

Providing care for a person with late-stage dementia at home: What are carers' experiences?

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Abstract:

Background: It is widely reported that carers who provide care for a family member with dementia endure physical and psychological burdens. Not only do they fulfil an important role for the person with dementia but also for the wider society. This study aims to explore the experiences of carers who provide end of life care for a person with late stage dementia at home.

Method: Semi-structured interviews were conducted with 17 current carers and 6 past carers of a family member with late stage dementia. Data was analysed using interpretative phenomenological analysis.

Results: Four super-ordinate themes were identified which described the challenges faced by carers at different stages of their care giving journey: 1) The experience of dementia grief; 2) Parenting the parent; 3) Seeking support; 4) Death, dying and life after death. 2 themes which specifically focus on end of life issues will be presented.

Conclusion: Dementia grief was experienced by carers as a result of a relationship change and an inability to recognise the person with dementia as their mother, father or spouse. A role transition ensued resulting in the carer adopting the role of parent. Carers expressed a desire to provide care for the person with dementia at home until the time of death however support is required in this area at both individual and community level. Family carers require education to help identify the dying phase which will assist to minimise the shock of death. Strong evidence suggests that the burden of care may leave family carers poorly equipped to adapt to life after the death of the person with dementia. Greater pre-death support is required to facilitate a better post bereavement adjustment.

Background

In Ireland, it is estimated that there are 350,000 people are living with dementia in the community (Pierce, Cahill & Carney, in O'Shea, Cahill & Pierce, 2017). According to Cahill, O'Shea & Pierce (2012), there are currently an estimated 50,000 family carers in Ireland, caring for someone with dementia or a symptom of dementia; however, due to a reduction in family size and more women returning to the workforce, this figure is expected to decline in the coming years (O' Shea & Monaghan, 2016). At present, community – based services in Ireland are fragmented and limited despite government policy to support people with dementia to remain at home. The latest Irish Central Statistics Office (2016a, 2016b) figures reveal that 92.1% of those aged 65 years and over live at home and for those individuals with dementia, the burden of care largely falls on family and friends. This results in significant costs on caregivers who receive little or no financial support. In addition, without adequate support for caregivers, and the improvement of community based services, continued reliance on family carers may be untenable in the longer term.

Cahill et al. (2012) estimates that the overall median daily provision of care received by a person with dementia (PWD) from a family carer was 8.33 hours duration. Carers reported needing greater relief and more support to assist with the ongoing burden of care provision. While it is not clear from Cahill et al. (2012) report what stages of the dementia disease process these care receivers were at, it may be assumed that greater care requirements would be necessitated at end of life stage, which inevitably increases carers' stress and strain.

Caregiver burden is the most commonly studied topic in clinical gerontology (O' Rourke & Tuokko, 2004) and equally it is well documented that women account for the majority of informal caregivers (Schulz & Martire, 2004; Stieber Roger, 2006; Chiao, Wu, & Hsiao, 2013). Tretteteig, Vatne, & Rokstad (2017) echo this, reporting that as well as providing care, women are more likely to attend to housekeeping duties than male caregivers and experience a greater burden from care giving. Chiao et al. (2015) also contend that spouse caregivers and adult children caregivers experience higher levels of burden compared with other informal care givers of people with dementia. Studies focusing on the issues of dementia care illustrate the burden family members bear, with common findings including risk of mental and physical illness, social isolation, stigmatisation, financial difficulties, stress

and difficulty coping (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Orgeta, Lo Sterzo, & Orrell, 2013; Reily, Evans, & Oyeboode, 2018).

Carers can experience profound pre-death grief similar to post death bereavement. This reaction is as a consequence of experiencing the loss of the person they formally knew and an inability to recognise them as their mother, father, spouse. This paradoxical disconnection between psychological and physical losses, captures the crux of ambiguity in the receding of the known self in dementia grief (Blandin & Pepin, 2017), and is a response to the perceived losses in a loved one with dementia (Lindauer & Harvath, 2014). Significant losses, experienced as compounded serial losses are a feature of the carer's experience (Chan, Livingston, Jones, & Sampson, 2013; Santulli & Blandin, 2015) and these losses increase in size and number as the disease advances.

Studies have also been conducted on the experiences of family carers of a PWD in a care home or long term care setting (Schulz, Belle, & Czaja, 2003; Hennings, Froggatt, & Keady, 2010), however less attention has been focused on family carers' experiences of providing care to the PWD in the home or on the impact of providing end of life care to a family member with dementia on the carer. Research has been overlooked on this topic in Ireland and knowledge about the experience of providing end of life care to a PWD at home is required to develop this field of research.

Method

Aims & Objectives

This study aimed to illuminate the experiences of family carers who provided end of life care for those with late stage dementia at home. The objectives of the study were to gain an understanding of (a) what facilitates or hinders caring for individuals with late stage dementia at home; (b) participants' experiences of supports available or required to facilitate caring for individuals with late stage dementia at home; (c) the educational and training needs of family carers; (d) specific end of life care needs for individuals with late stage dementia.

