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Citation:

Turner, M and King, C and Milligan, C and Thomas, C and Brearley, SG and Seamark, D and Wang, X and Blake, S and Payne, S (2016) Caring for a dying spouse at the end of life: 'It's one of the things you volunteer for when you get married': a qualitative study of the oldest carers' experiences. *Age and Ageing*, 45 (3). 421 - 426. ISSN 0002-0729 DOI: <https://doi.org/10.1093/ageing/afw047>

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Caring for a dying spouse at the end of life – “It’s one of the things you volunteer for when you get married”: A qualitative study of the oldest carers’ experiences

Abstract

Background: Older people aged 80 and over are increasingly providing end of life care to spouses at home, and often do so for long periods of time, whilst also trying to manage their own illnesses and disabilities. Little of the research on older spousal carers has focussed on the oldest carers, hence the needs of this particular population are not fully known.

Objective: To explore the experiences of the ‘oldest carers’ in caring for a dying spouse at home.

Methods: Secondary analysis was undertaken on a subset of data from a larger qualitative interview study; this dataset comprised 17 interviews from participants aged 80 or over. Framework analysis methods were used, with items derived from the thematic analysis of the main study.

Results: The oldest carers in this subset demonstrated high levels of resilience, and the ability to adapt to their caring role. Caring until death was accepted as an integral part of the commitment made to their partner as part of the ‘wedding contract’. Carers felt they benefitted from the support provided by family, friends and care services; however their own care needs were not always recognised by health and social care services.

Conclusions: These findings underscore the complexity of the oldest carers’ experiences and challenges in times of illness and end of life. Healthcare professionals should be alerted to the myriad ways caregiving is enacted in serious illness and seek opportunities for developing supportive interventions specifically for older carers.

Introduction

In almost every country in the world the population is ageing; in the UK, the number of people of state pension age is predicted to increase by 28% from 12.2 million in 2010 to 15.6 million by 2035 [1]. As the population ages, an increasing number of older people approaching the end of their lives require the help and support of health and social care professionals, family members, friends and neighbours, and a growing number of those who choose to stay at home are cared for primarily by another older person, their spouse [2].

In the United Kingdom, 16% of people aged 65-74 and 13% of those aged 75 or over are family carers [3]; this equates to over 1.6 million carers over the age of 65, based on population data from 2013 [4, 5]. When providing end of life care in the home, family carers express a desire to maintain a normal life for as long as possible [6]; however for older carers, this may be particularly hard to achieve. Care-giving is more prevalent in later life [7] and spouses may be caring for partners with non-malignant diseases, where the duration of care is often prolonged and marked by sudden events such as falls [6]. In diseases where the pattern of dying is less predictable, palliative care is less likely to be sought because it can be very difficult to recognise when the end of life is approaching [8]. In addition, more than half of older adults have three or more chronic conditions [9], and multiple morbidity increases substantially with age [10]. Approximately 65% of older carers have a long-term condition themselves, which can be further exacerbated by the caring role, due to missed medical appointments, stress and the physical toll of lifting and moving the person being cared for [3].

The term 'older people' is generally used to refer to those aged 65 and over; this older population can be divided into 'young old' (aged 65-74), 'middle old' (75-84) and 'oldest old' (85 and over) [11]. This paper focuses on carers aged 80 and over, a group that straddles the middle and oldest old; this age group has been selected because although there is a significant literature on older spousal carers (those over 65) [12, 13], little of it addresses the specific needs of the oldest of these when caring for a dying spouse. For simplicity, spousal carers aged 80 and over will be referred to throughout this paper as the 'oldest carers'. The paper reports findings from a qualitative interview study which explored the experiences of 17 of these oldest carers who had cared for a dying spouse at home. These interviews constitute a subset of data from a larger study called 'Unpacking the home: family carers' reflections on dying at home' [14, 15, 16].

Study design

The 'Unpacking the home' study used a cross-sectional qualitative design, comprising in-depth interviews with bereaved family carers of older people who died at home (see Appendix 1: Interview Guide). Interviews were analysed using a thematic approach [17], and selected transcripts also underwent narrative analysis [18]. A full description of recruitment, data collection and data analysis is provided in the 'Unpacking the home' protocol paper [14].

