Research is needed about the relationship between nursing home residents and nursing staff, and its effect of both emotional lives. It is necessary to know more about the attributes of nursing staff who do provide emotion-oriented care, in order to ascertain the components of this aptitude. We do not know to what extent the nursing staffs' capacity for emotion-oriented care whether can be nurtured through training and coaching. Further research is needed to understand nursing staffs' experiences of grief at different stages of their professional career and how education and interventions can enrich care environments to be cognizant of grief, loss and bereavement in older persons. Finally, action research could explore how grief care can be tailored to the needs of the older persons, their caretakers, their HCPs and the institutions in which they reside.

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Summary

SUMMARY

As family members in general play an essential role in the cancer trajectory, insight in the parental perspective is valuable. The past two decades have seen an influx in the literature in regards to partners' psychological response to cancer. Unlike the breadth of literature on these middle-aged children or spouse caregivers, there is a dearth of literature about the cohort of older parents and the impact that care provision has on their mental health and well-being. Parent-child relationships are usually lifelong and reciprocal and older parents can assume particular significance when a middle-aged child has cancer.

Therefore, this dissertation set out to provide insight in both the experiences of older parents and middle-aged cancer patients. This dissertation broadens our understanding of communicating with older parents amid a cancer experience and highlights the mutual influence parents and children exert. In addition, we focused on the experience of bereaved older parents of whom the adult child died due to cancer. Besides this we sought to know how nursing staff (nurses and care-assistants) deal with grieving residents in nursing homes. Our insights were gained by means of literature review, and qualitative research based on constructivist grounded theory.

In **Chapter 2** we investigated what published research reveals on the perspective of parents having an adult child with a critical illness in which death is possible or imminent. An early evaluation of the limited literature revealed the clear predominance of cancer-related articles. Existing studies were merely descriptive and gave no concrete recommendations for health-care providers in daily practice.

In **Chapter 3** we investigated what it meant to parent a middle-aged child with cancer. Regardless of their child's age, parents experienced a strong desire to protect them which refers to the parents' sense of a life-long duty and commitment to their children. However older parents reported being relegated to a non-participant status and being overlooked by health care providers (HCPs). Nonetheless, our findings confirm that in some cases older

parents provided help to middle-aged children with cancer past the life stage in which it is normative for support to flow from parents to their offspring. We found that the cancer diagnosis required both parties to negotiate new ways of doing their relationship**.** The changes in the child's health led to a change or discontinuity in the established relationship as new dependencies and interactions had to be negotiated. As a result, three patterns of parenting were displayed: involved parenting, bystander parenting and helpless parenting. In addition, many parents tactfully withheld their worries as a way of supporting their child. As these parents have to contend with a kaleidoscope of feelings in the same way and to a comparable degree as the adult children themselves, their suffering in silence requires considerable emotion work. Further, older parents were confronted with the dual stressor of caring for their sick child while dealing with their own aging-related changes in health and functioning, such as physical disability and greater vulnerability to illness.

In **Chapter 4** we focused on the experience of older parents grieving their child's death due to cancer. When an adult dies, the social support system nearly automatically directs its care towards the bereaved nuclear family. Even so, the older parents' experience of grief exceeded the hierarchical position allowed by their social network. Parental grief at old age is therefore often not recognized and/or acknowledged. These parents continually searched (often furtively) for ways to stay emotionally connected by keeping belongings and cherishing the memories of the deceased child.

Insight in the experiences of middle-aged cancer patient vis-à-vis their parents is provided in **Chapter 5**. Communication with parents (and the wider environment), required a lot of decision making with many factors weighted and seemed a real tug-of-war. Communication about the illness was a process of delicate negotiation dependent on the personalities, needs and coping strategies of the patient, spouse, children and parents. Cancer patients needed to choose between trying to communicate in a manner that would best match their preferences, or communicating in a way that they believed would be most agreeable to their parents. Participants had difficulty finding a balance regarding what their parents needed to know-making them feel included yet not wanting to needlessly worry them. There were apparently competing impulses (cf. three crossing continua) in that many participants espoused open communication as an end to itself, but they also expressed a number of other desired end states (i.e., protecting oneself and others) that they pursued by avoiding topics. Instilled by the wish to shelter others, they made efforts to anticipate and gauge people's reactions. Self-care was put forward as an important consideration in relation to the decision to avoid discussing feelings and unpleasant subjects that might upset themselves/the other. Both cancer patients and older parents struggle with the competing needs of open communication and avoidance, with a communication divide possible between the patient and older parents or among other family members.

In **Chapter 6** we addressed the experiences and perceptions of nursing staff (nurses and care assistants) in caring for grieving older persons in nursing homes. Various barriers and difficulties appeared to be paramount in the provision of grief care to older persons. Several individual and organizational aspects were shown to encourage or discourage the enactment of grief care actions.

