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Abstract

Context

Older women commonly assume a caregiving role for their husbands at end-of-life and are more vulnerable to poorer health, wellbeing, and social and economic challenges.

Objectives

The aim of this study was to ascertain older women's experiences of spousal caregiving at end-of-life and the ways in which this experience impacts on the transition to widowhood.

Methods: Longitudinal in-depth semi-structured interviews were conducted with older women three times over a one year period following the death of their husbands. This report focuses on the initial interviews that examined the transition from caregiving to widowhood. Transcripts were analysed using Interpretive Phenomenological Analysis methods. Participants were community-dwelling women over the age of 65 who had recently been caregivers for their husbands who died within the past two years.

Results: Older women caregivers described their caregiver role as taxing, particularly in light of their own chronic conditions, which they failed to prioritise and address. They did not ask for help in managing their roles and health problems, but quietly endured. Hence, they did not communicate their needs or strains explicitly. The degree of perceived adequacy of communication and interaction with health professionals were important factors impacting on their bereavement.

Conclusion: It is imperative for health professionals to appreciate that older women caregivers may need more supportive interaction and information during end-of-life caregiving, they may have expectations of communication, and they may deny or fail to focus on their own health issues. A patient/family/carer-centred approach could negate this oversight and improve outcomes for these women as they transition into widowhood.

Keywords: Caregivers; widowhood; older women; qualitative

Running Title: Transitioning to widowhood

Background

Women commonly outlive their male spouses and often assume a primary informal caregiving role during their partner's end-of-life(1). Older caregivers are considered to be more vulnerable to poorer health and wellbeing than their non-caregiving counterparts and can face significant social and economic challenges, particularly women, who are generally poorer and more disadvantaged(2, 3). Of women caregivers who commenced caregiving in their early 60s, 15% were living in poverty compared to 4% of non-caregivers(4).

Caregiving can take a toll on health and wellbeing, the effects of which can compound the disproportionate incidence of chronic disease and disability in women(5). Research has indicated that strain and psychological distress associated with caregiving may have a negative impact on post-bereavement well-being(6). Perceptions of circumstances surrounding the death have also been found to impact on subsequent adjustment(7). The historical predominance of women in caregiver, domestic, and social roles has potentially contributed to perceptions of fewer unmet needs in these women as compared to their male counterparts, particularly upon spousal bereavement(8). This perception suggests attention to the unique circumstances of older recently bereaved women is less warranted(8).

A recent literature review of widowhood in older women underscored the complexity of this life stage and the need to apply a gendered framework to appreciate the social and cultural contexts that shape this life event for women(9). The transition from caregiving to widowhood is characterised by unique issues in which older women are vulnerable to poor health and wellbeing, economic insecurity, social instability, and potentially, untimely death(9). Although ongoing costs associated with a spouse's medical expenses may subside, implications of the loss of income, potentially in the form of pensions, combined with significant coping demands associated with this life-altering event, place older women at risk for a range of chronic health conditions and economic deprivation(10). Early bereavement, within 2 years of spousal death, represents a period of significant upheaval and has been implicated as a period of increased health risk in older women.

The aim of the study was to generate insight regarding older women's caregiving experiences during their husband's end-of-life, perspectives of barriers and facilitators to coping and transitioning from caregiving to widowhood, and their needs in relation to information, support, and services throughout this period.

Methodology

In-depth semi-structured interviews were conducted with older women who had been caregivers for their recently deceased husbands. Three interviews were carried out with each participant over a 12-month period. The Time 1 interviews focused mainly on care giving while Time 2 and 3 interviews explored the participants' experiences following their husband's death. Although the findings reported in this paper reflect data collection from Time 1, these interviews were enriched by the participants' knowledge that the researcher was committed to meeting with them for three interviews over a year. Such serial qualitative interviews allow the researcher to develop rapport and facilitate discussion of a very personal and sensitive issue during an important life transition(11). The study was advertised in newsletters and websites disseminated to health professionals or older women with support of peak professional bodies. Study information was also available at two palliative care services' memorial events. Potential participants were able to contact the researcher directly or through a health professional or family member. Participants were included if they were women, aged over 65, had experienced the death of their husband/partner within the past two years, and were fluent in English. Recruitment ceased when analysis revealed no new information was being generated.

