

BMJ Open Qualitative exploration of emotional and social changes from diagnosis to bereavement for spousal caregivers of persons with dementia

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To cite: Gibson K, Peacock S, Bayly M. Qualitative exploration of emotional and social changes from diagnosis to bereavement for spousal caregivers of persons with dementia. *BMJ Open* 2019;**9**:e031423. doi:10.1136/bmjopen-2019-031423

► Prepublication history for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2019-031423>).

Received 02 May 2019

Revised 30 August 2019

Accepted 05 September 2019



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ABSTRACT

Objectives To understand how bereaved spousal caregivers of persons with dementia perceive and respond to changes over the course of their spouse's disease, from diagnosis into bereavement.

Design Qualitative interview study with convenience sampling and thematic analysis approach.

Participants Participants included eight women and two men (n=10) who had been spousal caregivers for a person with dementia prior to his/her death. Participants were older adults who self-reported good health and were bereaved longer than a year.

Setting Data collected in a small Canadian prairie city between fall 2014 and winter 2015.

Findings Two overarching themes were developed as important components of participants' caregiving journey: emotional reactions to change and variation in social connectedness throughout the caregiving and bereavement journey. Four key sub-themes developed through the analysis of emotional reactions to events: memorable grief overshadows persistent grief, a progressive feeling of hopelessness and overwhelmed, relief is common but hidden and gratitude is a milestone in a constructive bereavement. Three key variations of social connectedness throughout the caregiving and bereavement journey were developed: the importance of social inclusion throughout a caregiving and bereavement journey, the repeated loss of companionship and withdrawing from social interactions is contingent on needs.

Conclusions The findings suggest that emotional changes throughout caregiving and bereavement are not linear. The need for support from family, friends and new social supports is influential in enabling the caregiver to move forward during caregiving and bereavement.

INTRODUCTION

A considerable amount of the care delivered to persons with dementia is provided at home by family members, specifically spouses.¹ Compared with other family caregivers, spousal caregivers of persons with dementia encounter unique challenges throughout caregiving and bereavement due to the demands of caregiving while also experiencing the loss of a partner.² Furthermore,

Strengths and limitations of this study

- Qualitative research has an important role in understanding the variability among persons that quantitative analysis may fail to measure. This in-depth qualitative study explores bereaved caregivers' perceptions of how they changed, emotionally and socially, throughout their journey as a caregiver to a spouse with dementia.
- We interviewed caregivers two times during bereavement (2 weeks apart), which provided participants the opportunity to discuss additional experiences that may have been missed during the first interview.
- By exploring experiences from diagnosis to bereavement, we are able to understand what experiences and interactions are perceived as the most important. We present the caregiving and bereavement journey as a whole, rather than focusing on one timepoint.
- The current study sample included an unique group of bereaved caregivers who perceived their partners' deaths as *good* and had a strong support system throughout their time as a caregiver and as a bereaved caregiver. Therefore, the sample might not be representative of the wider population of bereaved caregivers of spouses with dementia.
- Findings are reliant on recall and narration from the participants. A longitudinal investigation may elicit different perspectives.

spousal caregivers report significantly higher burden than other caregivers of persons with dementia^{3,4} and experience severe or complicated grief due to the prolonged period of caregiving and stress at the time of their spouse's death.⁵ Therefore, exploration into the experiences of spousal caregivers of persons with dementia is warranted as a means of understanding the unique population.

Caregivers' reactions to caregiving

Caregiving can be challenging for spouses of persons with dementia and can have a significant impact on the well-being of spousal

caregivers. Grief is a fluid and dynamic⁶ emotional and physical response to a perceived loss of a relative.⁷ Grief often occurs during states of separation or when an individual suffers significant loss in the present or anticipated future.⁸ Pre-death grief is experienced by 71% of caregivers of persons with dementia⁵ as a result of experiences such as witnessing the person with dementia's abilities diminish, observing changes in the person with dementia's behaviour and personality,⁹ feeling isolated,^{10,11} as well as anticipating multiple losses (eg, companionship, personal freedoms and changes in the person with dementia).⁵ Although much attention is placed on the deleterious effects of caregiving, desirable psychological effects and health benefits are associated with the spousal caregiving experience.¹² Spouses can find meaning in their care, acquire new skills and feel close to the person with dementia through their caregiving journey.

Caregivers and social supports

Informal social supports,¹³ formal social support programme and resources,¹⁴ and engagement in pleasant activities are associated with improved psychological health and resilience in caregivers of persons with dementia.¹⁵ Yet due to the amount of care required by later stage dementia, caregivers often retreat from their social community, making reintegration with their previous social circles difficult once the caregiving role has ended.¹⁶ This is important because although one third of caregivers experience mental health concerns during bereavement,¹⁷ much of the literature on community supports is situated within the context of caregiving. While caregiving and bereavement may have unique properties there is benefit in exploring the caregiving and bereavement as an entire course, where experiences throughout caregiving feed into the experiences during bereavement.