Study Design

Interpretative Phenomenological Analysis (IPA) was selected as a research design over alternative qualitative approaches as it is consistent with the epistemological position of the

research question. The principal aim of IPA research is to ascertain how people make sense of their experiences. The focus of IPA is on 'the detailed examination of personal lived experience, the meaning of experience to participants and how participants make sense of that experience' (Smith, 2011, p.9).

Participants and Setting

Given the sensitive nature of the research, and the potential difficulty to recruit family carers who would be willing and able to participate, the small, idiographic, homogenous sample size typically used in IPA was appealing. Participants were selected if they were the main carer for a family member with late stage dementia at home, were physically and cognitively able to participate, were aware of a dementia diagnosis for the PWD (all types of dementia were included) and were aware that the PWD was in the late stage of dementia. For the purpose of this study, past carers also had to satisfy the same inclusion criteria however an additional criterion was that the PWD had died within the last 6 – 12 months.

Gatekeeping is the process by which researchers are permitted access to a research setting under investigation and/or to the participants in that setting (Kawulich, 2011). Gatekeepers were instrumental and of paramount importance in the selection of participants for this study. Initial contact was made with gatekeepers (managers of carer support groups, home help services or nurse managers working with PWD) by telephone. Once the gatekeepers understood what the study involved, and had information about the first author's background and experience in this area, they were willing to provide access to participants deemed suitable for the study. Gatekeepers then distributed information letters to potential participants, allowing participants the opportunity to self-select to take part in the study by contacting the first author.

Procedure

Semi-structured interviews were conducted by the first author in participants' homes. All interviews were audio-recorded and ranged in length from 30 minutes to 1 hour and 53 minutes. While interviews were being conducted, the person with dementia was present in the home or in a respite facility. Two interview schedules were developed and utilised in this study; one for current carers and the other for past carers. Interview schedules were used in a flexible manner and acted as a guide, however, the researcher's role was that of active

listener and it was often preferable to set aside the structure and to fully concentrate on the participant's needs instead (Smith et al, 2009). Questions posed reflected the aims and objectives of the study. In addition, interview schedules were developed in consultation with experts in IPA, those with expertise in the area of interviewing people with dementia and from questions based on an examination of previous literature.

Data Analysis

Smith et al (2009) contend that the core of IPA rests in its analytic focus; that focus directs analytic attention to the research participant's efforts to make sense of their experiences. The analysis moves from "the particular to the shared, and from the descriptive to the interpretative" (Smith et al, 2009, p.79). A sequential series of steps to analysis was developed by Smith et al (2009) which acted as a framework for analysis used flexibly and innovatively. Each transcript was read and re-read before initial notes were made. Emerging themes and sub-ordinate themes began to develop leading the analyst to identify connections across emerging themes. The researcher then moved to the next case and repeated this process for each transcript. Finally, patterns were sought across cases leading to the identification of super-ordinate themes.

Results

The experience of providing care to a person with late stage dementia can be a protracted and difficult journey. The challenges of providing care to a person with late stage dementia at home was the overarching theme to emerge from the analysed data. However, the challenges were abundant and varied depending on where the carer was situated within the caregiving trajectory. Participants included 17 current carers and 6 past carers for a family member with dementia (Table 1). Twenty one interviews were conducted in total, 2 of which were with couples while the other 19 interviews were one-to-one interviews (n=23). A brief demographic form was utilised to collect information pertaining to the participant's age, gender, number of years caring, and support services used by the person with dementia. Almost three quarters of participants were female (n=16), the average age of a carer was between 50-59 years, the average length of time caring was between 5-9 years and the majority of participants cared for their mother (n=17). All current carers resided with the PWD. Past carers also resided with the PWD prior to their death.

Table 1. Demographic Profile of Participants.

Carer's Pseudonym	Age Range	Gender	Years of Caring	Relationship to person receiving care
Mary	40-49	Female	5-9 Years	Mother
Lisa	50-59	Female	0-4 Years	Mother
Kate	70-79	Female	15-19 Years	Husband
Maureen	60-69	Female	5-9 Years	Husband
Fiona	60-69	Female	10-14 Years	Mother
Ava	30-39	Female	0-4 Years	Mother
Donna	50-59	Female	10-14 Years	Mother
Michael	50-59	Male	10-14 Years	Mother in law
Derek	50-59	Male	10-14 Years	Mother
Alec	50-59	Male	0-4 Years	Mother
Isobel	50-59	Female	0-4 Years	Mother in law
Caroline	50-59	Female	0-4 Years	Mother
Cillian	50-59	Male	5-9 Years	Mother
Ben	30-39	Male	15-19 Years	Mother
Grace	60-69	Female	5-9 Years	Mother
Jack	60-69	Male	10-14 Years	Mother
Aaron	40-49	Male	5-9 Years	Father
Emma	50-59	Female	0-4 Years	Mother
Hannah	50-59	Female	5-9 Years	Mother
Helen	50-59	Female	0-4 Years	Mother
Natalie	30-39	Female	0-4 Years	Mother
Ellie	70-79	Female	5-9 Years	Husband
Irene	50-59	Female	5-9 Years	Mother

Four super-ordinate themes collectively describe the challenges faced by carers at different stages of their caregiving journey (Table 2).