The interview schedule was informed by the Stress Process Model in caregiving (SPM-C)(12) which recognises that contextual factors can have implications for types, appraisals, and outcomes of stressors facing caregivers. The ecological framework, life course, and social roles theories additionally informed data collection and analysis. An ecological framework recognizes factors such as age, gender, ethnicity, and socioeconomic status, that affect health and well-being (13). The life course theory extends this to include historical, social, and geographical influences on people's health and wellbeing(14). Interview topics included women's experiences of caregiving for their husbands, his death, social support, roles and relationships, her health, health

behaviours and wellbeing, and perceived met/unmet needs, particularly in relation to information, psychosocial support, and support services.

In the first round of data collection (Time 1), interviews lasted between 1-3 hours. As data were collected and analysed concurrently, interviews with the initial subjects informed subsequent interviews. The collaboration between participant and researcher inherent in this type of interviewing enabled flexibility in the data collection process as meanings were clarified throughout the interview and emerging topics discussed. The interviewer was an experienced qualitative researcher with expertise in coping and adjusting in chronic conditions. Interviews were recorded with participants' permission, transcribed, and pseudonyms applied to preserve anonymity.

Data Analysis

Transcripts were analysed using an Interpretive Phenomenological Analysis (IPA) approach (15) which is informed by phenomenology and symbolic interactionism. IPA incorporates phenomenological and interpretive methods with a psychological focus on personal meaning-making in specific contexts (15). This is an iterative and inductive approach committed to understanding the individual's point of view. Analysis began with multiple readings of the text (16). The researcher 'bracketed' her critical perspective to focus on the actual transcript. Transcripts were re-read, notes written in margins, interpretive comments recorded in a reflexive diary, and codes and themes identified that captured essential qualities of interviews. A second researcher enacted independent parallel coding (17) to facilitate procedural rigour. Connections between themes were considered while reviewing earlier transcripts and within the context of the informing theoretical frameworks to develop an overall structure of findings (16).

Ethical considerations

Approval to undertake this study was granted by the hospital and university ethics committees relevant to the research team and sample. This study was conducted in accordance with the ethical standards of the National Health and Medical Research Council and Helsinki Declaration(18). Participants were advised that they could be linked to a health professional or psychological support if desired given the potentially distressing nature of interview content. The

researcher facilitated links to any requests and followed-up with all participants the day after interviews to ascertain their wellbeing.

Results

Participants were twenty-one women with a mean age of 71.4 (SD 6.1). They ranged in age from 63-82 and had been married an average of 43 years, yet this ranged from 8-63 years. Most participants (81%) had been caregiving for their husbands who were sick for a period before their deaths, which mainly occurred in hospitals (33%), at home (29%), or in palliative care departments of hospitals (29%). At Time 1, the median number of months since the death was twelve, although this ranged from 2-47 months. Three participants exceeded the original age and time since death inclusion criteria, however, we adopted an inclusive approach for ethical reasons and the exploratory nature of this study.

This paper centres on women's perceptions of caregiving for their husbands, his death, and the early bereavement period, and thus presents excerpts from Time 1 interviews to support thematic descriptions. Prominent in women's accounts of their caregiving experiences were perceptions of inadequate communication and information provision which impacted on mental and physical health outcomes in their transition to widowhood. Although health professionals featured as perpetrators of inadequate information provision, the women implicated themselves as withholding information regarding their own support needs.