Taken together, our findings can assist health professionals and clinicians to form a more complex and nuanced understanding of parenting dynamics at old age in a family affected by an adult person's illness. A cancer diagnosis in a middle-aged child raises many issues around parents' views of their parenting role. Attuned care requires gaining insight in what is at stake for both adult cancer patients and their older parents and to attune care to that information. This dissertation points to parenting as a dynamic process that continues its reach into late life and places the parental role after children become adults in the centre of attention and accentuates the distinction between how parents of sick adult children experience their role, versus the way they experience their affective relations with their sick adult children.

Samenvatting

SAMENVATTING

Onze kennis over en aandacht voor de mogelijke impact van kanker op de naaste gezinsleden van een volwassen kankerpatiënt, zoals de partner en/of kinderen, neemt de laatste decennia ook toe. Een groep die echter wat vergeten wordt zijn de ouders van deze volwassen kankerpatiënten. Zij worden zelden opgenomen als belanghebbenden in het zorgproces. Door middel van literatuuronderzoek en kwalitatief onderzoek werden de ervaringen van zorgverleners m.b.t. rouwzorg en de beleving van oudere ouders en hun volwassen kind met kanker bestudeerd.

In **Hoofdstuk 2** onderzochten we aan de hand van een systematische literatuurstudie de huidige kennis over hoe oudere ouders hun positie en rol ervaren wanneer hun kind ernstig ziek is of overlijdt. Onderzoek naar hoe oudere ouders omgaan met het ziek-zijn en/of overlijden van hun kind is eerder schaars. De 19 artikels die in de internationale literatuur werden geselecteerd geven een eerste inzicht in het domein maar worden geplaagd door methodologische beperkingen. Zo is het kwantitatieve onderzoek begrensd door o.a. kleine steekproeven, een focus op slechts zeer specifieke aspecten, en cross-sectionele designs. Hierdoor ontbreekt nog steeds een diepgaand inzicht in de belevingen van deze ouders.

In **Hoofdstuk 3** hebben we een antwoord gezocht op de vraag wat het voor oudere ouders betekent ouder te zijn van een volwassen kind met kanker. De kankerdiagnose zet verhoudingen tussen hen en hun kind(eren) op scherp. De kankerdiagnose daagt hen uit om een evenwicht te vinden in gepast emoties en informatie delen zonder te belasten (evenwichtsoefening 1), in gepast ouderlijk zorgen voor hun kind met respect voor de autonomie van hun kind (evenwichtsoefening 2) en in gepast zorgdragen voor hun zieke kind zonder andere (klein)kinderen, naasten en zichzelf te vergeten (evenwichtsoefening 3). In de verhalen van de ouders herkennen we een duale dynamiek waarin ze enerzijds hun volwassen kind willen afschermen van slecht nieuws en potentieel pijnlijke emoties en anderzijds zelf het gevoel hebben afgeschermd te worden van bepaalde informatie door hun eigen kind. Vanuit de interviews tekenen zich drie ouder-kind relatiepatronen af: betrokken ouderschap, beteugeld ouderschap en ouderschap in machteloosheid. De vorm van ouderschap dat oudere ouders uiteindelijk uitoefenen is een resultante van een complex samenspel van kunnen, mogen en willen en wordt bovendien door verschillende factoren beïnvloed zoals de relatiegeschiedenis, de mate van zorgafhankelijkheid en de burgerlijke status van het kind. De zorgzaamheid voor hun zieke kind kan je doortrekken naar een zorgzaamheid voor anderen in hun naaste omgeving die tevens door de kankerdiagnose getroffen worden. Vaak zien we eenzelfde beschermingsreflex ten aanzien van de eigen partner, de schoondochter/-zoon en de kleinkinderen.

In **Hoofdstuk 4** hebben we ons gericht op de ervaring van oudere ouders die rouwen om de dood van hun volwassen kind ten gevolge van kanker. Bij het overlijden van een volwassene richt de omgeving haast automatisch alle zorg en aandacht naar het rouwproces van het kerngezin (m.n. partner en kinderen). Vaak staan deze ouders in de schaduw, omdat verlieservaringen worden beschouwd als eigen aan hun hoge leeftijd. Kenmerkend is dat deze ouders zich op het tweede plan plaatsen, waardoor ze dikwijls zelf niet op zoek gaan naar ondersteuning of waardoor hun pijn niet (meer) herkend wordt. Familie veronderstelt hierdoor vaak dat de impact van het verdriet op de oudere niet groot is. Deze dynamiek zorgt ervoor dat vele ouders het verlies in stilte doorleven. Deze ouders zoeken voortdurend (vaak heimelijk) naar manieren om de emotioneel verbondenheid met hun kind te behouden door het houden van bezittingen en koesteren van herinneringen aan het overleden kind.