While bereavement is considered a continuation of the caregiving journey,¹⁸ the current literature lacks a qualitative exploration of spousal caregivers' journeys from diagnosis to bereavement.¹⁹ Past research has explored emotions and community connectivity at specific stages utilising primarily quantitative methods,²⁰ with limited qualitative work exploring the importance of community during caregiving and end of life care.^{21–23} The primary purpose of the study is to provide an exploration of the social needs and emotional changes of spousal caregivers throughout their caregiving and bereavement journey. In doing so, we hope to reveal spousal caregivers of persons with dementias' needs for interventions and/or supports throughout caregiving and bereavement journey.

METHODS

Design

The study was a qualitative analysis of interviews with bereaved spousal caregivers of persons with dementia. The data were collected as part of a study that sought to understand how spousal caregivers of individuals with

dementia navigate bereavement in order to develop a bereavement writing intervention. Participants were made aware of the intentions of the goals of the original study prior to participation. The original study is published elsewhere.²⁴

Setting

The setting was a small city in Western Canada and interviews were carried out between the fall of 2014 and winter of 2015. All interviews were conducted in the participants' homes at a time convenient to them.

Participants

The aim of the original study was to recruit a diverse sample of older adult participants with differing lengths of spousal caregiving experience and amount of time bereaved. We required at least 12 months of bereavement so that participants had lived bereavement while not interrupting their bereavement experience too early. We focused on spouses 60 years or older because research demonstrates that adult children and older adult spousal caregivers of persons with dementia have differing experiences in the dementia caregiving journey.⁵

Participants were recruited through one of two convenience sampling procedures: (1) by newsletters and website advertisements with the local council on ageing and the provincial Alzheimer Society, or (2) were approached by three social workers within a large older adult care community on behalf of the research team. Individuals interested in participating contacted SP by phone. SP verified the individual's willingness, ability (ie, read/speak English and provide informed consent) and eligibility to participate. Eligibility was determined by current age (minimum 60 years old), length of bereavement (minimum 12 months), whether the individual cared for a spouse with dementia and willingness and ability to share their bereavement experiences. Recruitment efforts ceased after multiple rounds of recruitment produced no new volunteers.

Eight women and two men (n=10) who were bereaved spousal caregivers of persons with dementia participated in the study. Participants had a mean age of 81.6 years, self-reported as having good health and had a strong support system throughout their caregiving and bereavement journey. All participants perceived their partners' deaths as *good* and were bereaved longer than a year (M=41 months). The mean amount of time from diagnosis to death for persons with dementia was 5.4 years. It appears from our sample that spousal caregivers who perceived their partners' death as *bad* did not respond to recruitment advertisements. Additional participant characteristics are presented in [table 1](#). All persons interested in participating completed the study.

Data collection

Participants were interviewed twice (n=20 interviews) face-to-face by one female interviewer (KG, Master's student research assistant who was new to the research

Table 1 Participant demographics

	Category	N
Living arrangement	Own home	4
	Seniors apartment	2
	Assisted living	4
Type of spouse's dementia	Alzheimer's	2
	Frontotemporal	1
	Lewy body	4
	Temporal	1
	Vascular	2
Place of spouse's death	Hospital	3
	Long-term care	7

For participants, 'living arrangements' refers to the participant's living arrangements at the time of the interview. Own home refers to any home within the community that does not provide amenities such as housekeeping, dining or activities; 'seniors apartment' refers to a communal living environment that provides amenities such as housekeeping, dining or activities that make life easier for the older adult; 'assisted living' refers to a communal living environment that provides assistance with daily activities (eg, medication, bathing, dressing, etc); 'long-term care home' refers to a living facility that provides intermediate care; 'hospital' refers to residing or admission within a hospital setting without a plan to move to another living environment.

area with graduate level qualitative training). Initial interviews lasted 60–120 min and second round interviews lasted 20–60 min. Participants received a \$25 gift card during the initial interview meeting. No relationship was established prior to the start of the study and non-participants were absent during data collection. No interviewer characteristics were reported to the participant prior to the interviews. Semi-structured interview guides were guided by a review of the literature on bereavement experience in the context of dementia. Interview guides were not piloted; however, the guides were approved by a team of experts within the field of caregiving and/or dementia (one clinical psychologist and three registered nurses).

Informed consent and demographics were obtained immediately before the initial interview. Interview questions were open-ended and began with the statement, 'Please feel free to begin when or where you like in your caregiving journey.' Participants were then given the opportunity to discuss their caregiving and bereavement journey and prompts were used as a means of direction throughout the interview (see **Box 1**). All interviews were digitally recorded. Following the primary interview, each initial transcript and associated field notes were analysed for themes and areas of interest of the original study (ie, additional questions regarding caregiving and bereavement experiences). Questions were established from the initial interview transcript, which developed the interview guide for the second interview session (KG and MB). Interviews were transcribed verbatim and verified for completeness and accuracy (MB). Data were stored on password-protected computers, only accessible to the research team. Recruitment continued until the pool

Box 1 Interview guide

Please feel free to begin when or where you like in your caregiving journey:

What has life been like since your spouse died?
 How has your grieving changed over the months/year(s)?
 What thoughts do you have about finding balance?
 What are some ways you find balance in your bereavement?
 What are some ways that hinder your finding balance in bereavement?
 Are there any individuals who help you to find balance?
 Are there any that hinder your ability to find balance?