This paper reports the findings from a secondary analysis of a subset of data from this study. Of the 59 bereaved carers who took part, 17 (29%) were aged 80 or over; analysis of demographic data revealed that both the mean and median length of time that these oldest

carers provided care to a family member who ultimately died at home were much longer than for their younger counterparts, as shown in Table 1.

Table 1: Length of time care was provided at home

	N (%)	Range	Mean	Median
Whole study sample	59 (100)	2 weeks – 11 years	29 months	11 months
Carers aged up to 79 years	42 (71)	2 weeks – 11 years	23 months	9 months
Carers aged 80 and over	17 (29)	1 month – 11 years	43 months	24 months

This unexpected finding raised important questions about the experiences of the oldest carers when faced with caring for a dying spouse over a long period of time. It is important to note that those who required care for many years were not in the dying phase for the whole of that time, but nevertheless they were cared for by their spouse right up to the point of death in their home. The research team decided to explore their experiences by conducting further analysis of these 17 transcripts. Using a framework approach [20], themes from the original analysis that specifically related to the oldest carers were developed into a framework, against which this subset of data was re-analysed. The initial framework contained five major themes from the original analysis; ‘support’, ‘fulfilling promises and doing duty’, ‘burden of caring’, ‘adaptability, coping and resilience’, and ‘after the death’. Each transcript was re-read and analysed for these themes, and subthemes were identified. As the analysis progressed, the themes and sub-themes were revised and developed. To facilitate the analysis, a table was constructed containing the interview number, description of the theme, related subthemes, and illustrative data extracts. Two researchers (MT and CK) undertook the analysis, and discussed the emerging themes

regularly to reach consensus on the interpretation of data; this was agreed with the rest of the team.

Results

Characteristics of the sample

All study participants had cared for spouses who died at home. Table 2 summarises the demographic data, including the number of years participants had been married where stated during the interview (this question was not specifically asked). Nine (53%) participants were female, and 8 (47%) were male; all were aged between 80 and 90. Cancer was the diagnosis/cause of death given for 9 (53%) of cared-for persons, and non-malignant conditions for the remaining 8 (47%). The length of time cared for varied widely; notably, none of the cancer patients required care for more than 2 years, whereas the five patients who needed care for 9 or more years all had non-malignant conditions.

Table 2: Characteristics of the sample

Participant number	Gender of carer	Age of carer	Ethnicity of carer	Spouse's diagnosis	Spouse's age at death	Number of years married	Months cared for at home
P01	Male	88	White British	Cancer	85	Not stated	1
P02	Female	82	White British	Renal failure	89	50+	108
P03	Female	80	White British	Cancer	83	40+	1.5
P04	Male	80	White British	Cancer	87	47	3
P05	Male	87	White British	Cancer	86	63	24
P06	Male	85	White British	Cancer	80	59	24
P07	Male	82	White British	Dementia/old age	94	Not stated	24
P08	Female	83	White British	Parkinson's Disease	87	62	120
P09	Female	83	White British	Cancer	86	60	2
P10	Male	82	White British	Dementia	76	Not stated	120
P11	Female	82	White European	Heart disease	88	60	18

P12	Male	90	White British	Old age	91	Not stated	36
P13	Female	88	White British	Cancer	87	Not stated	12
P14	Male	82	White British	Cancer	88	50+	1.5
P15	Female	82	White N American	Cancer	81	Not stated	1
P16	Female	80	White British	Parkinson's disease	77	42	108
P17	Female	87	White British	Old age / previous stroke	91	Not stated	132

Key findings

Two interconnected major themes were developed from the framework analysis:

'Willingness to care' and 'Ability to care'. These themes and their sub-themes are presented in Table 3, together with illustrative extracts of data.

