

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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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

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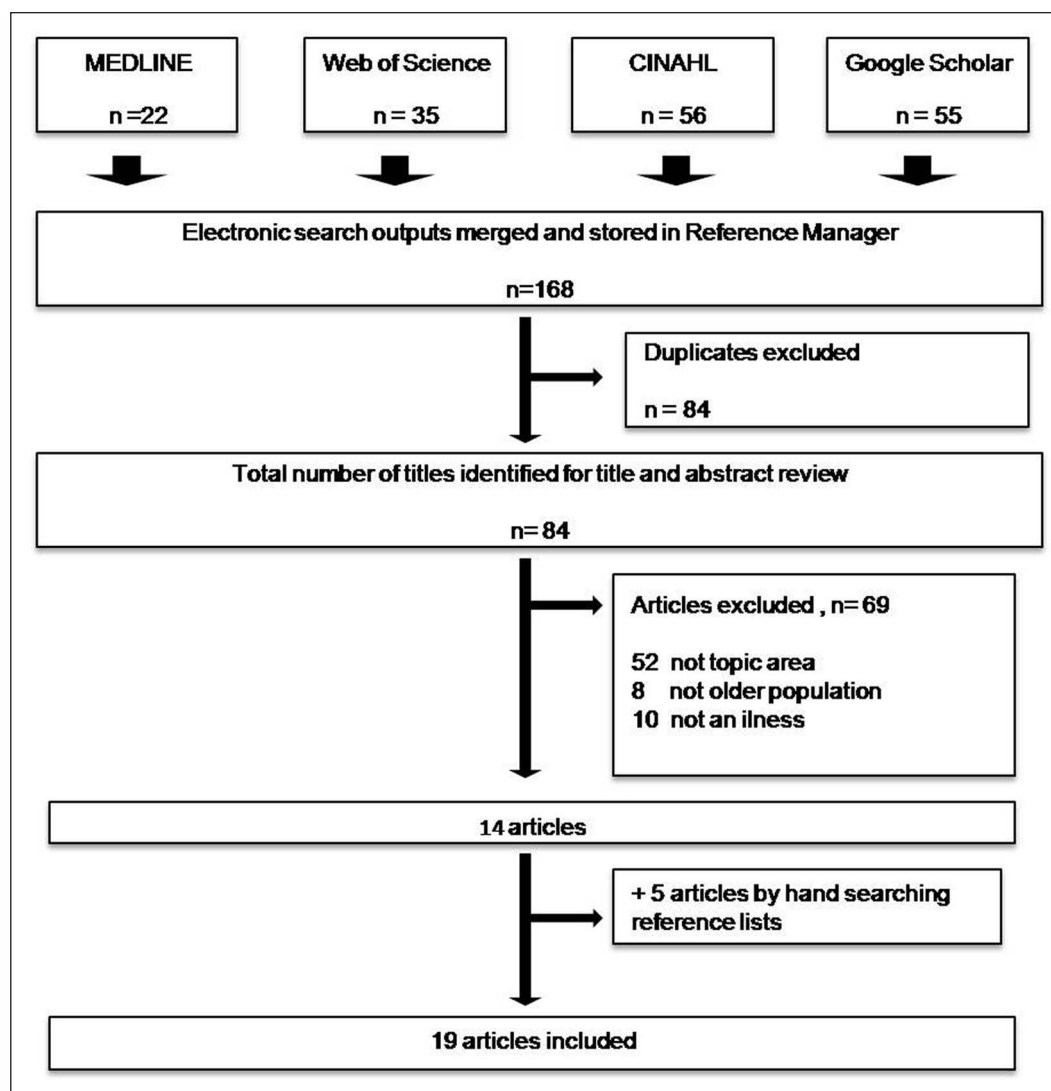


Figure 1. Flow chart of selection process of studies.
CINAHL: Cumulative Index to Nursing and Allied Health Literature.

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.

