


An Exploratory Study of Grief and Health-Related Quality of Life for Caregivers of People With Dementia

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Abstract

The aim of this qualitative study was to explore key positive and negative factors that impact on grief resolution and health outcomes of caregivers who were caring, or had cared, for a family member with dementia who had died. The study was a scoping study and involved face-to-face interviews with these family caregivers (N = 13). Results indicated a complex interaction of issues (many unique to dementia caregiving) which in different combinations acted as protective or risk factors for caregiver outcomes. Interaction of individual characteristics, role appraisal, value of intrinsic and extrinsic resources, and experiences with health professionals during the caregiving period and around the death of their relative were shown to have the most influence on caregiver outcomes. Psychological resilience and satisfaction with caregiving were protective against negative outcomes while unresolved grief was a risk factor. These findings highlight the potential benefits of multicomponent, holistic dementia caregiver interventions.

Keywords

dementia, family caregivers, grief, health outcomes, protective and risk factors

Introduction

The vital role of, and the burden placed on, family caregivers of people with dementia, whether the relatives reside in care facilities or at home, has gained increasing recognition.^{1,2} Family caregiving for people with dementia is now regarded as an important health issue, and the need to support these caregivers, especially when the care recipient is in the severe stage of the disease and beyond their death, is crucial.³⁻⁵

The trajectory of dementia from the early stage to the terminal stage that varies with individuals presents challenges for professional and family caregivers alike and has been described as “long dying.”⁶ For family caregivers, this represents not only a series of losses but also potential conflict provoking decisions compounded by guilt and the inability to explain and reassure their relative as a result of communication challenges posed by their cognitive decline.² In addition, family caregivers of people with dementia have been described by Doka⁷ as having endured a continuous and profound sense of loss through the deterioration of their loved one including their psychosocial death. Doka⁸ also states that grief is the constant yet hidden companion of dementia and may be complicated for the family caregiver after death by issues that have been confronted throughout the caregiving experience. These challenges faced by the caregivers are significantly linked to the long and variable trajectory of the role of caregiver for a person with dementia and contribute to their experience of predeath or anticipatory grief. Anticipatory grief can have a protective

influence, ameliorating postdeath grief, or a negative influence, exacerbating postdeath outcomes.⁹ Two elements that are integral to anticipatory grief and contribute to a more complex response to the death are ambiguous loss and disenfranchised grief. Ambiguous loss takes away the possibilities of closure and occurs when a loved one is physically present but psychologically absent. Disenfranchised grief develops through lack of understanding or acknowledgment by significant others with the depth of grief commensurate with the losses inherent in caring for a relative with dementia.^{7,10,11} With family caregivers of people with dementia, this issue of disenfranchised grief and ambiguous loss is particularly relevant and has the potential to be a barrier to addressing their grief.^{3,12,13}

The greater burden of care on this group compared to other caregivers together with the experience of anticipatory grief places them at greater risk of maladaptive emotional coping

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strategies that culminate in adverse outcomes.¹⁴ Complicated or prolonged grief is one such outcome with 20% of bereaved caregivers of people with dementia diagnosed with complicated grief in a study by Schulz et al.¹⁵ Complicated grief occurs when integration of the death into their ongoing life does not take place following bereavement and normal grief¹⁶ and has become a significant topic of grief and bereavement research in general^{17,18} and more specifically in caregivers of people with dementia.^{15,19}

The role of grief, both anticipatory and complicated grief, has not been previously widely considered as a factor in its own right and it has largely been subsumed under the rubric of depression and burden.²⁰ Recent studies on grief in caregivers of a relative with dementia have concluded that grief is one of the greatest barriers to caregiving and is a primary determinant of caregiver's well-being.²⁰⁻²²

The reality of these issues and challenges for caregivers of people with dementia is profound; however, a growing body of literature is indicating that a focus on caregiver perceptions of positive aspects of their role has the potential to ameliorate the negative outcomes, for example, valuing the time to prepare for the death, relief at the end of suffering for their loved one, and placing value on services and support.¹⁵ The value of identifying and integrating these positive aspects into research and development of interventions aimed at supporting these caregivers has been demonstrated.²³⁻²⁶ Despite this, negative post-death outcomes relating to grief are a reality for many caregivers and a sizeable minority continues to experience postdeath psychiatric morbidity.¹⁵

Limited studies have been undertaken to explore the influence of grief as a factor within the multiple, complex series of circumstances experienced by caregivers of people with dementia^{21,27} or to include positive perceptions of some experiences.^{23,28} Many studies in this area have tended to focus on burden and the impact of individual characteristics, issues, or experiences at a single point in time.^{15,29} The interaction of factors, including grief, over the caregiving period has not generally been comprehensively addressed.^{27,30} The study described in this article is exploratory and seeks to address the gap identified in the literature through focusing on the influence of grief and other aspects of the long-term dementia caregiving experience.