Table 3: Categories, themes and illustrative data extracts

Categories	Sub themes	Illustrative data extracts
Willingness to care	Preparation and discussion	<i>So we didn't have long discussions about end of life or anything like that; we were too busy living our life (chuckling) if you know what I mean. (P16, Female, 80)</i>
	Fulfilling wish to die at home	<i>...she said she wanted to die at home and I wouldn't disagree with her, no, no. I loved her a lot (sighs) [...] that was what she wanted, that was what she got (laughs). I want to die in my own bed she said, right, and she did. (P01, Male, 88)</i> <i>I promised her in the form of a pact between the two of us, because we were together for 63 years and we were soul mates in that sense. I said [...] 'When you kick your clogs, I'll make sure that you're in this room'. (P05, Male, 87)</i>
	Acceptance of 'duty'	<i>Ill-health has crept up on me, I've got breathing difficulties which have got worse over the last twelve months, but even though in the last six months she was incontinent, doubly incontinent, it's one of those things your volunteer for when you get married. (P07, Male, 82)</i> <i>I still am pleased he died at home [...] I think if a person can take it, it's much, much better that you were there, whichever way, even if they are unconscious, but it's just something you feel is right. (P11, Female, 82)</i>
Ability to care	Physical and emotional strain	<i>Towards the end I was getting very, very tired myself, because he would call me up two or three times every night. I slept down on here to be with him and I was really getting exhausted. (P08, Female, 83)</i>
	Coping with crises	<i>I went in and saw she was on the floor which I was very concerned about indeed, and tried to lift her up myself, deadweight, and then actually fell back against a sort of corner of a small table and thought oh goodness, what have I done? (P04, Male, 80)</i>
	Support from family and friends	<i>I was lucky. I mean I had a lot of support from the family.(P12, Male, 90)</i> <i>These young people were in and out like yo-yos actually, you know, and they turned up: either they drove down just to spend a night here and drove back again and this sort of thing. They were very, very good, you see. So that I never felt that I was alone, though in fact there were periods of a couple of days between their arrivals. (P14, Male, 82)</i>

		<i>[Our daughters] were always extremely helpful when they could be [...] but of course they had their own families to look after. (P10, Male, 82)</i>
	Lack of family support	<i>We've got one son and unfortunately he's got lung cancer so he was not able to do what he'd like to have done. (P06, Male, 85)</i> <i>Well I haven't got any children at all but my nephew lives 50, 60 miles away. (P01, Male, 88)</i>
	Community services	<i>Well, towards the end, in the last couple of months, we had carers in in the morning for... it was only for an hour, and carers in the evening because at the end I could no longer get him in and out of bed myself, I just could not manage it, so we had carers in the evening to help get him to bed. (P08, Female, 83)</i> <i>I couldn't have done without them because I could not have washed him and cleaned him myself all the time because he was quite heavy and, as the illness progressed, he was very, very stiff. (P16, Female, 80)</i>
	Using bells and call systems	<i>When night came she had a little bell by her bedside and I knew that at different times during the night she'd need help so I'd be sort of listening for that bell. (P04, Male, 80)</i>
	Finding ways of doing things	<i>He had different pills and the names we never understood at all so I drew funny faces by all the pills and then in my book I put funny faces so then we ticked off, I did manage to do on the computer a big charty thing and one of the boys when he was here he did it with the names of the pills and the funny faces and then we ticked off and I ticked off all those things yes and the morphine and things yes. (P03, Female, 80)</i>
	Resilience	<i>I'm that sort of person, I've never done any intensive nursing in my life. Then you're there in a situation, you handle it, you deal with it. It was bit like being thrown in at the deep end really. But it amazed me what I managed to do actually. (P02, Female, 82)</i>

Willingness to care

Despite spending many years together, most of the oldest carers had not discussed end of life care in detail with their spouses. Reasons given included unwillingness on the part of the dying person to talk about dying, and a perceived lack of cognitive ability due to conditions such as Parkinson's disease and dementia. Regardless of this, participants accepted that caring for their spouse was part of the contract they entered into when they married, even if they had health problems themselves that made it difficult, and there was a strong sense of commitment to fulfil a spouse's wish if they had expressed a preference to die at home, even if that discussion had occurred many years previously. Whilst recognising that the responsibility of caring was at times difficult, many of the oldest carers viewed their role positively and felt privileged to be able to provide care to their dying spouse.