Final question(s):

Do you have anything more you would like to add?
 What has it been like for you to participate in this interview?

of eligible participants was exhausted. All participants refused their right for transcript review.

Analysis

We used Braun and Clarke's²⁵ thematic analysis approach to identify themes. This method was chosen because it is useful for exploring multiple perspectives, highlighting similarities and differences, providing well-structured guidelines for handling data and identifying unanticipated insights, all of which help produce clear and organised findings.^{25 26} The following steps were followed: (1) All transcripts were initially read for familiarisation throughout the data collection phase. Transcripts were then re-read line-by-line using an inductive, open coding process²⁷ to identify links between developing codes and to search for patterns across the interviews. Two patterns developed: social and emotional experiences throughout caregiving and bereavement. (2) Thematic coding was conducted by one researcher, KG, who kept an audit trail throughout the research process. NVIVO V.12 was used to organise and manage themes. KG explored the data to produce initial codes that focused on spousal caregivers' social and emotional experiences throughout caregiving and bereavement. In order to address the need for trustworthiness and credibility, the codes derived from the data were then presented to SP for critique of interpretations. (3) Codes were sorted into potential themes and grouped together to form overarching themes. Examples of codes were: companionship, relief, grief, gratitude and staying connected. Codes pertaining to social or emotional aspects of spousal caregivers' experiences were reviewed and combined into themes where they coalesced around a broader meaning or concept. (4) Themes were reviewed and refined. Potential themes were judged on whether the codes fit together to create the theme or whether the themes accurately reflected the meanings of the data. (5) Themes were defined and named. Detailed analysis of each theme was written at this point. (6) A write-up of the findings was then produced. Quotations were chosen to illustrate the themes and to include a range of participants and their experiences.

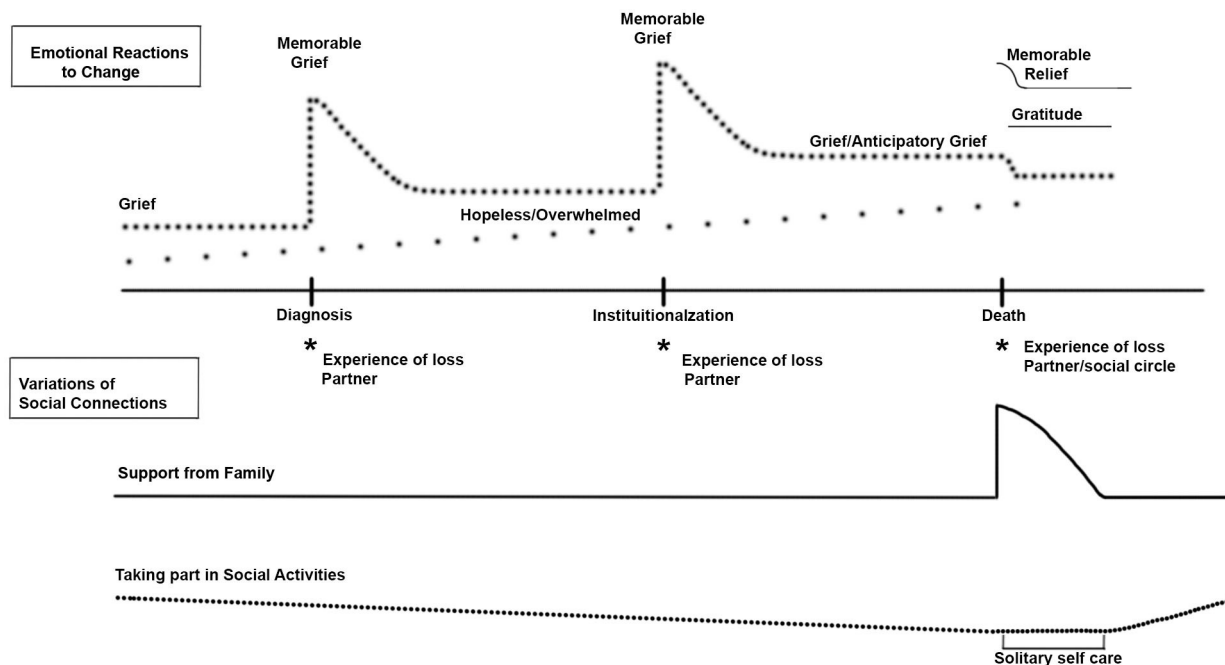


Figure 1 Depiction of the emotional reactions to change and variations of social connections throughout the caregiving and bereavement journey.

FINDINGS

Experiences and interpretations of emotional changes and relationships were important to participants' caregiving and bereavement journey. Two main themes developed after rereading and reflecting on the categories: emotional reactions to change and variation of social connections through the caregiving and bereavement journey. Four key sub-themes developed through the analysis of emotional reactions to events (memorable grief overshadows persistent grief, a progressive feeling of hopelessness and overwhelmed, relief is common but hidden and gratitude is a milestone in a constructive bereavement), while three key sub-themes of variations of social connectedness throughout the caregiving and bereavement journey were developed (importance of social inclusion throughout a caregiving and bereavement journey; repeated loss of companionship; and withdrawing from social interactions is contingent on needs). See [figure 1](#) for a depiction of the two concurrent themes and their sub-themes.