The caregiving toll: Her health on the backburner

All of the women reported at least one chronic condition of their own that had pre-existed their husband's declining health and several of these women experienced exacerbations while caregiving. The following excerpts provide insight into the women's health experiences during this time:

Well, I won't say I stopped looking after my own health, but I didn't look after myself as well as I should have and I did go through a period where I had an internal hemorrhage through one of my medications and I lost quite a lot of blood. (Alice)

If I'm looking after somebody else, I don't cope well with looking after myself at the same time...my sugars were high while he was in hospital because I was eating anything and everything. (Pat)

...since I'd been caring for him, it (blood pressure) was going up and staying up and they decided that I needed extra medication. (Gloria)

These excerpts reflect women's de-prioritising their health due to the competing demands imposed by their husbands' health conditions. These women neglected to engage in self-management of their own health conditions and in some cases suffered severe consequences.

Non-disclosure of need for caregiving support

In several cases, women did not disclose their needs for caregiving support nor did they attend to their own health problems, until their capacity was depleted or when they had a health emergency. Reasons for this non-disclosure included lack of awareness, denial, having multiple competing demands rendering their own health less prioritized, a generational cohort characteristic of stoicism and perseverance, and applying downward social comparisons to their husband's worse health condition.

Strains of caregiving, extending over months or years, personal care work enacted, both at home and following hospital admission were described. In some cases, their husbands refused home-based formal caregiving visits, thus necessitating their wives to assume personal care responsibilities. One woman recounted the moment she realized her limits:

Extremely (taxing) and I didn't realize just how much because I'm one of these people that if something's got to be done, you just get in and do it and more and more was being loaded onto me and I just kept churning through it, but then it got to the stage where I thought, oh I can't do this anymore. (Gloria)

Despite ongoing strain, these women persevered out of necessity, devotion, and habit. They spoke of enacting these tasks without hesitation as normal behavior, some referencing their core

values and behaviors developed since childhood. ‘Getting on with things’ and enduring distress silently without complaining or ‘feeling sorry for yourself’ were ingrained values exemplified in women’s behaviors.

A façade of coping despite suffering in silence

Some women felt that in retrospect, their relentless caregiving also reflected an inability to ask for help:

I coped maybe too well, I don't know...I wasn't good at telling people that it wasn't easy coping and so the family just got used to me plodding along and not saying much I guess, and not sitting down in a heap and crying, which wasn't my style...I'm not one to talk to people about what's going on, I try to keep bright and not elaborate and usually say, 'I'm fine'... (Olivia)

This woman discussed her habit of suppressing emotions to maintain a pleasant and perceived socially acceptable disposition. She explained her reasons for ‘suffering in silence’:

I think it's because I've had a sick husband and so it hasn't been that important... I've put it on the backburner which I had to do...I'd think, 'why am I like this? Look what he's coping with' ... He'd be getting up in the night, having trouble breathing and having to go on the machine...So my problems pale in significance, but it's still cancer and it feels scary. (Olivia)

This woman perceived her concurrent life-limiting health conditions as less significant than her husband’s after comparing their circumstances. Because he had more acute and distressing symptoms, she perceived her condition as less worthy of complaint. Although this rationalisation supported her motivation to endure, not communicating her anxiety to anyone isolated her during a vulnerable period.

Health professionals as facilitators and barriers to caregiver coping and adjustment

Women described interactions with health professionals who contributed to their husband's care as facilitating or hindering the experience of caregiving and the subsequent transition to widowhood. Women, whose husbands died in palliative care units or with palliative care home support, generally described positive interactions with this model and the health professionals involved. For example, palliative care nurses were favorably described as playing an important role in facilitating communication between care recipient, caregiver, and health professionals. Some described a sensitive and personable approach wherein they were attended to with compassion and dignity, both during end-of-life and upon bereavement. Communicating with bereaved spouses following the death of the husband was regarded highly as another instance of caring:

I was just blessed with the doctors and two of them got in touch with me the day after he passed away and asked how I was coping and what a privilege it was to have looked after him. (Olivia)