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

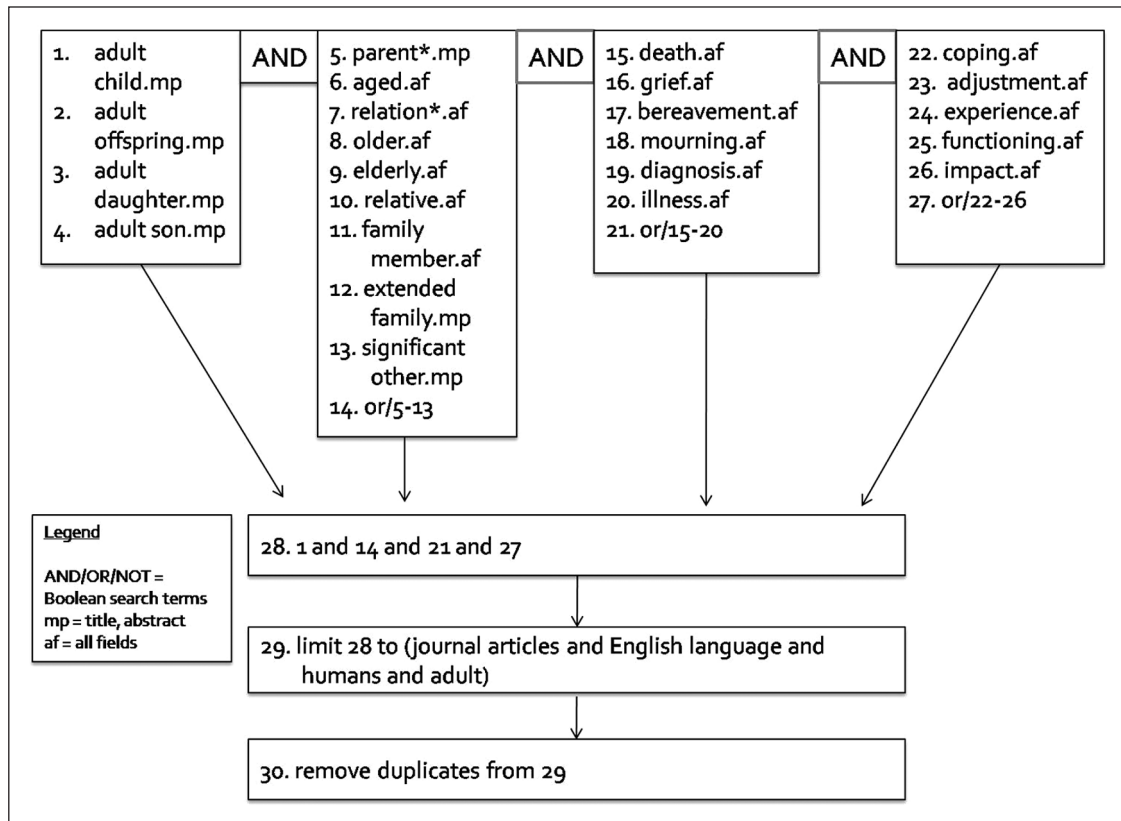


Figure 2. Search strategy.

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. 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.

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 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. More comprehensive

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

Study	Country	Methodology	Sample	Limitations	Clarity of reporting (0–8)	Robustness of the study methods (0–8)	Quality assessment sum-score (0–16)
1. Cacace and Williamson ²⁴	United States	Semi-structured interviews	N = 7 (4 mothers and 3 fathers)	Relatively small and self-selected sample	6	4	10
		Grounded theory	Age range parents: 60–72 years Age range children: 18–45 years Cause of death: cancer	Inclusion of only one ethnic group No longitudinal analysis			
2. Dean et al. ²¹	Canada	Semi-structured interviews Latent content analysis	N = 13 (9 mothers and 4 fathers) Age range parents: 40–77 years. Age range children: 21–54 years Cause of death: cancer	Inclusion of one ethnic group No longitudinal analysis	7	6	13
3. Edvardsson and Ahlström ²⁰	Sweden	Interviews Latent content analysis	N = 28 (of which 8 parents) Age range parents: 25–77 years Diagnosis: low	Focus on one type of cancer Small sub-sample of parents No data on age children	6	4	10
4. 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
5. Goodman et al. ¹⁶	United States	In-depth interviews Ethnography	N = 29 mothers Age range parents: 61–93 years Cause of death: violent and non-violent	No description of analysis and no longitudinal analysis No socio-demographic details about deceased children Fail to address the potential role of cultural issues within interview context	6	3	9
6. Harper et al. ²³	United Kingdom	Interviews Interpretative phenomenological analysis	Convenience sample N = 13 bereaved mothers	The interviewer was also a bereaved parent Interviews with mothers only	7	6	13

(Continued)

Table 1. (Continued)