Table 2. Super-ordinate and Sub-themes.

Super-ordinate theme 1	The experience of dementia grief Questioning the self and their own sanity The struggle to care Burden of Care
Super-ordinate theme 2	Parenting the parent Conflicted parenting Being in control Parental guilt
Super-ordinate theme 3	Seeking support Support in the form of information Accessing formal support and services Informal support: A help or a hindrance

	The need for social support
Super-ordinate theme 4	Death, dying and life after death “That’s not my mother” Regret of not discussing death and dying Place of death Life after death

Super-ordinate Theme 1: The Experience of Dementia Grief

Questioning the self and their own sanity

This theme highlights the struggles experienced by carers to provide care during the initial stage of their caregiving journey. Carers identified unusual behaviours, changes in personality and signs of dementia often years before a formal diagnosis was made. Despite carers reporting these concerns to other family members and medical professionals, they felt unheard, disbelieved and frustrated. Carers expressed their discontent with medical professionals throughout the dementia disease trajectory, especially in the initial phase related to receiving support and a diagnosis of dementia.

Fiona (daughter): I must be two years telling them but they didn't believe me. Because you see things, you know your mother. [] Then I remember being at the doctor and I said 'I don't know, there is something not right' []. But he put it down to old age [], then I went in to him, I had enough, [] and I told him that, that there was something not right. But eventually he had to, so he brought her in and it was vascular dementia.

As a result of having an intimate knowledge of the PWD, carers reported instinctively knowing there was something amiss with the PWD however found it difficult to articulate exactly what that problem was. Frustration was evident when other family members dismissed the carer's concerns. Ben described having to almost set a trap to catch his mother out in an effort to prove to his family that his concerns were justified.

Ben (son): They would deny it and it felt like I was putting her under pressure to find something wrong with her, when I knew there was something wrong with her but I couldn't find it and like everybody else was in denial about it, but I could see her.

Carers struggled with the enormity of their situation attempting to be all things to all people, that of carer, mother, father, problem solver and liaising with many individuals coming and going in their family home. The multifactorial role had adverse effects on a carer's ability to cope resulting in feelings of concern for their own mental health. Emma acknowledged that her mental health was adversely affected as a consequence of her caregiving role, however had to struggle on to fulfil her obligations.

Emma (daughter): They thought it was me. They thought I had Alzheimer's []. I couldn't go to the toilet on my own, I wasn't sleeping on my own, she was with me 24 hours a day, with no break, and deteriorating in front of my eyes, physically and mentally. And they were all looking at me as if I was exaggerating, as if I was going mad. [] And looking back on it, I do not know how I didn't end up myself, crazy.

The struggle to care

Dementia is a very unpredictable disease with no two individuals experiencing the same symptoms. Carers described the uncertainty of not knowing what to expect from one day to the next, exacerbating their struggle to provide care.

Fiona (daughter): You just go from day to day and you don't know what is going to happen. [] It is a tough and a hard job and you are on your own.

Jack (son) described caregiving as *'an impossible situation that was developing before me that I knew nothing about'*.

The struggle to provide care was compared to a battle between those in authority who sanction resources and the carers themselves. There was a sense of 'them versus us' whereby any support carers received was due to a battle with 'them'. Kate illuminated that unless carers sought additional support or resources due to changing needs, support was not voluntarily offered to them.

Kate (daughter): You have to fight, I have to fight for it, I had to fight for every hour that I got. And I'm not finished yet [] I'll keep fighting, I mean I'm getting the same hours now that I was getting 2 or 3 years ago. So I think it's time that somebody did something about this situation.

Burden of Care

Already feeling over-burdened, carers frequently discussed their dissatisfaction with having to adopt extended roles and responsibilities, such as managing medications for the PWD. Carers identified their lack of knowledge and training in the pharmacological and medical field.

Aaron (son): And even with the medication now they say to me well it's at your own discretion, you can up it if you like and I said no, I couldn't do that, I can't. I have enough responsibility []. I'm not going to start prescribing medication here as well, I can't do that.

Other carers described how the burden of providing full time care resulted in having to withdraw from full time employment, social activities and ultimately sacrificing their freedom. Carers had enforced restrictions on their time and on their freedom. Lisa detailed not being in control of her life any longer

Lisa (daughter): Not being able to do your own thing, have your own life. My life is not my own. My life is centred around mammy.

In an effort to engage in outside activities, careful planning was required and organisation of a replacement to take over caregiving in the carers absence. Caregiving impacts not only on the carer but also on family life, resulting in dramatic changes to the way a family previously functioned

Alec (son): The other thing I wasn't ready for, but our family life was absolutely turned upside down. And we couldn't do anything without first thinking.