In contrast, a lack of post-bereavement follow-up left caregivers dissatisfied and hurt:

When he died, even the palliative care doctor at the hospital didn't speak to me or ring me or anything and the amusing bit is that at about the same time, my son's cat died and the vet sent a card of condolence and he said to me, 'Mum what did you get from the specialist?' I said, 'not a word, not a phone call, not a nothing'... when you've had that length of time with a specialist, just a phone call would have been nice. (Helen)

It was like we'd been in this situation for three and a half months and nobody really cared. (Julie)

Communication gaps protract grief

In addition to a lack of acknowledgement upon bereavement, some women discussed dissatisfaction with communication regarding her husband's care while he was an inpatient. In the following excerpts, one woman described missed opportunities for health professionals to communicate with her regarding her husband's prognosis:

I definitely would have liked a realistic view. If somebody had said to me, 'Julie, the end is nigh', you know? Nobody ever said that. The only thing was the young doctor and only about 3 weeks before he died he was in the room and he was always so lovely, and he said to me, 'Julie, have you ever heard of sepsis?' And I said, 'yes, I have.' End of conversation... Maybe if I'd answered no, he might have expanded... I remember thinking, 'he hasn't got sepsis', but thinking, 'why did he ask me that question?' I thought about that as I drove home that night. I thought, did he know something more than I knew? Maybe I should have followed up on it... At that stage of an illness, I was waiting for them to give me information, not to have to solicit it. That's what I was waiting for. I actually really did think, why wasn't I given more information? All these doctors were coming around and nursing staff, but nobody was telling me anything. To go through the same thing again, I'd be asking a lot, lot more questions. I think I was a bit reticent to ask. I'd keep thinking, they'll tell me if there's something that I should know. I would have liked somebody to have come to me who knew the situation wasn't going to be good and sort of alerting me to what I was going to face. I think that would have been helpful to me... (Julie)

These excerpts reflect the interactions and inner dialogue Julie experienced during her husband's final days in hospital. Although her caregiver role had partially acclimated her to her husband's condition, she did not have enough knowledge to understand his illness trajectory. Julie was left ruminating over the experience following her husband's death with feelings of guilt and anger which culminated in a formal complaint to the health service. She had an expectation that information would be provided without necessarily having to seek it out. She wondered whether emphasising her lack of understanding would have facilitated more and better information provision.

Perceived poor quality death compounds grief

Quality of death emerged as a factor in the women's subsequent adjustment and wellbeing. In instances where participants perceived medical or health service mismanagement to have contributed to their husbands' suffering or otherwise difficult circumstances at death, anger

resulted and persisted throughout bereavement in some cases. Descriptions of multiple, poorly coordinated transfers to different facilities, neglect of pain, inappropriate use of medications, under-appreciation of frailty, and failure to communicate prognosis followed by unexpected, perceived sudden deaths were described.

The circumstances surrounding death had a resounding impact on subsequent adjustment for some of the women. Quests for and denials of accountability perpetuated the women's anger:

My husband just died a terrible death which is why I am really angry. (Marie)

He was in and out of hospital... We had a really bad time with the hospital system. .. It was horrible for him, it was horrible for everybody. (Julie)

... I was colored by what happened. I thought, what if I'd said more? I don't know in my case whether it would have altered the outcome, but I think I could have made things a little bit better for him. (Julie)

These statements provide evidence of the damage inflicted on family caregivers when they perceive that their loved ones have not been cared for adequately. Self-blame and sorrow for their husband's experience persisted.

Whose job is it to provide information on practical issues and financial support?

Disparities between communication expectations and provision were described by other women as well. Upon describing distressing circumstances of her partner's death at home, one woman said she would have liked to have known what to expect. She, too, recalled missed opportunities during discussions with health professionals:

There were things that were just not talked about and we had lots of conversations with doctors and nurses...Even if the palliative care doctor had just given us some literature to read, we would have read it. No-one provided us with that practical "how you do it" stuff. (Beth)

This woman believed forewarning and advance planning would have alleviated some of her distress, which was still evident during the interview. Others described being unaware of eligibility to receive government-funded caregivers support payments.