Emotional reactions to change

Participants described a variety of emotional reactions throughout their caregiving and bereavement journey. These reactions included grief, feeling overwhelmed and/or hopeless, relief and gratitude. Many participants discussed common events that coincided with universally reported feelings, suggesting that key experiences and the feelings associated with such incidents may have minimised their perceptions of other emotions or the caregiving journey as a whole. The pattern of memorable experiences coinciding with integral experiences is reflected in the greater expression

of emotions felt during particular stages of caregiving/bereavement. Specifically, the progression of dementia symptoms coincided with spousal caregivers' memories of emotional reactions.

Memorable grief overshadows persistent grief

All participants expressed experiences of grief throughout caregiving and bereavement. Unlike other emotional experiences reported by the participants, grief was reported prior to diagnosis, varying in intensity throughout the journey and never thoroughly dissipating. Participants described feeling grief throughout their journey; however, it was at key transitional points that intense experiences of grief were most memorable. For example, prior to diagnosis, some participants discussed a subtle feeling of grief that was spurred by recognising memory issues and the decline in their spouses' abilities. Pre-diagnosis grief was often overshadowed by the intensity of grief at the time of diagnosis, which was deepened by fear and an array of emotions.

P3: The final word when (the physician) say that final word, then that's like a little bit of a sledgehammer hitting you... I can't say that I was angry. I don't know if it's stoicism... I really can't say that I was depressed... I was certainly very sad, and I presume I felt sorry for myself, I felt sorry for [wife]...

P8: I think grieving kinda happens the moment that your spouse is diagnosed with dementia. Cause you know this person is never going to be the same, as what he has been for fifty-some years.

For spousal caregivers who placed their spouse in long-term care homes, the decision and experience of institutionalisation was the greatest and most memorable period of grief. This decision often followed the realisation and recognition of their spouses' decline in health and their own limitations to care for their spouse.

P3: ...the day I had to sign her into [facility]. That was probably my worst day. That day I really felt down... So when you bring her, [the long-term care staff] talk to her and take her aside, and when you see that she's aside, you take off... I think that was the part that maybe bothered me the most, is not being able to say goodbye...

Anticipation of death-related grief was a key factor in handling grief and stress. Although anticipation did not halt grief, those who expressed anticipating their spouses' death reported less overwhelming chronic grief during this time. Anticipation was perceived as an integral means of self-management that provided the opportunity to experience grief, as well as constructive emotions, with less guilt.

P1:... that's another thing about chronic grief... makes it easier to deal with a death, because you anticipate it... I don't expect to get over it. It is just part of my life. I am a happy person, and I don't feel guilty when I'm happy, but it's just part of my life.

P2: The bereavement was way sooner than after death. I have been doing very well after death. Sure you remember them, you miss them, but you're so relieved that they don't have to suffer anymore.

A progressive feeling of hopelessness and overwhelmed

Feelings of hopelessness often accompanied the experience of watching a spouse live out the end of their life in a long-term care home. However, the feeling of hopelessness was not reported at the diagnosis phase, but rather was conveyed at times of frustration in the early stages of caregiving.

P3: I was sure I was grieving, but as far as I know [the diagnosis] didn't affect my outlook, or my actions, or anything like that.

P8: Even to go down for coffee, he would get so upset with some people, he would just let them have it! It was embarrassing for me, and very hard because it wasn't his natural self, but what could you do.

Many participants cited that they avoided expressing how they felt throughout their caregiving journey in order to continue unobstructed care for their spouse. Although caregiving was expressed as overwhelming, many participants discussed their sense of duty to look after a spouse.

P3: I would suppose that some days... you felt like you were being snowed under... I suppose there was sometimes feelings of why me, you know?

P7: I wasn't feeling good... but I didn't go and see a doctor [for depressive symptoms], because I had to look after him.

Relief is common but hidden

Many participants discussed the differences between expectations and experiences of bereavement. All participants stressed that they felt relief once their spouse passed away, for themselves and/or for their spouse. Relief for self was attributed to the release of duties associated with care. However, with this sense of relief came an internal struggle to hide these emotions from others.

P4: I wouldn't want the poor soul to go on any longer... it was time for him to go. That's the way I felt, it was time to let go.

P6: Well when she passed away... that was more like the end of the grieving. It was more of a relief, because I felt duty-bound to go over to the nursing home every day, and to go over there and see her gradually going downhill, was difficult.

P9: I think that if I'm totally honest and I want to be, that I was relieved, rather than depressed, when he died. I know I was relieved because he was suffering... For him, and for me. And you kind of had to hide that, because people were always saying these stupid things about, gone to a better place, and all that.

Gratitude is a milestone in a constructive bereavement

Some participants discussed how grief transformed into gratitude during bereavement. The development of gratitude allowed spousal caregivers to work through their grief and appreciate their past and present experiences. In doing so, participants were able to reclaim aspects of self that were valued pre-caregiving.