Super-ordinate Theme 2: Parenting the Parent

Conflicted Parenting

This theme details findings of the challenges faced by carers during the middle stage of the caregiving journey where the PWD's ability to carry out most activities of daily living had diminished. Out of necessity, carers took on an unconditional and somewhat conflicted mothering or fathering role. A role reversal was experienced which was an evolving and novel experience for carers and one which did not sit comfortably with them. Ava recalls a difficult time during caregiving when she had to constantly tell her mother what she could or couldn't do, speaking to her like a child who needed guidance.

Ava (daughter): It is hard, it's very, very hard, its, in the beginning its emotionally traumatic would be the only way to describe it. I used to tell my mother don't do this, don't do that, you can't have this, you can't have that, please come back, sit down, stop; and you are speaking to your parent in a way that you were never reared to talk. We were told what to do by our mum and dad, you didn't tell them what to do, and it's very, very hard in the beginning just coming to terms with the change.

Many carers were parents themselves; however for Aaron, the role of parent was both novel and challenging

Aaron (son): I was never married and I never had children of my own but I have one now, [] I've a ten and a half stone baby really. Basically I had become a single parent.

Contrary to professional advice, carers used experiential knowledge when it came to coping and providing effective care for the PWD

Aaron: Some professionals would say oh don't ever treat a person with dementia or Alzheimer's like a baby but unfortunately there actually comes a time when it's better to do so because I'm a firm believer that if it's possible for you to keep that person content and happy, then you will have a greater degree of success when it comes to doing other work with him.

Not all carers reported negative feelings towards their role change. Some positively adopted the reverse parenting role, found satisfaction in caring and observed the relationship between the PWD and themselves flourishing and strengthening. Aaron illuminated the role change encountered when he took on the role of parent for his father and articulated how the relationship between both men had become closer than before as a consequence of this role change.

Aaron (son): I've lost my father a long time ago, what I'm about to lose is my son, you know, and it's gonna be probably even harder to take, you know what I mean. [Pause] I didn't envisage this in the beginning, and I suppose nobody could have told me.

Quality of care

In an effort to manage the inherited role of caregiver, carers were able to cope with the situation if they felt in control of where and when the PWD went to respite, medication administration, dietary requirements and the co-ordination of professional carers who assisted in the care of the PWD. There was an evident mistrust of health care staff, hospitals, care facilities and respite centres. Carers provided a high standard of care for the PWD at home; however, based on past experiences in clinical settings, they felt that the quality of care would diminish once the PWD left their home

Kate (wife): I would not let him go anywhere because he wouldn't survive. He wouldn't survive a week in a nursing home or if he went into respite care, he wouldn't survive because they're not going to spend an hour giving him his breakfast, an hour, two hours giving him his dinner and dessert and glass of wine, they're not going to have time for that.

Similarly, Aaron believed his father would be in danger if he was cared for by someone other than himself. In an effort to assist healthcare providers deliver person centred care to his father while in respite, Aaron provided a care plan to staff, with the aim that staff would continue to provide quality care to his father while in respite

Aaron (son): I prefer to look after him here because I firmly believe that he's safer here with me than in the hospital, believe it or not, and that's a sad reflection on our society that that's the way things have gone []. Even when he goes to respite, I worry all the time. I created a four-page document, I've a care plan, in the hope that they will follow it exactly as I've things stated, but they don't, they never do.

Parental guilt

Guilt is a complicated emotion, commonly felt in the landscape of caregiving. Carers often feel guilty for recognising a need in them which is exacerbated if the carer acts on this need. In the case of Ellie, she described feeling guilty about 'everything' with the worst guilt experienced when she recognised a need for respite. Despite acting on this need, the carer's guilt was immense, resulting in her not receiving the benefit of a break from her care giving role

Ellie (wife): Guilt, guilt, guilt. Guilty he was like that, guilty for getting annoyed, guilty that I was getting frustrated that I was repeating everything, guilty that I wasn't doing enough, [] just guilty about everything. [] Do you know when I felt the most guilty? When I was putting him into respite. I felt dreadful for leaving. And I didn't get over it for days.

Carers reported feeling compelled to provide the best care they could reflecting the care they received as a child and subsequent guilt of not being able to meet those high standards

Irene (daughter): And sometimes no matter what you do you feel guilty that you don't do enough. Because you know they are your parents and they have been the best in the world you know. So you just kind of, you feel guilty about that.

Caregiver burden coupled with guilt is evident in the following extract from Helen. This carer illustrates the impact the caregiving role has on her and on her family, and how conflicted she feels attempting to meet the demands of her mother against the demands of being a mother and a wife

Helen (daughter): the focus has to be on the individual, it has to be on the person. [] All our lives were just totally focused around mum and dad prior to that. And you had no time for anybody else and any time you had for somebody else, you were feeling so guilty that you should have being given it that way. You're so divided.

Theme 3: Informal support. A help or a hindrance?

This theme examines the supports carers had available to them to assist with caregiving. There was an apparent lack of certain vital supports which would have made the caregiving role less arduous. Ten carers has some form of sporadic family support in the delivery of care while the remaining 13 carers provided care on their own. Several carers would like to have had 'hands on' support or acknowledgement from their siblings for the role they were fulfilling

Aaron (son): I had nothing, nothing, just myself for the first few years []. All I ever wanted was just appreciation from my own family for what I've done.