Inzicht in de ervaringen van de volwassen kankerpatiënt ten opzichte van hun oudere ouders (en hun ruimere omgeving) wordt gegeven in **Hoofdstuk 5**. Communicatie met de ouders (en de ruimere omgeving), vergde veel besluitvorming waarbij verschillende factoren in overweging genomen werden. Kankerpatiënten moesten kiezen tussen proberen op een manier die het beste overeenkwam met hun eigen voorkeuren te communiceren of communiceren op een manier die het beste voor hun ouders was. De participanten hadden moeite met het vinden van een evenwicht ten aanzien van wat hun ouders moesten weten zodoende ze zich voldoende betrokken voelden zonder dat ze onnodig zouden piekeren. Wat aan de oppervlakte hoorbaar en zichtbaar is in de verhalen van de volwassen kinderen kunnen we samenvatten vanuit drie perspectieven van zich verhouden tot de omgeving, en oudere ouders in het bijzonder, m.n. het IK-perspectief, het ZIJ-perspectief en het WIJ-perspectief. Onder deze perspectieven gaan verschillende processen schuil die niet zo vanzelfsprekend zichtbaar zijn voor de omgeving: zorgzaamheid voor zichzelf-zorgzaamheid voor anderen, openheid-geslotenheid en afstand-betrokkenheid.

In **Hoofdstuk 6** beschrijven we de ervaringen en percepties van verpleegkundigen en zorgkundigen werkzaam in een woonzorgcentrum m.b.t. rouwzorg. De aandacht voor verliessituaties onder de vorm van rouwzorg blijkt niet altijd vanzelfsprekend te zijn en wordt in de hand gewerkt door een samenspel van factoren gerelateerd aan de zorgverlener zelf enerzijds en de zorgorganisatie anderzijds.

Dit doctoraatswerk toont aan dat de ouders niet gezien en erkend worden als ouder en/of hierop aangesproken te worden. Onze bevindingen onderlijnen het belang van systeemgericht multigenerationeel denken in de oncologische zorg. Zorgverleners werkzaam binnen de oncologische en palliatieve zorg en de ouderenzorg kunnen aandachtig zijn voor de schaduwpositie van deze oudere ouders en over de grenzen van instellingen of diensten heen van betekenis zijn voor deze ouders. Afgestemde zorg vereist dat zorgverleners inzicht krijgen in wat er op het spel staat voor zowel de volwassen kankerpatiënt als de oudere ouder(s). Dit proefschrift wijst op ouderschap als een dynamisch proces.

Curriculum Vitae

CURRICULUM VITAE

PERSONAL DATA

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OTHER SPECIFIC TRAINING

Summer course Qualitative Research (UA)
Communication Skills (Doctoral Schools UGent)
Conflict Handling (Doctoral Schools UGent)
Networking skills (Doctoral Schools UGent)
Creative thinking (Doctoral Schools UGent)
Project management (Doctoral Schools UGent)
Speed reading (UZ Gent)
Mind mapping (UGent)
Clinical studies: study design, implementation and reporting (Doctoral Schools UGent)
Effective graphical displays (Doctoral Schools UGent)
Stress management (UGent)
Academic English: Conference Skills (Doctoral Schools UGent)
Academic English: Writing Skills (Doctoral Schools UGent)
Focus Groups: theory and practice (Doctoral Schools VUB)
Systematic review and meta-analysis (Doctoral Schools VUB)
Developing effective interventions to improve public health (Doctoral Schools VUB)
Two day program Qualitative Evidence Synthesis CEBAM KUL
Feedbacktraining (UGent)
Practicumtraining (UGent)

The intensive course on foundational approaches, contemporary and educational issues in the field of nursing ethics (KU Leuven)

Summer Schools (2013-2017): European Association of Nursing Science (Nijmegen, June 23-July 5, 2013; Halle, July 11-July 15, 2016; Malmö, July 3-July 7, 2017)

SCIENTIFIC MEMBERSHIP

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AWARDS

Prijs Belgische Vereniging voor Gerontologie en Geriatrie voor de beste Poster Juniores- 2014

PRESENTATIONS

Abstracts presented in international congresses

2015

Van Humbeeck, L. (2015). Grief at old age: (un)detected by health care providers in nursing homes ? Oral presentation at IAGG-ER 8th Congress, Dublin 2015, 23-26 April.