P10: I think in some ways the grief turns to gratitude, gratitude that I had him as a spouse, and for all the things that we did and shared. So I can transform it from deep grief into more gratefulness, for what was.

P2: Before you grieved because you were sad at how he was. Afterwards you grieve and you say oh Lord, thank you so much, he's so blessed that he's not here anymore. Then you have put everything into place, and you do away with it all, and then you say thank you Lord, that part of the life is over.

P7: I feel a lot happier than what I was. I'm more outgoing, I talk to more people than what I used to. I'm getting more like myself!

Many participants discussed the importance of gratitude and optimism in working through their bereavement. Although participants reported experiences of grief, it was apparent that a change in mindset through gratitude and optimism was integral in working through the grief.

P8: It's not good for yourself just to dwell on it, cause it just gets you down. You have to feel optimistic and say that you need to be strong and carry on.

Variation of social connections throughout the caregiving and bereavement journey

Social connections were an integral part of participants' caregiving and bereavement journey, with all participants discussing the importance of family, friends and new connections unprompted. Three key patterns developed: the importance of social inclusion throughout a caregiving and bereavement journey, the experience of loss from multiple sources of companionship and the need to withdraw from social interactions. The significance of interacting with others appeared to be reliant on the personal decision to stay connected with others.

Importance of social inclusion throughout a caregiving and bereavement journey

Throughout the beginning of caregiving, participants described their social circles as supportive and their community involvement as frequent/unchanged.

P10: I got a lot of support from his family as well. They were extremely supportive, of me in my journey with him, when he was still alive.

P3: In the first 4 years of Alzheimer's, we didn't curb our activities. We went to the symphony as per regular, [theatre] as regular, we were part of [volunteering organization].

For many, support from family and friends near the end of caring for their spouse provided ties to their community and encouraged self-care that they could not devote to themselves.

P7: My daughter said "If you can look after him til that day, I have two days off from nursing, I'll come and look after him and you can go to the other daughter and get a couple nights' sleep."

Increased social support was perceived as a vital resource at the first stage of bereavement. Although some participants experienced new friendships after the passing of their spouse, many discussed the impact old friends and family had on the reintegration within the community.

P2: I think just because you have family around that supports you, friends that support you, church that supports you, and all that, it all comes together at the end.

New activities and friendships were also an important part of reintegration during bereavement. Communal living provided some participants a means of addressing loneliness and a fresh start to their bereavement journey. This environment provided a social network to turn to in times of grief, specifically during meals.

P5: In this building, there's a great deal of support, you get to know your neighbours on the floor and you get to know other people, and it's a community, it is a community within itself here.

Repeated loss of companionship

Participants' first loss of companionship occurred during one of two events: the time of diagnosis or the institutionalisation of their partner.

P3: He said you know, "You know, you've lost your wife once, and you're going to lose her again." With the diagnosis and the actual death. I lost her twice.

P5: You realize that the end is sort of in sight... The loss of support from your spouse has gone. Somehow you don't really notice that when they're still in the house with you. But once they're in a nursing home, you realize that's gone.

As a result of their spouse passing, spousal caregivers expressed a sudden shift from an abundance of support to infrequent social experiences, which exacerbated the realisation of loss. Participants expressed that the expectation that loneliness would subside as time passes was helpful in their adjustment as a bereaved spousal caregiver. This expectation allowed the spousal caregivers to periodically assess their feelings and adjust their involvement within their community to address their feelings of loneliness or grief.

P7: It's still hard for me to go on alone, especially downstairs, I don't take part in a lot of things. But I'm happier than what I have been. I'm getting over it, I'm starting to take into more things. I'm doing a lot better. Well it's five years, I should be getting better!

While many of the participants focused on the vast amount of social support received throughout caregiving and bereavement, one participant's experience demonstrated how companionship may decrease in multiple relationship categories including their spouse, close friends and even family members as symptoms of dementia progress. Rejection from others impacted the spousal caregiver's sense of well-being, where she continued to ruminate in the loss of companionship during bereavement.

P2: I think when you lose a spouse, you lose a lot of friends. I know that the people that we used to get together with, like they shy away. I'm not sure whether they can't deal with it, or whether they think well there's nothing more left and the man is gone, what are we going to do with just the woman... Once my husband was gone it was done and I haven't heard from them for years.

Withdrawing from social interactions is contingent on needs

As a result of stress and physical exertion required in caregiving, participants made the choice, either willingly or out of necessity, to retract from community activities.

P7: We played cards when he was alive too, but then when he got so bad I had to quit for a while, because he wouldn't play with us... And shuffleboard, I had to stop with that too when he got bad...I couldn't leave

him alone... He said to me one day "How come they don't ask us to do communion anymore?" And I said "They don't need us," ... But he couldn't do it. And I had to quit too, cause I couldn't leave him alone. I didn't dare.

During bereavement, all participants stressed their need for self-care after an emotionally and physically draining journey. Many participants no longer wanted to take part in activities that were not enjoyable, discussing the benefits of living for themselves. The ability to live on their own schedule was a relief. Participants described a need for self-reflection and regaining the energy lost during their caregiving experience, where many wanted a break from obligations as a means of recovery. All participants reported taking time alone to recharge after their spouses' death, with times ranging from a day to 2 years.