Family siblings were frequently identified to be a hindrance, often judgemental of the care that was provided and failing to offer any beneficial assistance. Ben (son) depicts how his sister comes and 'looks at her in the bed and that's about it' while Aaron (son) highlights his family's lack of involvement stating that 'there's never been a weekend where they've taken him'. Grace also illuminated the need for family involvement to assist her cope with the enormity of the role

Grace (daughter): More time from the family, [] they were more supervisory than hands on and one sister in particular, [] she could have said to me, I'll take mum out to our place and give her her tea []. That would have been nice, just to give me a few hours to catch my breath.

There were many carers who did receive good support from other family members and friends. Participants living in rural areas identified neighbours as a valued additional support available to them. Seventeen participants lived in a rural setting versus six who lived in urban areas.

The need for social support

The need for social support was recognised by many carers and the requirement to have time out to 'care for the carer'. While the desire is evident to have time away from caregiving, in the absence of adequate funding or either professional or informal carers to take over caring for the PWD, many carers have to forego any break available to them.

Grace (daughter): that is very important that you keep up and involve yourself in certain activities. [] You're very constrained for time when you are looking after somebody, but it's very important that you've some little bit of me time.

Carers highlighted the difficulty and effort attributed to leaving the home and were resolute that the activity outside the home had to be worthwhile to entice them to go.

Maureen (wife): It has to be something really tempting now to get me to go out and enjoy myself because it is a hassle getting a carer in and it is very hard to totally unwind because it is just on your mind all the time. [] You are very careful of your spare time.

Despite the presence of support groups in close proximity to where carers lived, some opted not to attend as they found the group to be of no benefit in terms of support or information. Additionally, the support group was not tailored to meet their specific needs.

Maureen (wife): It is very depressing to talk to other carers. I have gone to some of these workshops [] but the stories were just heartrending and it didn't do me one bit of good. I had a carer for the whole day. It cost me a lot of money []. There was nothing new that we got out of it to help us to handle the situation. [] I had to get someone in for €25 per hour for the whole day and really when I came back I wish I had gone somewhere else for the day.

Super-ordinate theme 4 – Death, dying and life after death

"That's not my mother"

Participants changed the way they interacted with and related to the PWD, no longer recognising them as their mother, father or husband. A paradox exists in the subsequent extract when Lisa states 'that's not my mother' because despite her mother being present with her, the mother she once knew was no longer there

Lisa (daughter): I don't know how long more, mammy, my mother could last another 10 years [] and it's not that I am going to be very remorseful about it either and of course I am very sad about it but it's not my mum, that's not my mother sitting there, [] so that is why I distance myself.

Also

Ben (son): And seeing someone with Alzheimer's taking the best part with you, it's not nice, you don't recognise that person at all or who she is. But that is another point that I couldn't come to terms with, that this woman was gone totally do-lally with Alzheimer's and this was not my mother.

There was an apparent disconnect between the way Lisa spoke about her mother comparing her to an inanimate object. Lisa used powerful imagery likening her mother to an egg. The shell of the egg represented the strong protective person her mother used to be. When the shell is taken off, the inside of the egg is vulnerable, penetrable, and in her mother's case, unrecognisable. Lisa further illuminated how she had withdrawn from the pre-dementia relationship by the way she referred to her mother as 'this' or 'it'

Lisa (daughter): about 2 years ago when I saw this getting worse and I realised this is not mammy this is not my mother, my mother would never talk or carry on like this [], but that's not my mum, never has been, never would be. [] It's like when you take a shell off an egg, you are left with this but this has nothing to do with me. But I am minding it probably out of respect for the fact that my mother was very good to us [] So then you look at what am I minding, you know, there is a shell there, it's like peeling an egg, isn't it? You know, she is gone, the peel is gone and there is just this, there.

Similarly, in an effort to cope with the loss of the person they once knew, Ava experienced conflicted grief and detailed having to emotionally draw back or pull away from her mother. Carers adopted practical approaches to coping with situations, justifying detaching from the PWD to achieve a happier family life. Ava saw the detachment as reciprocal, whereby she no longer recognised her mother and her mother no longer recognised her

Ava (daughter): I know I have detached because for the sake of my kids I had to, [] you really do have to detach from the situation and realise that she's, it's a vessel, it's not your mother anymore and she doesn't recognise me as her daughter and I don't recognise her as my mother anymore, that might sound cold [] It's honest.

Also

Helen (daughter): I feel anyway with dementia you've lost the person such a long time before that, it's like as if they've died a long time ago and a lot of it, now this is being just entirely honest, a lot of it is going through the motions

Maureen experienced a similar loss however still felt a connection, albeit in a different form of relationship. As well as grieving for her husband, she mourned the loss of their relationship as a couple and the activities they enjoyed together.