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Dankwoord

DANKWOORD

Het lezen van dit dankwoord betekent dat het einde van de verdediging van mijn proefschrift en daarmee de afsluiting van een bijzondere periode in mijn leven dichtbij is. De laatste jaren hebben veelvuldig in het teken gestaan van mijn doctoraatstraject. Zonder de inzet en steun van velen was het mij niet gelukt om dit proefschrift te voltooien. Ik wil dan ook graag een aantal personen bedanken.

Speciale dank gaat uit naar DE OUDERS, KANKERPATIËNTEN EN ZORGVERLENERS die we mochten interviewen. Dankzij hun openheid en tijd konden we tot deze bevindingen komen. Ook een grote dank aan zorgverleners en andere personen die hebben meegewerkt aan de rekrutering van participanten. Dit heeft veel geduld en inzet gevraagd, waarvoor dank.

Dit onderzoek was maar mogelijk door de financiële ondersteuning van KOM OP TEGEN KANKER. We willen hen ook bedanken voor hun erkenning van het belang van dit onderzoek.

Verder wil ik ook graag mijn PROMOTOR EN CO-PROMOTOREN bedanken voor hun goede raad, ondersteuning en kritische blik.

In eerste plaats gaat mijn dank uit naar mijn promotor PROF. DR. VAN DEN NOORTGATE. Beste Nele, bedankt voor de bevlogenheid en jouw bereidheid tot samen nadenken, ondanks de overvolle agenda, is erg gewaardeerd. Bedankt voor het vertrouwen dat jij in mij hebt als onderzoeker en de vrijheid die je mij geeft om onderzoekswegen in te slaan.

Dank ook aan PROF. DR. SOFIE VERHAEGHE, die ooit nog de promotor van mijn masterproef was. Bedankt voor het luisterend oor ! Je snelle en kritische feedback was zeer waardevol en jouw suggesties stimuleerden me steeds om verder te gaan.

PROF. DR. PIERS, beste Ruth, bedankt voor je vertrouwen en blijvende motivatie. Je geloof in mijn capaciteiten als onderzoeker en je onvoorwaardelijke vertrouwen in de goede afloop van mijn doctoraat zullen me altijd bijblijven.

PROF. DR. GRYPDONCK, Mieke, bedankt voor je betrokkenheid, secure feedback, het gezamenlijk analyseren. Ik heb het zeer gewaardeerd dat je de stukken elke keer grondig las en van inspirerende, niet altijd even leesbare, suggesties voorzag. Bedankt om me wegwijs te maken in de wereld van kwalitatief onderzoek. Veel dank dat u uw jarenlange expertise in kwalitatief onderzoek en levenswijsheid heeft willen inzetten voor dit doctoraatsonderzoek.

PROF. DR. DEVEUGELE, Myriam, wil ik bedanken als lid van de stuurgroep en begeleidingscommissie. Bedankt voor die ene mail in de laatste feedbackronde die me een boost van vertrouwen gaf.

PROF. DR. MIRKO PETROVIC, PROF. DR. WILFRIED. SCHNEPP, PROF. DR. ANN. VAN HECKE, DR. PETER PYPE, DR. JO HOCKLEY EN VOORZITSTER PROF. DR. KRISTIAN VAN LIERDE wil ik bedanken als leden van de examencommissie. Dank u wel voor jullie constructieve feedback en kritische blik op de eerste versie van dit proefschrift.

Special thanks go to dr. Jo Hockley for her guidance and support throughout the PACE-project. I have thoroughly enjoyed my time in Lancaster and the conversations we had.

Beste LET, wat prijs ik mezelf gelukkig dat je mij hebt begeleid tijdens dit doctoraatsonderzoek. De laatste drie jaar hebben we intens samengewerkt. Projecten afgewerkt en opnieuw opgestart. Dank je wel om samen te innoveren, om de onbekende wegen van actieonderzoek te bewandelen, het meedenken en meeleven, je neus voor detail, de vele teksten na te lezen. Het is een plezier om met jou te mogen werken. Bedankt voor de warme en lieve persoon die je bent !

Mijn (ex-)collega's, vrienden, LET, STEFANIE, GWENDA, KAREN, RUTH, TINA, KATRINA, REBECCA, CYNTHIA, INEKE bedankt voor jullie luisterbereidheid, de ondersteuning, de motiverende babbels, de spontante gedachtewisselingen, het delen van het leed en jullie tips along the way.

Een deel van dit onderzoek gebeurde in samenwerking met masterproefstudenten. Bedankt aan JOLIEN EN SARAH voor de interviews die ik mocht gebruiken. Vele uren zitten er in de zorgvuldige transcriptie van de interviews. Daarvoor wil ik LUDO VANTHOURNHOUT oprecht bedanken. Speciale dank ook aan STEFANIE voor alle hulp bij het vormgeven van het proefschrift. Door het gebruik van koppen, tabs, stijlen ging een hele nieuwe wereld binnen Word voor mij open ☺.