Ability to care

However, the analysis revealed that willingness to care is tempered by the ability to care, and factors such as physical and emotional strain, coping with crises, support available, adaptability and resilience all impacted on the experience of caring (see Table 3). Most of the oldest carers provided the majority of care for their spouses, including personal care such as washing and feeding. Many participants discussed their own health problems, and highlighted the physical and emotional strain of caring, and the extreme fatigue caused by the relentlessness of providing care 24 hours a day. Strain was further accentuated by crises, and falls were a particular concern; 11 of the 17 oldest carers related occasions when their spouse fell, sometimes at night. They described having to call neighbours, ambulance crews or nearby workman to help them lift their spouse, as they were unable to do it alone.

Instances such as these left both the carer and their dying spouse mutually vulnerable, and caused fear and anxiety about their ability to continue to care.

Participants reported having to cope alone for much of the time; formal care appeared to be limited to a few hours per day, until the last few weeks or days before death, when additional support, such as night sitters, would become available. Formal care seemed to be better coordinated when the patient was dying from a cancer-related illness, as specialist palliative nurses were more likely to be involved, suggesting the challenges of caring may be greater for carers of people with non-cancer conditions.

The amount of support received from family and friends differed greatly between participants. Carers acknowledged distance to travel, family commitments and ill-health as reasons why family members could not provide greater support. Regardless of the support provided, carers stressed their gratitude to family and friends for the practical and emotional support they gave.

Support from community services, such as district nurses, GPs and palliative care nurses, was also highly regarded by the majority of carers, especially when they felt they could no longer cope with their spouse's medical care needs. Participants did however identify a number of issues with formal end of life care, including a lack of information about what to expect, little sense of continuity (e.g. high turnover of carers, lack of consistency in carer attendance times, and GP seen) and at times inflexible, impersonal care provision.

Overall, the oldest carers demonstrated great resilience and ability to cope with the end of life caring role. Despite having to manage difficult and often stressful situations, and ultimately face the loss of their life partner, participants talked about caring with positivity and humour. Some participants seemed surprised at their own resilience and stamina in being able to cope with the demands of caring over a very long period of time. Some also described a number of practical solutions they had found (such as providing bells or whistles), which helped them to respond to the needs of their spouses.

Discussion

Compared with their younger counterparts in the full study [15, 16], the oldest carers spent substantially longer caring for a dying spouse at home, and many of them also had to contend with problems that younger people may not have to face, such as their own illness, disability or frailty. This study therefore suggests that the 'burden' of caring in this specific group is much greater than for younger carers.

Interestingly, however, the oldest carers did not perceive caring as a burden. Despite the challenges, they felt that caring for a dying spouse was a positive experience, even a privilege. They appeared to accept the caring role as something they signed up to when they married. Many of the participants in the study were married in the 1950's in Britain, at a time when Christianity was the predominant religion. Two decades before divorce rates significantly increased in the UK [21], this was an era of marital stability, when marriage was viewed as a life-long commitment. The duty to provide care to a frail spouse "till death us do part" has been described as one of the central tenets of the institution of marriage,

enshrined in the Christian marriage vows [22], and in contrast, unmarried older people who cohabit may be less inclined to provide partner care than married individuals [23]. As the number of cohabiting unmarried couples reaching older age increases [21, 24], more demand may be placed on care services in the future.

The oldest carers acknowledged the support received from care services, and many praised staff who visited their homes; however, there was evidence that care services may not be geared towards their specific needs. Carers identified a lack of continuity in health and social care provision, and services appeared to be less well coordinated when patients were dying from non-cancer conditions, reflecting previous findings [25]. Palliative home care services are often designed for people dying from cancer, where the end of life phase is better defined and relatively short [26]. However, as evidenced by this study, older people are increasingly required to offer care in situations where there is a long, gradual process of decline [2, 27], which is likely to result in greater turnover of care staff and variation in contact with GPs and District Nurses. Considering the amount of care older spouses provide, consistent, well-coordinated care services are required [15]. It is also arguable that societal norms are changing and that, although the current older population are largely stoical and grateful for even the limited services received, in the future this may change, as the baby boom generation reaches old age with a very different set of expectations.