P9: I now recognize that there was about a year and a half to two years, where I just very self-indulgently didn't force myself to do any work...I didn't criticize myself for it... that's one of the basic reasons I enjoyed my freedom here, after the bad five years. Is that I'm basically selfish, and finally I can look after only me!

For some it was essential to reintegrate nearly immediately within their community, while others discussed a need to grieve and recuperate from the stress experienced throughout caregiving. Community involvement was based on desire rather than social expectations, suggesting that reintegration is most appropriate when the spousal caregiver is ready, rather than through force.

P5: I gave myself a day by myself, and then I made myself go. It's like trying to get in the water, you know the lake is cold, and you put your toe in and you sort of ohhh. You're better to just jump in and get wet all over and then you're ok. That was my attitude...

DISCUSSION

In summary, grief, relief, hopelessness and gratitude were common feelings among participants. Strategies such as anticipation and optimism were employed as a means of alleviating some overwhelming feelings (eg, grief) throughout caregiving and bereavement. Spousal caregivers indicated that socialisation was integral in managing the stress and grief associated with caregiving and bereavement. However, many participants also explained the importance of time away from others at particular points in their journey. For some, time alone was a choice, while others felt excluded from social events. How participants perceived time with others and time alone was reliant on their autonomy of the situation.

This study highlights the key experiences of the caregiving and bereavement journey of spousal caregivers. Past research suggests that spousal caregivers will employ an emotional reaction of denial²⁸; however, this was not

reported within the current study. The current analysis suggests that for spousal carers the experience of caregiving and bereavement is emotionally fluid with particular instances of deep grief, dependent on the individual's progression of dementia symptoms. This fluidity supports previous proposals that caregiving does not end at the death of a person with dementia. As suggested by Orzeck and Silverman,¹⁸ bereavement is a continuation of caregiving where bereaved spousal caregivers of persons with dementia continue to experience emotional changes as a result of caring for their spouse. Therefore, although spouses may experience the greatest grief during caregiving, it is important to recognise and address the needs of spousal caregivers during caregiving and bereavement, rather than ending caregiving services once the person with dementia has died.

It should be noted that the current findings might not be generalisable to adult children caregivers of persons with dementia. Although reports of depression, grief and perceived stress are reported by adult children and spousal caregivers, severity of grief is different. For example, adult-children caregivers typically experience grief curvilinearly, where the intensity of grief is minimal soon after diagnosis, highest in the moderate stages of dementia and less severe in the last stages of dementia.²⁹ Grief literature suggests that grief for spousal caregivers of persons with dementia begins at diagnosis and increases linearly from early to late stages³⁰ with the greatest perceived grief experienced during the later stages of dementia.⁵ For the current study, greatest experiences of grief coincided with events associated with cognitive decline: diagnosis and institutionalisation within long-term care homes. This finding is unique because it suggests that grief may not be linear, but rather wave like, and thus spousal caregivers may benefit from interventions that are event focused. Therefore, although the findings deviate from past patterns of spousal grief, spouses and adult children caregivers continue to experience grief differently.³¹

Anticipation was identified as an integral tool for managing death-related grief. Seeing as the current study's spousal caregivers discussed diagnosis and institutionalisation as periods of greatest grief, more efforts to prepare spousal caregivers for these events (through aids or interventions) may be beneficial. Supporting previous findings,^{32 33} relief, rather than grief, was experienced at the time of participants' spouses' death and was the most salient emotion experienced during the death of a cared for spouse. This means that due to the unique experiences of losing their spouse, spousal caregivers may grieve for the loss of their spouse during caregiving. Having already grieved throughout their caregiving experience while simultaneously recognising their spouse's suffering, bereaved spousal caregivers may be overwhelmed with relief rather than grief.³⁴ Although participants understood why they felt relief, many spousal caregivers felt apprehensive expressing their relief because it did not align with the social expectations of grief. Therefore, formal supports throughout caregiving and bereavement

may benefit from including education about unique experiences of grief associated with caring for a person with dementia. Recognising that the journey is distinct may provide the permission to express atypical emotional reactions (eg, relief) at the time of their spouse's death.

A key finding was the significance of support systems within participants' lives during bereavement. Dementia spousal caregivers may give into the responsibilities of caregiving, forgetting their own needs for the sake of their spouse. Therefore, it is important to recognise that social networks are essential during caregiving^{35 36} and bereavement.³⁷ However, social support must be perceived in order to be an effective resource.³⁸ Similar to Donnelan, Bennett and Soulsby's³⁹ findings, the current study included one participant who experienced a loss of support due to their spouse's decline in health and death. Such experiences can influence a spousal caregiver's well-being. Individuals experiencing a decline in social supports may require additional care in identifying remaining support networks.

Lastly, the current study highlights how vital reintegration is for a healthy bereavement. Previous research supports the current finding that spousal caregivers tend to release activities that they once enjoyed as a means of balancing time and new responsibilities.^{40 41} The current study indicates that solitary self-care can also be beneficial for a healthy bereavement; however, the amount of time needed varies depending on the spousal caregiver's needs. Research has suggested that reclaiming past activities assists the bereaved caregiver through their grieving journey,⁴² a finding that is supported by the current study. Together these findings signify that an open dialogue regarding reintegration is needed between spousal caregivers and their supports throughout early bereavement, where flexibility of restoring community involvement is endorsed.