Voor de praktische ondersteuning gaat mijn dank uit naar MIEKE EN VIRGIE. Dank voor het vinden van gaatjes in Nele’s en Ruth’s agenda, het plannen van vergaderingen, het vele printwerk, het regelen van de receptie etc.

HILDE, PETRA, SIGRID EN RÉGINE dank je wel voor de gezellige babbels, het gezelschap tijdens vele etentjes, de opkikkers.

Bedankt ELKE EN FAUNE voor het babysitten zodat ik kon verder werken aan de laatste delen van mijn doctoraat.

Lieve VRIENDINNEN EN VRIENDEN (KIM, TIM, ANN, JOHAN, LINDSAY, KEVIN, AXEL, CINDY, PETRA, JELLE, JAIN, KRISTINE) van de Kempen bedankt om me op de nodige momenten van mijn werk af te leiden tijdens de vele uitstapjes, etentjes en weekendjes weg.

MARIE, FREDDY, VAKE EN ANJA bedankt voor de tijd, energie en liefde die jullie ons in overvloed schenken. Bedankt ook voor de vele ritjes die jullie naar het verre Zele maken.

Een speciale dankjewel voor MOEKE EN ERIC, voor jullie interesse, steun, voor jullie hulp in ons huishouden. Superdikke merci om er voor te zorgen dat ik weloverwogen keuzes maakte en jullie me stimuleerden om het Gentse avontuur op te zoeken. Lieve moeke je bent een ontzettend groot voorbeeld voor me. Ik ben trots op wat je allemaal bereikt hebt. Jouw doorzettingsvermogen en je manier van opvoeden zijn een inspiratie.

Lieve PETER, je hebt het volste vertrouwen in mij gehad en gehouden. Je diepgewortelde liefde voor mij maakte dat je mee de sprong waagde naar Oost-Vlaanderen. Vijf jaar later hebben we samen een huis gekocht en Victor op de wereld gezet. Dank je dat je er voor me bent !

VICTOR, lieve zoon van me. Je hebt mij de wereld met heel andere ogen laten zien (lees: kleine, vermoeide ogen met donkere randen en wallen eronder). Het is zo leuk om jou bezig te zien, hoe jij naar dingen kijkt. De gelukzalige momentjes van samen spelen en het toekijken terwijl je ligt te slapen. Maar ook je hemeltergende kuren en de “ik ben wakker” momentjes stipt om vijf uur ’s morgens horen erbij. Ik heb de afgelopen 14 maanden samen met je papa ontdekt dat het ouderschap in zekere zin paradoxaal is: je geeft de volledige liefde aan je kind om het op weg te helpen weg te groeien van zijn ouders en onafhankelijk van hen te worden. In die zin herken ik het balanceren van de geïnterviewde oudere ouders zeer goed. En nu snap ik zeer goed wat men met volgende quote bedoelt:

“You don't really understand human nature
unless you know why a child on a merry-go-round will wave
at his parents every time around- and why
his parents will always wave back.”
William D. Tammeus

Liesbeth Van Humbeeck

Zele, November 2016

Appendix I.

Table S1. Characteristics of extracted qualitative studies.

Authors, year, country	Methodology	Sample	Results	Limitations
Cacace and Williamson, 1996, USA[24]	Qualitative Semi-structured interviews	Convenience sample *N*=7 parents (4 women, 3 men) Age range parents: 60-72 y. Age range children: 18- 45 y. Time Since Death (TSD): 1-2 y. Cause of death: cancer	5 themes: • Personal disruption • Unnatural survivorship • Isolation • Reminders • Coping strategies	Relatively small and self-selected sample. Inclusion of only one ethnic group. No longitudinal analysis.
Dean et al., 2005, Canada[21]	Descriptive, explorative qualitative study	Convenience sample *N*=13 parents (9 women, 4 men) Age range parents: 40-77 y. Age range children: 21-54 y. Cause of death: cancer	• A tension between a strong desire to "parent" the sick adult child, and recognizing their child as an autonomous adult, sometimes with a spouse and family who take precedence over them. • Parents felt helpless, and sometimes unrecognized by health care professionals. • To cope, they reconfigured their parent role using various strategies. • After the death of their child further reconfiguring takes place, including preserving memories of the child, and talking about him/her.	Inclusion of one ethnic group. No longitudinal analysis.

Edvardsson and Ahlström, 2008, Sweden[20]	Mixed method Descriptive qualitative and quantitative data analysis	*N*=28 (of which 8 parents) Age range parents: 25-77 y. (mean = 52.5 y.) Diagnosis: low-grade glioma	Qualitative analysis: 4 themes: • Extremely stressful emotions • Being invisible and neglected • Changed relations and roles • Enabling strength in everyday life Quantitative analysis: The theme 'Extremely stressful emotions' was predominant in the case of patient's parents compared to spouses and siblings.	Focus on one type of cancer. No longitudinal analysis. Small subsample of parents. No data on age children.