Maureen (wife): It is not your husband any more, it is somebody very close to you that, it is like looking after your father or somebody. And you have said good-bye to your husband really. It was very difficult in the beginning alright. But I guess time, you get used to things. And the hard part, is the social isolation, because you have no husband you don't have a partner, and a lot of things you would have gone to as a couple, you don't go to any more.

Regret of not discussing death & dying

Carers spoke of having regrets, one of which was not discussing death and dying early in the disease trajectory while the PWD was able to communicate their wishes and feelings. Due to being ill-informed about the progression of dementia, Caroline missed the opportunity to ascertain her mother's wishes regarding end of life care or preferences after her death

Caroline (daughter): I think what's so important is [] that you make the most of the time you have. Why didn't I know mum would lose her speech [crying]. Because I should have spoken to her, I should have talked to her about death. I think the other thing I learned was they know they are dying. And we pretend, oh we can't upset them. It's not them we are afraid of upsetting, [] I'm disgusted I didn't do that, [crying] but maybe I did know. I think I did to be honest. I just wasn't doing it.

Irene also acknowledged missing the opportunity to discuss her mother's wishes about death and dying and regretted not paying attention to the subject when her mother requested to discuss it. The subsequent extract depicts how the PWD wished to speak about their own mortality however it was the carer who was uncomfortable discussing this topic or accepting that this was a reality.

Irene (daughter): a few years ago she actually was talking to me about what she wanted to do with her end of life. And of course at the time I wasn't in a place to hear it, so I told her 'stop that will you, no need to be talking about that, we'll look after that when it happens, forget about it'. And of course now, [] I would appreciate it if she started the conversation again because I think I'd write down if she had any things, any, requests, but I don't know how to broach it now you know. So it's a lost opportunity but at the time I wasn't, you know I wasn't in a place to talk about it. I didn't think it was really that relevant.

Several other carers cited what they believed to be the PWD's opinions of dementia and the fear and anxiety the PWD had of developing this disease. There was a tangible sense of knowing the PWD and their loathing of the disease and wish to die rather than live with it. Fiona spoke candidly about her mother's wish to die by suicide rather than live with dementia. This extreme response emphasised the feelings of the PWD towards having this disease

Fiona (daughter): she said 'I am going down the road and I am going drowning myself'.

Similarly, Ava also discussed suicide, illuminating how having dementia had changed her mother unrecognisably from the person she was pre dementia and believed her mother would have thought it preferable to die by suicide than live with the disease

Ava (daughter): For a woman that was so vibrant and had a bubbly personality and embraced life with both arms its really, really horrendous to see them like this and if she had known the way things were going she would have gone off that bridge down there herself ten years ago before getting to this.

Ava gives specific and graphic examples to support her beliefs in the following extract

Ava (daughter): She often said that, the words would be 'shoot me', 'shoot me' 'put a bullet in me before I get like that', 'I don't want to be a burden on anybody'. And we would say, 'you are not a burden'. She is not a burden, she is still not a burden, its hard work, but she is not a burden. But I know I would put pen to paper for my own life and say get rid of me if I end up like that. I wouldn't want to be like that, I know she didn't want to be like that, but I wouldn't do it, I wouldn't do it.

When asked about their opinions on end of life care for people with dementia, both married couples initiated a discussion surrounding the ethical dilemma of allowing the person with dementia to die naturally versus intervening with medical treatments. It is noteworthy that both Isobel and Donna had a medical background and prior knowledge and experience of caring for people with dementia in healthcare settings

Isobel (daughter in law): It is a difficult one, are they obliged to leap straight in there and go ahead, or would that bit of common sense come to play, [] no one wants to mention it, you know, people with dementia, you know, they're looking for a way out of it and you know these things crop up, chest infections or whatever and you know in a lot of ways I think they're denied the opportunity to die.

This dilemma is echoed by another couple who also discussed the end of life phase for people with dementia and offered their opinion of dementia being a terminal illness

Michael (son): It's a difficult one, you have to take care of them, until nature takes its course basically. The only thing is that if they do get such a thing as pneumonia then you just let that...

Donna (daughter in law): But we do give her antibiotics []. It's a difficult call because I have to say that is one thing that I found very difficult over these years was that, say the time she got the blood clot in the leg and we took her to the hospital and the first doctor we met was kind of like, why are you here, why did you bother? [] Some people define it as a terminal disease, now I have cared for my father and the neighbour over the road with cancer and you know the terminal part of that you can see it, [] and you feel like it's ok to let them go, they are suffering. You don't see the same kind of thing [with dementia], it's hard to call that as much as a terminal illness even though it is terminal.

Striving for a good death

Despite caring for the PWD for many years, and seeing the declining progression of the disease, carers reported feeling surprised when death occurred. The shock felt by carers when the PWD died was due to a lack of information on the disease process and what to expect in the final stages of life

Alec (son): So when she did finally die it was kind of a bit of a shock to us really, you know she just faded away really didn't she []. Oh yeah a nice peaceful death, you couldn't wish for a better one. We hadn't a clue that that was going to happen.