It never occurred to me to ask for it (Carer's Allowance). I didn't know it existed. Nobody ever suggested it. (Rebecca)

The day that they put him in Palliative Care, the two nurses said, 'oh, we'll be taking the Carer's Pension off you now.' ...I looked at her and I said, 'what Carer's Pension?' For the five years I looked after him, I never once got the Carer's Pension. Nobody put me in for it and I didn't know anything about that.... Even before he passed away, they were so quick to take it off me. (Alice)

These communication gaps highlight significant oversights that impacted on the women's experiences of caregiving and the transition to widowhood.

Discussion

The findings of this study support and extend previous research indicating that women situate their own health needs secondary to their caregiving for others (19). Our data show that women sometimes consciously withhold information regarding their own health states during caregiving, as well as needs for assistance with caregiving and coping. Gender stereotypes and assumptions that women are more likely to attend to, communicate, or verbalize emotional or personal needs than men, may mean that women's unspoken needs go unrecognized and unaddressed(8). Yet, research has indicated that caregivers may feel their concerns, issues, and questions are not important enough to 'bother' health professionals(20).

Consideration of life course factors that contribute to non-help-seeking behaviours is necessary. Although based largely on American society, Generational Cohort Theory (21) suggests that historical events and social changes in individuals' formative years impact on a person's inclinations and cognitive styles over time (22). The majority of women in the current study were

born between 1923-1945 and dubbed, ‘The Silent Generation’, characterized by traditional values such as discipline, self-denial, hard work, obedience to authority, commitment, responsibility, and the adage ‘children were seen and not heard’(23). Similarly, ‘suffering in silence’ was endorsed by American Catholics of this era as appropriate stress coping behaviour (24). One strategy employed by the women was downward social comparisons which can enhance well-being and has been documented in breast cancer patients(25, 26). Conversely, ‘suffering in silence’ outside the context of religion, has been linked to feelings of isolation despite presence of supportive family in women with postpartum depression(27).

Implications for health professionals and services

These data indicate that health professionals can play key roles in older women caregivers’ coping and adjustment with the transition to widowhood. This finding is aligned with previous research linking family caregiving experiences to adjustment(28). Research supports the need for improvements in caregiver–health professional communication to better prepare caregivers for the death (29-32). Herbert and colleagues(1) proposed a framework for end-of-life conversations that argues for preparedness for the death of a loved as an important contributor to caregiver well-being and bereavement outcomes.

Appreciating the various contextual factors impacting on older women caregivers during this time is an important step in interacting with and supporting the caregiver effectively. A holistic assessment of caregiver needs and wellbeing as part of palliative and non-palliative departments in hospitals and in primary care is one strategy. Providing pro-active bereavement services, follow-up and clarifying processes for providing practical and financial support information among health services staff and teams will help to ensure gaps in information are minimised.

Limitations

The research team acknowledges that recruitment of caregivers following spousal death disallowed exploration of ongoing caregiving experiences. The self-selected sample may have had more negative experiences and thus were more willing to participate to voice their experiences. Although a small sample, the use of serial qualitative interviews helped to ascertain in-depth nuanced descriptions of experiences, thought processes, and needs during a sensitive

period. Rapport established through this method facilitated collection of rich data and multiple opportunities for elaboration and clarification which contributed to development of themes.

Conclusion

This study has provided examples of older women's experiences with caregiving for their husbands at end-of-life and in doing so, has highlighted important gaps in communication with lasting consequences. The feminization of ageing signals the importance of better understanding the needs of older women caregivers who likely will be playing dual roles of caregiver and patient. Tailoring interventions to support the needs of older women caregivers is a necessary health initiative.

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