Conceptual Framework

Identifying a conceptual or theoretical framework or model that had the capacity to capture the complexity of events and issues that influence caregivers contributing to both burden and resolution of caregiving experiences posed a challenge. The objective was to identify a model that was sufficiently robust to support a holistic investigation of caregiver adaptation over time.²⁶ Ultimately, the conceptual framework that underpinned the study was based on the integration of 2 conceptual frameworks, both of which are based on the concept of adaptation of the individual over time. The first, Kramer's²⁶ Conceptual Model of Caregiver Adaptation views the individual as a

system that adapts prospectively through 3 domains: Background and Context, Intervening Processes, and Well-being Outcomes.²⁶ The use and value of resources are postulated to provide an interface between the first and the second domains in this model. The second model is Boelen et al's³¹ Cognitive-based Behavioural Conceptualisation of Complicated Grief in which complicated grief is postulated to also develop prospectively through 3 domains similar to that of Kramer's. These are Background Variables, Intervening Processes, and Persistent Complicated Grief.³¹ The integrated framework developed for this study consisted of 3 domains drawn from these models with elements within these domains capturing caregiver experiences and outcomes. These were: Background Variables—individual characteristics of caregivers and relatives with dementia; Intervening Processes—caregiving experiences and appraisal of the role of caregiver in terms of both strains and gains; and Outcomes—grief and health outcomes. In a similar way to Kramer's²⁶ model, use and influence of resources were postulated to provide an interface between the first and second domains in this framework. Adaptation of the caregivers to their role is postulated to occur over the time spent as caregiver with experiences and outcomes represented by the elements in each domain exerting a flow-through effect from the first through to the second and then the third domain. This study included elements from all the domains within this conceptual framework, exploring their interaction and highlighting indications of their influence on the caregivers that would warrant further, more focused research in future studies.

Method

Aim and Research Questions

The aim of this qualitative exploratory scoping study was, in conjunction with the literature, to inform future research and practice in relation to caregivers of people with dementia. The broad research questions that guided the study were:

What are the most significant issues central to the experience of being the primary family caregiver of a person with severe dementia?

What are the most significant issues central to experiencing the death of a relative after being engaged in the role of primary family caregiver?

Study Participants

This was a descriptive qualitative study that explored and highlighted experiences and issues that most influenced caregivers of people with dementia both prior to and following the death of their relative. Purposive recruitment of the participants in the study, as described by Huberman and Miles,³² was an attempt to ensure that they were representative of the range of these caregivers. Participants were either spouses or adult children of people with dementia and met the following inclusion

criteria: an English-speaking and cognitively sound spouse or adult child who had been the primary family caregiver of a relative with a formal diagnosis of dementia for a minimum of 1 year and currently caring for their relative at home or whose relative had been placed in a care facility or the surviving caregiver of a relative who had died in the previous 12 months.

A sample size of 13 was considered adequate based on the characteristics of sample sizes in qualitative research described by Huberman and Miles³² who explain that in qualitative research, small samples of people are studied in depth, and researchers do not seek statistical significance. This study was descriptive and exploratory and as such was not intended to make causal links but to provide indications of important factors that influence caregivers of people with dementia.

Procedure

The location for this study was South East Queensland in Australia, and several major aged care (including dementia care) organizations in South East Queensland were identified as potential recruitment points for the study. Ethical clearance to conduct the study was obtained from Queensland University of Technology and participating organizations prior to undertaking recruitment. Recruitment flyers explaining the purpose of the research and the requirement that participants would participate in face-to-face taped interviews were presented to family caregivers who were identified by managers as potential research participants. Caregivers who expressed an interest in participating in the study were given the option of making contact with the researcher directly or giving permission for the researcher to contact them. Ultimately, 13 family caregivers agreed to participate in the study.

Data Collection

Participants (N = 13) were provided with a participant information sheet informing them of their rights and assuring confidentiality and an informed consent document, including consent to audiotape the interview. Following informed consent, face-to-face interviews were carried out by the first author at the venue of choice of the caregivers (10 at their home, 2 at the facility where the relative with dementia was living, and 1 at the participant's place of work). Interviews ranged between 40 and 60 minutes in length, with an average length of 47 minutes.