Study	Country	Methodology	Sample	Limitations	Clarity of reporting (0–8)	Robustness of the study methods (0–8)	Quality assessment sum-score (0–16)
7. Lindholm et al. ⁶	Sweden	Interviews	Age range parents: 32–64 years Age range children: 0–29 years Cause of death: cancer, acute illness, suicide, accident N = 33 (17 women with breast cancer and 16 significant others)	No longitudinal analysis Different family members included	7	7	14
	Finland	Phenomenological case study approach	One mother included as significant other (6% of total sample) Age range women: 35–69 years Diagnosis: breast cancer	No longitudinal analysis Only small sub-sample of older parents Only mothers No socio-demographic data of significant others			
8. Persson and Sundin ³⁰	Sweden	Narrative interviews	N = 12 (6 women and 6 men): 5 partners, 6 children and 1 parent (8% of total sample)	Only one parent included	7	6	13
		Phenomenological approach	Age range participants: 24–83 years Diagnosis: inoperable lung cancer	No longitudinal analysis			
9. Raveis et al. ²⁸	United States	In-depth interviews	N = 13 mothers	Focus on one type of cancer	6	6	12
		Content analysis	Age range mothers: 56–78 years Age range daughters: 34–56 years Diagnosis: breast cancer	No longitudinal analysis Only mothers			
10. Smith et al. ³¹	United States	Focus groups	N = 31 parents (28 mothers and 3 fathers)	It is questionable if focus groups are ideal method to investigate lived experience of these parents	5	4	9
		Hermeneutical approach	Mean age parents: 72.63 years Causes of death: heart disease, cancer, suicide and homicide	No longitudinal analysis			

(Continued)

Table 1. (Continued)

Study	Country	Methodology	Sample	Limitations	Clarity of reporting (0–8)	Robustness of the study methods (0–8)	Quality assessment sum-score (0–16)
I1.Toller ³⁴	United States	Semi-structured interviews	N = 53 (36 mothers and 17 fathers)	Large variation in time since death	8	4	12
		Grounded theory	Age range parents: 27–64 years	Inclusion of parents whose children died at birth and children who died as adults			
			Causes of death: violent and non-violent	No longitudinal analysis			
I2.Wideheim et al. ⁵	Sweden	Interviews	N = 3 patients (1 men and 2 women) and N = 5 next of kin (2 partners, 2 parents and 1 adult child)	The analysis is done by a person other than the interviewer	6	5	11
		Prospective study	Age range patients: 25–88 years	Small sample size			
		Content analysis	Diagnosis: malignant glioma	No longitudinal analysis No socio-demographic data of next of kin			

tables can be consulted as supplementary files online (Tables S1 and S2).

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

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

Study	Country	Methodology	Sample	Limitations	Clarity of reporting (0–8)	Robustness of the study methods (0–5)	Quality assessment sum-score (0–13)
1. Arbuckle and de Vries ¹⁹	United States	Questionnaire	Three groups (bereaved parents, bereaved spouses, non-bereaved) Bereaved parents: $N = 41$ (22 women, 19 men)	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
2. Azaiza et al. ³²	Israel	Questionnaire	Mean age parents: 71.1 years $N = 97$ (49 bereaved parents, 48 non-bereaved parents) Mean age parents: 74 years Age range children: birth–52 years Cause of death: violent and non-violent	Lack of socio-demographic details Recruitment from one specific geographical region and cultural context. Small sample size No differentiation in analysis between violent and non-violent death	7	3	10
3. Fisher ²⁶	United States	Semi-structured interviews	$N = 230$ (152 spouses and 78 non-spouses): 120 women, 110 men Age of range (non-) spouses: 14–86 years Mean age patients: 60 years	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
4. Gilbar and Refaeli ²²	Israel	Questionnaire	Patient's first diagnosis of breast, colorectal or lung cancer. $N = 41$ parents (29 women and 12 men) of an adult married cancer-diagnosed child Mean age parents: 68.5 years	Small sample size One-time assessment	8	3	11

(Continued)

Table 2. (Continued)

Study	Country	Methodology	Sample	Limitations	Clarity of reporting (0–8)	Robustness of the study methods (0–5)	Quality assessment sum-score (0–13)
5. Gilbar ²⁷	Israel	Questionnaire	Mean age child: 40.1 years N = 41 parents (29 women and 12 men) of an adult married cancer-diagnosed child Mean age parents: 68.5 years Mean age child: 40.1 years	Interviews with just one parent Wide age range of both the patients and the parents Small sample size One-time assessment	6	3	9
6. Leshner and Bergey ²⁵	United States	Structured interviews	N = 18 (women) Age range mothers: 79–96 years	Participants had to be widowed as well as bereaved of an adult child Authors do not provide reasons for limiting study to only bereaved mothers	6	3	9
7. Persson and Sundin ³⁰	Sweden	Questionnaire	Cause of death: no details N = 233 (144 women and 89 men): 5 parents (2% of total sample) Age range next of kin: 31–91 years Age range patients: 23–94 years Diagnosis: different types of cancer	No socio-demographical data Questionnaire not been tested for test-retest reliability, criterion and construct validity Only small sub-sample of parents	8	3	11

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-sides' 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} Gilbar²⁷ 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 study¹⁸ 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.

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Conflict of interest

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

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