Table S1. Characteristics of extracted qualitative studies. ***[Continued]***

Authors, year, country	Methodology	Sample	Results	Limitations
Fisher, 2010, USA[26]	Qualitative In-depth semi-structured interviews	Purposive sample *N*=78 (40 diagnosed women in young, middle, and later adulthood and 38 of their mothers/daughters) Three age groups (diagnosed women): 8 young adults (age range 30-39 y.) 20 midlife adults (age range 42-51 y.) 12 later-life adults (age range 57-69 y.) Three age groups (mothers and daughters of diagnosed women): 25 young adults (age range 18-37 y.) 5 midlife adults (age range 51-56 y.) 8 later-life adults (age range 58-83 y.) Diagnosis: breast cancer	Similar experiences across age. • Adaptive emotional support communication: - Listening without interruption or unsolicited advice - Showing affection - Humour • Adaptive and maladaptive emotional support communication: - Staying positive Unique emotional support experiences across the life span. Diagnosed young-adult women and their mothers: “Being there” - Verbal expressions - Physical and emotional component of “being there” - Respecting each other’s space, to be aware of each other’s need for space - Health advocacy	No longitudinal analysis. Only mothers. No data on the exact number of mothers that participated.

Goodman et al., 1991, USA[16]	Qualitative In-depth interviews Ethnography	*N* =29 mothers Age range parents: 61-93 y. Cause of death: violent (murder, accident, suicide) and non-violent (acute and chronic illness)	Comprehensive analysis of the qualitative data from Jewish and non-Jewish bereaved mothers found three foci of difference: • The meaning of the death for the mothers • Their expression of grief • Their ability to restore themselves in the face of their loss	No description of analysis. No longitudinal analysis. No sociodemographic details about the children who died. Fail to address the potential role of cultural issues within the interview context itself.
Harper et al., 2011, UK[23]	Qualitative Interpretative phenomenological analysis	Convenience sample *N*=13 bereaved mothers Age range parents: 32-64 y. (mean = 52 y.) TSD (range): 1-40 y. (mean = 10 y.) Age range children: 0-29 y. Cause of death: cancer, acute illness, suicide, accident	Two main themes: (1) A continuing bond with the deceased • The physical connection • Linking objects • Symbolic representation (2) The prevalence of death and suicidal ideation • Ambivalence to personal mortality • Influence of other children	The interviewer was also a bereaved parent. Interviews with mothers only. No longitudinal analysis.
Lindholm et al., 2002, Sweden and Finland[6]	Qualitative A phenomenological case study approach	Purposeful sampling *N*=34 (17 women with breast cancer and 16 significant others) 1 mother included (6% of total sample) Age range women: 35-69 y. Diagnosis: breast cancer	The suffering of the significant other is experienced as a suffering ‘at second place’. It takes the form of standing close to their relative and experiencing a feeling of captivity in uncertainty and powerlessness. They live in a crossfire between the women’s and their own suffering. A vicious circle of mutual protection can intensify the suffering of the significant other.	Different family members included. No longitudinal analysis. Only small subsample of older parents. Only mothers. No sociodemographic data of significant others

Table S1. Characteristics of extracted qualitative studies. *[Continued]*

Authors, year, country	Methodology	Sample	Results	Limitations
Persson and Sundin, 2008, Sweden[30]	Qualitative Phenomenological hermeneutic approach Narrative interviews	Participants were recruited from an on-going longitudinal study. *N*=12 (6 women, 6 men): 5 partners, 6 children, 1 parent (8% of total sample) Age range participants: 24-83 y. Diagnosis: inoperable lung cancer	4 main themes: (1) Feeling dislocated in life (2) Being in an altered relationship (3) Being in a struggle (4) Feeling secure	Only one parent included. No longitudinal analysis.
Raveis et al., 2010, USA[28]	Qualitative In-depth interviews	*N* =13 mothers Age range mothers: 56-78 y. (mean = 68 y.) Age range daughters: 34-56 y. Diagnosis: breast cancer	3 main themes: (1) Family members' emotional responses to the illness • A cacophony of emotions • Feeling enervated, paralyzed and overwhelmed • Confronting an altered and uncertain future (2) Family functioning during the illness • Reawakening of parental nurturing • Parental rights and responsibilities • Asynchronous development event in family life cycle (3) Heredity and breast cancer • Reactions to personal risk • Culpability	Focus on one type of cancer. No longitudinal analysis. Only mothers.