Limitations

The current study provided an exploration of spousal caregivers of persons with dementias' experiences from diagnosis to bereavement, which offered the opportunity to understand what experiences and interactions are perceived as most important by the participants throughout their journey. However, the presented findings may be unique because of the aspects of the study including participants' overall optimistic assessment of their caregiving and bereavement journey, participants desire to provide their experience (all volunteered), participants' demographics (primarily women), perceptions of their spouses' deaths as good and large support networks. Many spousal caregivers and/or bereaved spousal caregivers may not interpret their journey in a constructive manner or have similar access to support networks. The way participants recalled and narrated their experiences was undoubtedly affected by time and their participation in an interview 12 months after the death of their spouse.

A longitudinal investigation, examining spousal caregivers' perspectives at different points throughout their caregiving and bereavement journey, may elicit different perspectives and stories that broaden our understanding. As well, further understanding in the importance of couples' marital relationship or circumstances is worth exploring. Lastly, findings from the current study are limited due to the small sample size and the reliance on data that was related, but not collected for the current analysis. These limitations may suggest why no differences were found between spousal caregivers of persons with different types of dementia. Future research may want to explore these differences in more detail. Therefore, the findings do not come from a saturated data set and thus may not be indicative of all spousal caregivers' experiences of caring for a person with dementia.

CONCLUSIONS

Caring for a spouse with dementia is complex, as is the journey during bereavement. The current study presents key emotional and social experiences discussed by ten bereaved spousal caregivers of persons with dementia from the time of their spouses' diagnosis to their current state of bereavement. The study suggests that relief is the most pronounced emotion felt during the death of a spouse with dementia, while grief is experienced throughout caregiving. While social supports are important, the study suggests that solitary self-care may be just as important to recovery; however, the amount of time varies between spousal caregivers. This study has added to the understanding of a spousal caregiver's experience from diagnosis to bereavement and the importance of social support to combat the emotional pain endured during caregiving and bereavement.

Acknowledgements The authors would like to thank the Saskatoon Council on Aging (SCOA), the Alzheimer Society of Saskatchewan (ASSK) and LutherCare Communities for their assistance with recruitment for this study and Kyle Brymer with his assistance in creating the figure. They would also like to thank all the people who expressed their interest or took part in this study.

Contributors SP conceptualised the original study and critiqued data analyses. KG conducted interviews, analysed results, conceptualised the current study, prepared the first draft and was responsible for the subsequent revisions of the manuscript. MB transcribed, checked the transcripts against the audio files. SP and MB provided feedback and approved the final version of this manuscript.

Funding This work was supported by a Saskatchewan Health Research Foundation, Establishment Grant.

Competing interests None declared.

Patient and public involvement statement This research was done without participant involvement. Participants were not invited to comment on the study design, were not consulted to develop participant relevant outcomes or interpret the results, and were not invited to contribute to the writing or editing of this document for readability or accuracy.

Patient consent for publication Not required.

Ethics approval University of Saskatchewan Ethics Committee (2014-2018).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available.