The semistructured interviews consisted of open-ended questions and covered a series of domains that had been selected based on current research relevant to the conceptual framework, study aim, and research questions. The premise that underpinned these interviews is summarized by Howitt and Cramer³³: "the agenda is less clearly researcher led... and is led by the concerns as felt by the participants." All the interviews began with the same open-ended, broad global question "What are your perceptions of being a family caregiver for a person with dementia?" This strategy provided the opportunity for participants to lead the discussion rather than have the

researcher influence responses through a more structured interview format. Evidence of the value of this was shown in the range of perspectives taken by participants. Following the initial broad questions, a series of predetermined domains based on the literature in this area were used to guide each interview in the same open-ended way and allowed the participants to respond without direct and specific prompting.

The domains that guided the interviews were perceptions of role and relationship with the care recipient; positive aspects of the caregiving experience (satisfaction or gains); challenges encountered throughout the caregiving experience; impact of other individuals/organizations on the participant caregiving experience; perceptions of end of life for the care recipient; and constructive reflections—what would be changed/done differently.

Data Analysis

The taped interviews were transcribed verbatim by the first author as each was completed which facilitated the contextualization of discussions where recordings were unclear and resulted in a high level of familiarity with the data that assisted with the analysis, as recommended by Huberman and Miles.³²

Problem-Driven Content Analysis. Problem-Driven Content Analysis (PDCA) as presented by Krippendorff³⁴ was used to analyze the interview transcript data. The central tenet of PDCA is to convert problems into questions and then attempt to answer them through a purposive examination of the texts.³⁴ As this was an exploratory study, the problem being considered was broad and encompassed many issues associated with family caregiving of people with dementia. The questions to which this complex problem were converted for analysis were the study research questions detailed previously.

According to Krippendorff,³⁴ the aim of PDCA is to make abductive inferences from texts and it is this that distinguishes it from other forms of analysis. Abductive inferences differ from deductive and inductive inferences in that abductive inferences are "made from texts to phenomena outside the texts"³⁴ rather than inferences that refer to the features of the same phenomenon being extrapolated either to a smaller (deductive) or to a larger (inductive) population, respectively. In this study, abductive inferences were made from the texts (interview transcripts) that focused on the experiences of the caregivers throughout and beyond their caregiving role to the phenomena outside the texts, in this case impact on the caregivers. Inferences applied in this way are not intended to demonstrate causal links but have the potential to identify areas for further, more rigorous, scrutiny.

Themes and categories were developed through scrutiny of the significant statements of participants in the interview transcripts, following which codes were developed for these. In order to increase the consistency of the coding and coding template, continuous consultation with a second objective coder who was trained and familiarized with the coding

Table 1. Summary of Themes and Categories.

Themes	Categories
Dementia	Awareness about; type; duration
Relationship with relative	Prior to dementia; change with role
Emotions	Mixed; negative; positive; neutral
Role	Appraisal (pos/neg); change in role; execution of role; attitudes toward role
Positive aspects	Significant; impact; strategies (coping, constructive)
Negative aspects	Significant; impact; strategies (coping, unhelpful)
Support	Source; physical; emotional; material; family
Professional health care—general	Supportive; unsupportive; negative; neutral
Placement in care	Placed; duration; guilt; positive; negative; respite
Professional EoL care	Satisfied; dissatisfied; knowledgeable
Death/post death of person with dementia	Readiness; positive environment; negative environment; future consideration
Bereavement	Outcome; support
Grief	Acknowledged; anticipatory; ongoing
Loss	Cognitive losses (pwd); loss—ambiguous
Future thoughts	Various
Reflection for changed actions	Various
Spiritual faith	Present (level)

Abbreviations: EoL, end of life; pos, positive; neg, negative; pwd, people with dementia.

process was initiated. The themes and codes are summarized in Table 1.

Applying Data to a Matrix. A matrix format described by Huberman and Miles³² was used to manage and display the coded data in order to determine the results of their interaction. The 13 study participants formed the columns of the matrix and the significant statements derived from the responses of each participant formed the body of the matrix within the rows. This approach facilitated scrutiny of significant statements for the purpose of identifying congruent and variant responses to generate the data that would underpin the results.

Results

The sample (N = 13) consisted of 7 spouses (mean age = 74.9, standard deviation [SD] 8.6 years) and 6 adult children (mean age = 58.0, SD 4.4 years). The spouse caregivers consisted of 4 wives, 3 of whom were caring for husbands at home and 1 who had experienced the death of her husband in hospital following care in a residential facility. All of the husbands had wives still living in care facilities. The adult children had all cared for their mothers who had died in care facilities.