This study also highlights challenges in relation to social care provision. One carer reported asking for help from care services to buy the ingredients to make a proper meal, because her own disabilities made this very difficult for her; this request was denied because in the UK, most social service departments in local councils do not fund home care support for

activities such as housework or shopping [28]. Funded home care aims to support activities of daily living (such as washing and dressing), and staff may be overly focused on completion of these tasks, therefore failing to foster trusting, personal relationships with carers and patients [29], and ultimately failing to respond adequately to the needs of the oldest carers. This study supports findings that in home settings, the family carer is often viewed as a co-worker and as such, may not be identified as having care needs in their own right [6]. Professionals and providers need to 'think family' and consider the support needs of the oldest carers, especially those with health problems who are providing care for a prolonged duration [6].

One limitation of this research is that only participants who responded to the invitation to take part in the wider study were included; those who had a particularly negative or traumatic experience of caring may have been more likely to decline the invitation. All 17 participants gave their ethnicity as 'White' and 14 (82%) as White British, so it is unclear whether there are cultural differences and if the findings are generalisable to other ethnic groups. A further limitation is that as this study used secondary data analysis, the original interview questions were not designed for this specific group of participants so may not have captured their particular needs.

Future research should look more closely at the healthcare needs of the oldest carers, as how the caring role impacts on their ability to manage these, as well as the sustainability of caring over a prolonged period. Further research to explore differences between oldest carers from different countries, different ethnic groups and between carers of patients dying from different conditions would also be valuable.

Conclusion

These findings add to our understanding of the attitudes, experiences and support needs of the oldest members of society who provide end of life care to spouses within their own homes. Caring for a dying loved one presents physical and emotional challenges to carers of all ages, but the oldest carers face additional challenges in also having to manage their own physical frailty, illnesses or disabilities alongside those of their spouses, often for prolonged periods of time. Most carers are willing to do this, and want to honour their marriage vows and commitments. However, both health and social care services need to be responsive to the particular needs of this population in order to ensure they are able to sustain caring until the death of their loved one.

Key points

- Increasing numbers of older people care for spouses in their own homes at the end of life
- The oldest carers shoulder a high burden of care in managing their own and their spouses' ill health
- Health and social care services need to be more flexible and responsive in order to provide adequate support for the oldest carers.

Funding

This study was funded by Marie Curie Cancer Care, grant reference number C1344/A12256.

Ethical approval

Ethical approval for this study was granted by NRES Committee North West – Lancaster, reference number 11/NW/0203 on 09/05/11.

Acknowledgements

The authors thank the bereaved family carers who took part in the research.

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Appendix 1: Interview guide

'Unpacking the home': family carers' reflections on dying at home Interview topic guide 19/09/2011

- Can you tell me how you came to be looking after your family member at home?
- Did your family member make an active choice to die at home? If so, how did you/other family members feel about that?
- Can you tell me about your experiences of caring for your family member at home?
- Did your family member do any planning around their wishes and preferences for how they were cared for prior to death?
- Could you talk through the final week or two of their life and tell me what happened?
- To what extent were you involved in providing 'hands-on' physical care (e.g. bathing, toileting, feeding)?
 - How did you feel about doing this?
 - Was any special equipment required?
- To what extent were you involved in administering medications?
 - How did you feel about this?
 - Did you get any support from a pharmacist or district nurse?
- Do you feel that you received enough support in caring for your family member e.g. from the statutory services, voluntary organisations, family and friends?
 - How easy did you find it to know who to contact for what help?
 - Was there somebody who was co-ordinating the care?
 - Were there too many people involved?
- What was helpful to you during this time and what made it more difficult?
- In retrospect, how do you feel about your family member dying at home?
- Are there any things you wish could have been done differently?
- What happened in the early period of time after the death?
 - Were there any visits from former care providers?
 - Was equipment/medication collected at an appropriate time?
 - Was there any involvement from a coroner?
- How has life been for you since the death of your family member?

- How do you feel about your home now?
 - How do you feel about particular rooms?
 - Were there any changes to room usage?
 - Do you have particular memories associated with the home?
- Have you made any changes to your home since the death?
- Is there anything else you would like to tell me about in relation to caring for your family member at home?