Smith et al., 2011, USA[31]	Qualitative Hermeneutical approach Focus groups	Convenience sample *N*=31parents (28 mothers, 3 fathers) Mean age parents: 72.63 y. TSD: 1-16y. (mean = 5 y.) Causes of death: heart disease, cancer, suicide and homicide	4 themes: (1) Losses • Special relationship • Achievements • Purpose in life • Present or future caregiver (2) Limited influence/power • Adult child's behaviour before death • Not present at time of death • Funeral arrangements (3) Regrets (4) Diminished Quality of Life • Broken heart/decreased joy • Survivor's guilt • Grandchildren	It can be questioned whether focus groups are the ideal method to investigate the lived experience of these parents. No longitudinal analysis.
Toller, 2008, USA[34]	Qualitative Semi structured interviews Grounded theory	*N*=53 parents (36 women, 17 men) Age range parents: 27-64y. TSD range: 6 months – 29 years Causes of death: violent (suicide, accident) and, non-violent (SIDS, stillbirth, illness)	• The death of a child impacts how bereaved parents perceive themselves as parents. • Experience of competing identities: being a parent without a child to parent and being both an insider and an outsider. • The powerful role of rituals.	Large variation in the length of time elapsed since death of child . Inclusion of parents whose children died at birth and children who died as adults. No longitudinal analysis.

Table S1. Characteristics of extracted qualitative studies. ***[Continued]***

Authors, year, country	Methodology	Sample	Results	Limitations
Wideheim et al., 2002, Sweden[5]	Qualitative Prospective study Interviews occurring 2-3 weeks after surgery and 3 and 6 months after the onset of the illness	*N*=3 patients (1 men, 2 women): *N*=5 next of kin (2 partners, 2 parents and 1 adult child) Age range patients: 25-88 y. (mean = 62 y.) Diagnosis: malignant glioma	(1) Onset of illness and learning the diagnosis • Deviant behaviour • Distancing • Recognition of death (2) Daily life • Fear and anxiety regarding losing the sick person • Physical and mental burden • Support and protection • Return to a normal life • Hope • Prevent ill health • Learn to cope (3) The encounter with staff and information received	The analysis is done by a person other than the interviewer. Small sample size. No longitudinal analysis. No sociodemographic data of next of kin.

Note. TSD = Time since Death

Table S2. Characteristics of extracted quantitative studies.

Authors, Publication date, Country	Methodology	Sample	Results	Limitations
Arbuckle and de Vries, 1995, USA[19]	Quantitative Measures of perceived health, self-efficacy, depression, life satisfaction, and future orientation	Subsample of large national survey 3 groups: - Bereaved parents - Bereaved spouses - Non-bereaved Bereaved parents: *N*=41 (22 women, 19 men) Mean age parents: 71.1 y. Mean TSD: 6.4 y. Cause death: no details	• Long-term effects on the personal functioning of older women and men after the loss of a spouse or an adult child. • Bereavement and gender effects.	Modest coefficients of reliability of used instruments. Instruments tested on and developed for younger populations. Reliance on secondary data. No data on age children and causes of death. Only small number of bereaved parents available within the sample for analysis.
Azaiza et al., 2011, Israel[32]	Quantitative Measures of fear of death and dying and religiosity	Convenience sample *N*=97 (49 bereaved parents, 48 non-bereaved parents) Mean age parents: 74 y. Age children at death: birth-52 y. Cause of death: violent (war, accident, suicide) and nonviolent (illness)	• Bereaved parents had significantly higher dying anxiety scores than nonbereaved parents. • No significant differences between the 2 groups in death anxiety. • Religiosity was unrelated to death and dying anxiety. • Dying anxiety was higher among bereaved mothers than bereaved fathers. • Death and dying anxiety were not associated with TSD or the nature of the child's death.	Not many socio-demographic details. Recruitment from one specific geographical region and cultural context. Small sample size. In the analysis no differentiation was made between violent and nonviolent death.