Analysis of the data revealed 3 key areas within which the results could be considered. The main issues identified in these areas were represented as elements within the domains of the conceptual framework. The first key area was caregiver and

care recipient characteristics, attitudinal variables, and use of resources. This included attitude to their role, perceived level of control over and involvement in relatives' care, and a strong desire/need to advocate for their relative. Resources included intrinsic resources of resilience and knowledge about the condition and care as well as the extrinsic resource of social support. The second key area included appraisal of the caregiving role and major issues associated with care of the person with dementia including grief, experiences with health care professionals including end-of-life care, and events surrounding the death of the relative. Interaction of the first 2 key areas generated the third key area. This interaction facilitated the expression of the complex and dynamic nature of the dementia caregiving experience.

Many issues common to most caregivers arose directly as a result of dementia being the primary condition of the care recipient, particularly when it was in the severe stage. Experiences in this situation were often driven by the caregiver's desire to advocate for their relative whose loss of cognitive function prevented them from being able to understand or rationalize their often traumatic situation. Compounding this was the caregivers' despair that their own ability to explain and reassure their relative was severely compromised by their relative's condition. In addition, the succession of ambiguous losses that characterizes dementia caregiving and the grief that is disenfranchised, both of which had seldom been validated at any point in the caregiving journey, were expressed as a source of ongoing and unresolved distress. The end of life of the person with dementia was a time when a constellation of all these factors occurred and it was at this time that a negative or positive experience in relation to professional care of the relative had the greatest impact.

Discussion about professional end-of-life care focussed on that experienced at care facilities, as this was where all but one of the relatives of these caregivers had died. In this study, professional end-of-life care was inconsistent across these facilities which resulted in a variety of end-of-life and palliative care experiences by the caregivers that ranged markedly from very positive to extremely negative.

Individual caregiver factors including role appraisal as well as intrinsic (psychological resilience) and extrinsic (social support) resources mediated influence of experiences, especially the impact of professional health care of their relative. Some caregivers took the approach that the health care professionals had the knowledge and skills and did not initially question any actions or decisions about their care. This was not always well-founded and in 2 cases, caregivers experienced profound, ongoing grief and trauma as a result of their encounters with health care professionals' approaches to end-of-life care of their relative, described by 1 daughter as "battling the system." In these cases, caregivers perceived that end-of-life care, delivered by health care professionals, increased the distress of their relatives, intensifying their heartfelt obligation to advocate for their relative. The anguish of 1 caregiver was exacerbated when, following the death of her mother in the middle of the night, she arrived the next morning to find her mother's

bedroom cleared and her clothes in a garbage bag on the bed. An emotional declaration “It haunts me” was the way she expressed the outcome of the experience 4 years after the event indicating a possible deep-seated and profound grief.

Other caregivers, who had made a point of being well-informed, challenged staff about the care of their relative, when they felt that their relative’s needs were not being met. Some of these caregivers considered that their concerns and requests were not respected or acknowledged, with the result that memories of their relative’s last days compromised their ability to move forward in their grief. One daughter described “how distressed (she) was with (her) last memories of Mum with her face screwed up and in so much pain . . . I’m having trouble remembering my mother now how she was prior to pain”. These findings demonstrate how experiences at this time remained fresh in the minds of some caregivers and in some cases appeared to present an ongoing barrier to their recovery from the initial bereavement and grief following the death of their relative.

Many caregivers, however, described positive end-of-life sequalae and it appeared that these positive experiences may have been related to the practice and application of documented palliative care principles and standards in particular facilities. For example, one participant described: “Afterwards, it was a positive experience, we had the family there and we stayed in the room with mum for an hour and a half just chatting away and I found myself still stroking mum’s head as I had been doing for the last week.” These caregivers reflected back positively on their caregiving journey, with constructive resolution of grief and bereavement experiences.

Most of the caregivers with a relative still living talked openly about the death of their relative and felt that they were prepared for this demonstrating resilience and optimism. This was explained by one wife: “I have just accepted it, it has happened, there is nothing you can do about it so live for today and live for the future. One day at a time—you have to be positive.” Another wife described her psychological preparation: “You see I have had a long time, it is not a sudden thing, I have had quite a while to get used to it.” Relief for the “end of the suffering,” both in an anticipatory sense and through experience, was expressed by many of the caregivers. In all these cases, the relief was directed at the person with dementia and not toward themselves. This study did not have the capacity to consider the longer term implications for the 2 men who refused to consider the death of their spouses, responding that they “just didn’t think about that.”