Mary detailed her uncertainty about the end stage of life and her wish for a quick death at home for her mother. The arrival of death would come as a blessing for her mother.

Mary (daughter): I don't know what's coming, I don't know how to care for, [] I hope, God forgive me, I hope it comes soon for her, I hope it comes when she is in her own home, you know in bed. My mother is alive but she is not living. She sits in a chair all day and watches the world go by. She doesn't interact. She has no quality of life, for the woman that she was, I do hope that the [] time comes quicker rather than later.

Two carers identified home as the ideal place for a good death, in addition to having family present and being pain free.

Grace (daughter): She died at home in her own bed surrounded by her family and with the priest on call and she wasn't in any pain, so if you want, if you like, it was as good a way as you could pick to go.

Maureen (wife): the deterioration is very slow but it is there. If I look back at last year I can see the deterioration, it's just awful to watch. I just hope he dies peacefully some night, no hospital.

Life after death

Carers experienced an additional role change after the PWD died. They were forced to re-invent their role within the family, in the work-place and in society as they no longer assumed the role of carer. Carers were bound by time management and routine while the PWD was alive, and reported difficulty adjusting to the ample amount of routine - free time they now had.

Grace (daughter): Well it's like I suppose if people retire, you know, all of a sudden from having your 9 to 5 or whatever, and having your routine, all of a sudden there is no routine. So it does, it's kind of a bit of a culture shock, you have to get into recreating a routine.

Being a single man living in a rural location, Aaron reflected on how his life would change after his father died and had an awareness of the loneliness which would occur. There is a sadness to this excerpt revealing pre-death grief, not only for the loss of his father but also for his caregiving role

Aaron (son): I often wonder how I will fill the void that's going to be left behind when he's gone, from this routine that I've been in for so long

Similarly, Jack was also a single man who lived in an isolated area and detailed the emptiness and quietness that now filled his home, only recently noting the ticking of a clock as a result of the silence following his mother's death

Jack (son): You have no one, you have no one of your own, [] and all I have is my neighbours or friends that come in to see me. When they leave here at night and you hear no sound coming there from the room and the heavy tick of the clock that you never heard when your mother was here with you, that's when you know you're on a lonely journey in your life but there's nothing you can do about it. Nothing. [] You have the time but you don't want to do anything.

Reflecting on the caregiving journey and the experience of death, Alec demonstrated the sadness experienced by his family immediately after the death of his mother. The sadness discussed was not as a direct result of the death of his mother, but a sadness as a consequence of the struggle of caring for the years preceding her death and due to the unhappiness experienced by his mother and family during the caregiving period

Alec (son): So it's nice to look after your parents, you know and do your best for them but I couldn't say it was a rewarding experience, you know when my mother died we thought we'd all have a great sense of relief, that we'd all let out a big sigh, ah well she's at peace, but we just all sort of sat there and just felt crest fallen really, like deflated. You know we thought it was going to be a great day when she did finally die, for herself and you're just, all we could come out with was just sadness.

Discussion

As evidenced from the findings, carers described their experiences of providing care throughout the caregiving trajectory, in addition to former carers illustrating the death and dying experience. A number of models describe the caregiving trajectory in dementia (Wilson, 1989; Lindgren, 1993; Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995) with Lindgren applying the term 'caregiver career'. This encompasses 3 differing but overlapping stages: an Encounter stage (the diagnosis and loss of previous life patterns), an Enduring stage

(managing extensive care routines and social isolation) and finally an Exit stage (the relinquishment of caregiving through the death of a spouse or loved one) reflective of the stages experienced by these carers.

Sweeting & Gilhooly (1997) pioneered the application of the constructs of 'anticipatory grief' and 'social death' to the process of caregiving and dementia. Anticipatory grief is experienced when there is forewarning or threat of loss before an actual death occurs (Coelho & Barbosa, 2017) while social death refers to the ways in which a person is treated as if they were no longer alive (Borgstrom, 2016). It is argued that people with dementia experience a loss of personhood as a consequence of their illness. In addition, since dementia is commonly linked with older age, people presume them to be approaching death and are "examples of individuals for whom life may not be worthwhile anymore" (Sweeting & Gilhooly, 1997 p.99)

Correspondingly, Blandin & Pepin (2017) describe pre-death grief experienced by dementia family carers specifically as 'dementia grief' which is a particular form of anticipatory grief expressed in response to compounded serial losses of varying significance and evidenced by the ambiguity which characterises the experiences of loss in dementia. Carers recounted emotionally withdrawing from their caring role in an effort to cope with loss associated with the disease. This ambiguity was highlighted by one carer who stated "that's not my mother". Despite her mother being alive and having the physical appearance of her mother, the carer finds it difficult to remain emotionally connected to her and unable to recognise the PWD any longer as her mother as a result of the profound changes in cognition, personality and physical disabilities now present and is an illustrative example of social death for the PWD. This ambiguous loss occurs due to an inability to identify personality characteristics or personal memories which lead to experiences of ambiguity in family members whereby the PWD does not appear to be emotionally accessible or the same person (Sanders & Corley, 2003; Large & Slinger, 2013; Blandin & Pepin, 2017).