Table S2. Characteristics of extracted quantitative studies. ***[Continued]***

Authors, Publication date, Country	Methodology	Sample	Results	Limitations
Ell et al., 1988, USA[18]	Quantitative Semi-structured interviews Measures of stage of disease, social support, personal sense of control, psychological adaptation	Sequential sample drawn from the cancer registries of 23 hospitals *N*=230 (152 spouses and 78 non-spouses): 120 women, 110 men Age of (non)-spouses: 14-86 y.(range), 50.1y. (mean) Mean age patients: 60 y. Patient's first diagnosis of breast, colorectal or lung cancer.	• Patients and significant others differ in psychological adaptation and in coping resources. • The psychological adaptation of patients and non-spouses was not significantly correlated. • The psychological adaptation of patients and spouses was highly intercorrelated.	No specification of category non-spouses. No subgroup analysis possible. No insight in how many were parents. Possible sampling bias: significant differences found between participants and non-participants with regard to gender, ethnicity and age.
Gilbar and Refaeli, 2000, Israel[22]	Quantitative Relationship between ill adult's adjustment to the illness and that of his/her parent in initial phase of the illness (3-4 months after diagnosis)	Sample drawn of computerized lists of newly diagnosed patients being treated in four oncology clinics *N*=41 parents (29 women,12 men) of an adult married cancer-diagnosed child Mean age parents: 68.5 y. Mean age child: 40.1y.	• A positive correlation between the adult child's adjustment to the illness and that of his/her parents. • A positive correlation between family support and adjustment to the illness on the part of the adult cancer patients. • Increased contact is initiated by parents with their ill adult child, and by the ill adult child toward his/her parent.	Small sample size. One-time assessment. Interviews with just one parent. Wide age range of both the patients and the parents.

Gilbar, 2002, Israel[27]	Quantitative Assessment of adjustment to illness, psychological distress, social support, the nature of kinship relationships	Sample drawn of computerized lists of newly diagnosed patients being treated in four oncology clinics *N*=41 parents (29 women,12 men) of an adult married cancer-diagnosed child Mean age parents: 68.5 y. Mean age child: 40.1y. Same as study 4	• Positive correlation between the psychosocial and psychological adjustment of the parents, and the amount of social support the parent receives. • Less social support is related to better psychological adjustment problems. No association between parent's social support and psychosocial adjustment. • Better adjustment of parents to illness if they receive more social support and when their child feels less distress.	Small sample size. One-time assessment. Wide age range of both the patients and the parents.
Lesher and Bergey, 1988, USA[25]	Quantitative Structured interviews Six domains: demographic background information, health information, the death and dying process of the adult child, help-seeking behaviour, changes in functional activities and family cohesion, thoughts and feelings regarding bereavement	Convenience sample of widowed nursing home residents bereaved of an adult child *N*=18 (women) Age range mothers: 79-96 y. TSD (mean): 6 y. Cause of death: no details	• Significant increase in mean number of reported health conditions since the death of the adult child. • A trend towards poorer health status among bereaved mothers. • No increase in cohesion between bereaved mother and her surviving children • Increased cohesion between bereaved mother and the children of the surviving adult child	The participants had to be widowed as well as bereaved of an adult child. It is not clear to what extent the findings are confounded by the impact of the spousal loss. The authors don't provide reasons for limiting the study to only bereaved mothers. No socio-demographical data.

Table S2. Characteristics of extracted quantitative studies. ***[Continued]***

Authors, Publication date, Country	Methodology	Sample	Results	Limitations
Milberg et al., 2004, Sweden[17]	Mixed-methods Cross-sectional Postal questionnaire with both Likert-type and open-ended questions	N = 233 (144 women, 89 men): 5 parents (2% of total sample) Age range next of kin: 31-91 y. (mean = 65 y.) Age range patients: 23-94 y. (mean = 73 y.) Diagnosis: different types of cancer	4 main components of powerlessness and/or helplessness: (1) Perception of patient's suffering (2) Perception of patient's fading away (3) Feeling of insufficiency (4) Reactions to powerlessness and helplessness	Questionnaire has not been tested for test-retest reliability, criterion and construct validity. Only small subsample of parents.

Note. TSD = Time since Death

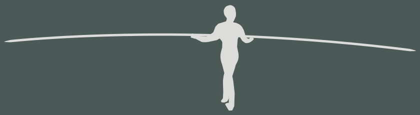
PARENTING A MIDDLE-AGED CHILD WITH CANCER

A DELICATE BALANCING ACT FOR PARENTS, CHILDREN AND HEALTH CARE PROVIDERS

LIESBETH VAN HUMBEECK

The past two decades have seen an influx in the literature in regards to partners' psychological response to cancer. Unlike the breadth of literature on these middle-aged children or spouse caregivers, there is a dearth of literature about the cohort of older parents and the impact that care provision has on their mental health and well-being. Parent-child relationships are usually lifelong and reciprocal and older parents can assume particular significance when a middle-aged child has cancer.

In this dissertation, several original studies are presented that provide insight into both the experiences of older parents and middle-aged cancer patients. This dissertation broadens our understanding of communicating with older parents amid a cancer experience and highlights the mutual influence parents and children exert.
In addition, we focused on the experience of bereaved older parents of whom the adult child died due to cancer. Besides this we sought to know how nursing staff (nurses and care-assistants) deal with grieving residents in nursing homes. Our insights were gained by means of literature review, and qualitative research based on constructivist grounded theory.



Parenting a middle-aged child with cancer:
a delicate balancing act for parents, children and health care providers
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