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REFERENCES

- Alzheimer's Association. Alzheimer's disease facts and figures. *Alzheimers Dement* 2014;10:1–75.
- O'Shaughnessy M, Lee K, Lintern T. Changes in the couple relationship in dementia care. *Dementia* 2010;9:237–58.
- Coen RF, Swanwick GR, O'Boyle CA, et al. Behaviour disturbance and other predictors of carer burden in Alzheimer's disease. *Int J Geriatr Psychiatry* 1997;12:331–6.
- Kim H, Chang M, Rose K, et al. Predictors of caregiver burden in caregivers of individuals with dementia. *J Adv Nurs* 2012;68:846–55.
- Chan D, Livingston G, Jones L, et al. Grief reactions in dementia carers: a systematic review. *Int J Geriatr Psychiatry* 2013;28:1–17.
- Konigsberg DR. *The truth about grief: the myth of its five stages and the new science of loss*. New York, NY: Simon & Schuster, 2011: 1–16.
- Lindauer A, Harvath TA. Pre-death grief in the context of dementia caregiving: a concept analysis. *J Adv Nurs* 2014;70:2196–207.
- Blandin K, Pepin R. Dementia grief: a theoretical model of a unique grief experience. *Dementia* 2017;16:67–78.
- Perren S, Schmid R, Wettstein A. Caregivers' adaptation to change: the impact of increasing impairment of persons suffering from dementia on their caregivers' subjective well-being. *Aging Ment Health* 2006;10:539–48.
- Noyes BB, Hill RD, Hicken BL, et al. The role of grief in dementia caregiving. *Am J Alzheimers Dis Other Dement* 2010;25:9–17.
- Bodnar JC, Kiecolt-Glaser JK. Caregiver depression after bereavement: chronic stress isn't over when it's over. *Psychol Aging* 1994;9:372–80.
- Brown SL, Smith DM, Schulz R, et al. Caregiving behavior is associated with decreased mortality risk. *Psychol Sci* 2009;20:488–94.
- Deist M, Greeff AP. Resilience in families caring for a family member diagnosed with dementia. *Educ Gerontol* 2015;41:93–105.
- Greenwood N, Habibi R, Mackenzie A, et al. Peer support for carers: a qualitative investigation of the experiences of carers and peer volunteers. *Am J Alzheimers Dis Other Dement* 2013;28:617–26.
- Harmell AL, Chattillion EA, Roepke SK, et al. A review of the psychobiology of dementia caregiving: a focus on resilience factors. *Curr Psychiatry Rep* 2011;13:219–24.
- Vasileiou K, Barnett J, Barreto M, et al. Experiences of loneliness associated with being an informal caregiver: a qualitative investigation. *Front Psychol* 2017;8:585–96.
- Chang H-Y, Chiou C-J, Chen N-S. Impact of mental health and caregiver burden on family caregivers' physical health. *Arch Gerontol Geriatr* 2010;50:267–71.
- Orzeck P, Silverman M. Recognizing post-caregiving as part of the caregiving career: implications for practice. *J Soc Work Pract* 2008;22:211–20.
- Peacock SC, Hammond-Collins K, Forbes DA. The journey with dementia from the perspective of bereaved family caregivers: a qualitative descriptive study. *BMC Nurs* 2014;13:42.
- Adams KB, Sanders S. Alzheimer's caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease: a mixed method analysis. *Gerontology* 2004;3:195–210.
- Bunn F, Goodman C, Sworn K, et al. Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. *PLoS Med* 2012;9:e1001331.
- Shanley C, Russell C, Middleton H, et al. Living through end-stage dementia: the experiences and expressed needs of family carers. *Dementia* 2011;10:325–40.
- Cheng S-T, Lam LCW, Kwok T, et al. The social networks of Hong Kong Chinese family caregivers of Alzheimer's disease: correlates with positive gains and burden. *Gerontologist* 2013;53:998–1008.
- Peacock S, Bayly M, Gibson K, et al. The bereavement experience of spousal caregivers to persons with dementia: Reclaiming self. *Dementia* 2018;17:78–95.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- King N. Using templates in the thematic analysis of text. In: Cassell C, Symon G, eds. *Essential guide to qualitative methods in organizational research*. London, UK: Sage, 2004: 257–70.
- Miles M, Huberman M, Saldana J. *Qualitative data analysis: a methods Sourcebook*. 3rd edn. Thousand Oaks, CA: Sage Publications, 2013: 69–104.
- Aminzadeh F, Byszewski A, Molnar FJ, et al. Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging Ment Health* 2007;11:281–90.
- Meuser TM, Marwit SJ. A comprehensive, stage-sensitive model of grief in dementia caregiving. *Gerontologist* 2001;41:658–70.
- Thompson GN, Roger K. Understanding the needs of family caregivers of older adults dying with dementia. *Pall Supp Care* 2014;12:223–31.
- Sanders S, Ott CH, Kelber ST, et al. The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Stud* 2008;32:495–523.
- Large S, Slinger R. Grief in caregivers of persons with Alzheimer's disease and related dementia: a qualitative synthesis. *Dementia* 2015;14:164–83.
- Stahl ST, Schulz R. Feeling relieved after the death of a family member with dementia: associations with postbereavement adjustment. *Am J Geriatr Psychiatry* 2019;27:408–16.
- Hovland C. Welcoming death: exploring pre-death grief experiences of caregivers of older adults with dementia. *J Soc Work End Life Palliat Care* 2018;14:274–90.
- Han JW, Jeong H, Park JY, et al. Effects of social supports on burden in caregivers of people with dementia. *Int Psychogeriatr* 2014;26:1639–48.
- Shurgot GR, Knight BG. Influence of neuroticism, ethnicism, familism, and social support on perceived burden in dementia caregivers: pilot test of the transactional stress and social support model. *J Gerontol B Psychol Sci Soc Sci* 2005;60:P331–4.
- Almberg BE, Grafström M, Winblad B. Caregivers of relatives with dementia: experiences encompassing social support and bereavement. *Aging Ment Health* 2000;4:82–9.
- Del-Pino-Casado R, Frias-Osuna A, Palomino-Moral PA, et al. Social support and subjective burden in caregivers of adults and older adults: a meta-analysis. *PLoS One* 2018;13:e0189874.
- Donnellan WJ, Bennett KM, Soulsby LK. What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging Ment Health* 2015;19:932–9.
- Hunt B, Truran L, Reynolds F. "Like a drawing of breath": leisure-based art-making as a source of respite and identity among older women caring for loved ones with dementia. *Arts Health* 2018;10:29–44.
- Schumacher LAP, MacNeill R, Mobilily K, et al. The leisure journeys for sandwich generation caregivers. *Ther Recreation J* 2012;46:42–59.
- Chattillion EA, Mausbach BT, Roepke SK, et al. Leisure activities, caregiving demands and catecholamine levels in dementia caregivers. *Psychol Health* 2011;2011:1134–49.