Caregivers with living relatives as well as those whose relatives had died described a drawn-out anticipatory grief that was perceived in some cases as positive in preparing them and in some as negative, in that it was a disenfranchised grief, not validated by others. One daughter described how: “When she died I had . . . so much support from everyone but I thought I don’t really . . . need it now, I needed it back then . . . I needed the sympathy . . . I needed the phone calls . . . but I didn’t get it because Mum was still alive—people would say “oh it so awful and we’re thinking of you” and everything but there wasn’t that

acknowledgment of the deep grieving.” Many caregivers commented on the issue of ambiguous loss “lost him/her twice” with the loss of the persons of the relative likened to bereavement. This was explained by 1 daughter in the following way: “It’s a hard balance to grieve and live with the person at the same time.”

Unresolved predeath grief and the associated ambiguous losses, as described by these caregivers, have been shown to contribute to prolonged or complicated grief years after the death of a close relative. Evidence of complicated grief in some caregivers emerged as they described the protracted distress and anguish that they had endured. Expressions such as, “I just can’t let it go” or “I think I have probably buried issues so deep down that I still haven’t got in touch with them,” signaled a potential risk factor for grief that might have become prolonged and complicated.

Discussion

A key finding of this study supported work by Meuser et al²⁷ and Nay and Garrett,³⁵ identifying the cascading consequences of the dementia-specific issues faced by these caregivers in which the cognitive decline of their relatives played a central role. This cognitive decline resulted in a sense of despair at their inability to ameliorate the experience for their relative due to the loss of reciprocal communication and the capacity to provide reassurance. This experience initiated a strong desire in the caregivers who were proactively engaged with the professional care of their relative to advocate for them, with different outcomes depending on the responses of health care professionals. Caregivers who were less engaged with professional care of their relative remained confident that their relative would receive good care and were not affected.

Experiences of predeath or anticipatory grief tempered the outcome depending on whether this was viewed pragmatically as having time to prepare for the “long dying” described by Dorenlot and Fremontier⁶ or whether caregivers felt a sense of ambiguous loss and disenfranchised grief. Consistent with other studies, caregivers without this intrinsic resource of resilience and positive approach to their role were more likely to experience ongoing and unresolved distress.^{36,37}

Exploration of the issues showed that the constellation of these experiences and the sequalae of their relatives’ end of life was a key point that has the potential to either facilitate resolution or create/perpetuate ongoing trauma. The reality of this was demonstrated by caregivers who described the debilitating nature of grief that had been complicated by traumatic end-of-life sequalae related to professional care of their relative. Remaining unresolved, this grief had become a source of distress and anguish. Conversely, even caregivers who had experienced problems with health care professionals over the caregiving period found that positive experiences with professional end-of-life care of their relative resulted in a feeling of optimism and closure that allowed them to move forward with their lives. These findings support the results of studies of caregivers of people with dementia that have highlighted the

pivotal contribution of health professional and caregiver interactions at the end of life of their relative to outcomes for the caregivers.³⁸⁻⁴¹

Although many of the issues that have emerged as important in this study are well supported in the literature, many studies in this area have tended to focus on burden and the impact of individual characteristics, issues, or experiences at single time points.^{11,13} This study has considered the importance of a range of combinations of factors in the caregiving experience and correspondingly complicated outcomes. The need for a more complex and comprehensive approach both to research and to interventions aimed at supporting caregivers of people with dementia, particularly at the end of their relative's life, has been emphasized.

Strengths and Limitations of the Study

The points highlighted in the discussion need to be considered in the context of the strengths and limitations of this study. Concerted efforts were made to obtain a sample that was fully representative of family caregivers, however aspects of this presented some challenges. No fathers with dementia were represented in the sample which could be explained by the fact that the percentage of women with dementia is higher than the percentage of men with dementia.⁴² In addition, life expectancy is greater for women than for men⁴³ making it more likely that men with dementia were able to be cared for by their wives and not their children. Conversely, widowed mothers with dementia would more likely than fathers to be cared for by adult children. In view of this, the proportions of characteristics in the sample were reflective of this population.

A major strength of this study is that it was supported by a conceptual framework that provided a multidimensional platform on which to present the dynamic process of interaction of several factors that contributed to the outcomes. This facilitated a holistic depiction of the experiences and issues that influence the dementia caregiving journey.

Conclusion

The findings in this study have implications for future research into caregivers of people with dementia and practice in this area. The value of considering the longitudinal nature of caregiving and the interaction of issues, experiences, and personal characteristics over time, in preference to 1 off measurements of discreet variables has been highlighted. The value of research to support initiatives that focus on both personal growth for caregivers and practice development has been demonstrated. This study has identified the need to focus on improving caregiver resilience and supporting caregivers to develop an approach that allows them to better cope with the challenges inherent in the role. Concurrently with this, the responsibility that is vested in health care professionals with regard to this vulnerable population has been clearly articulated and presents an imperative to address this through practice informed by research-based evidence.

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