In general, carers of people with dementia require greater emotional support and respite care prior to the person's death than afterwards therefore by receiving effective social support pre-bereavement, facilitates better adjustment post bereavement (Schulz et al., 2003; Shanley, Russell, Middleton, & Simpson-Young, 2011; Sinha et al., 2017). Carers

reported feeling isolated and left to 'get on with it'. Difficulties were experienced accessing respite care for the PWD when carers needed it while others expressed their reluctance to avail of respite care due to a mistrust of respite facilities. As a consequence, carers had no experience of the PWD being away from the home for a prolonged period of time and no experience of a break from their care giving role. Greater exploration into end of life decision making, adequate preparation for their loved ones death, and measuring quality of life at end of life is required for family carers (Chan et al., 2013; Raymond, Warner, Davies, Illiffe, & Manthorpe, 2014). Shock and devastation among carers after the death of the PWD is attributed with a lack of foresight (Hebert, Dang, & Schulz, 2006). Carers in this study also highlighted the need for information surrounding the dementia disease process and 'what to expect' from time of diagnosis until death. Carers reported having to find this information online or by word of mouth from other carers. Appropriate information and intervention strategies should be provided throughout the care giving trajectory so that the terminal phase is demystified and feared less (Adelman et al., 2014).

Carers expressed their regret not discussing end of life and death preferences with the PWD early in the disease trajectory while the PWD had the ability to communicate their wishes. The unique aspect of ethical issues in dementia relates to the increasingly and unavoidable need for others to make decisions for the PWD. Decisions are based on evidence for the effectiveness of the particular action. However often decisions are complex involving clinical and ethical aspects. One such issue at end of life which raised an ethical discussion amongst carers was the provision or withdrawal of certain treatments such as antibiotic therapy. While carers understood that administering antibiotic therapy to treat infections was a life-prolonging measure, there was a reluctance to 'let nature take its course' and saw non-intervention as an admission of failure or 'giving up'. These views are not unique to this research as Hennings, Froggatt & Keady (2010) reported family carers judging themselves responsible if death ensued following the withdrawal of treatment.

Prognosticators may suggest in certain cases that antibiotic therapy is required while in other cases it may be withheld in people with severe dementia. The distinction between ordinary and extraordinary means of treatment needs to be understood in the case of someone with dementia and when the burden imposed by the particular treatment against the likelihood of benefits accruing to the person concerned has traditionally found to be

useful (Hanrahan, Luchins, & Murphy in Addington-Hall & Higginson (2001). Additionally, a failure to identify the end-of-life phase results in prolonged exposure to unnecessary treatments (Marsh, Prochoda, Pritchett, & Vojir, 2000). Ironically it is claimed that throughout the disease process the PWD often receives 'too little' care, an example of which is the under treatment of symptoms such as pain (Martin et al, 2005; Herr et al, 2006; Sampson et al, 2006; Husebo et al, 2008; Barber and Murphy, 2011) whereas end of life care is often characterised by 'too much' (Small, Froggatt & Downs, 2007) specifically when advanced dementia patients are subjected to burdensome interventions such as tube feeding and parenteral hydration (Hertough, 2006; Arcand, 2015).

Carers discussed the concept of euthanasia and assisted suicide for the PWD as well as citing the PWDs preferences for dying by suicide instead of dementia. Carers wished to avoid an undignified death for the PWD and acknowledged their poor quality of life as a consequence of the disease. Belgium and the Netherlands are the only 2 countries to legally recognise euthanasia within a number of patient categories (Gastmans & de Lepeleire, 2010). In addition, The Netherlands legally recognises advanced directives for euthanasia of incompetent people such as those with dementia as part of the 2002 euthanasia law (de Boer, Dröes, Jonker, Eefsting, & Hertogh, 2011).

Involving carers is paramount in ethical decision making especially at the end of life stage when complex ethical issues may be frequent. The principle of autonomy must be adhered to and education involving a detailed discussion of how death comes about is required. The concept of the person helps to justify and should encourage greater willingness to involve carers in decisions concerning death and dying (Chan, 2004). This mirrors part of the palliative care approach and the philosophy of palliative care that carers should be involved in decisions especially in dementia.

Literature on caregiving in dementia suggests that carers generally consider the persons death as a relief (Shanley et al., 2011; Chan et al., 2013; Raymond et al., 2014) in contrast to general literature on bereavement (Earle, Komaromy, & Bartholomew, 2009; Eliot, 2014; Thomas, Hudson, Trauer, Remedios, & Clarke, 2014). However, findings from this research suggest otherwise, with carers expressing surprise and shock when the PWD died, despite knowing that death was imminent. There is strong evidence to suggest that the

physical, psychological and social health of caring may leave family carers poorly equipped for life after death. When caregiving ends due to the death of the PWD, carers often struggle to deal with this significant change in their life circumstances. Larkin (2009) identifies 3 post bereavement phases encountered by bereaved carers: the post-caring void, closing down the caring time and constructing life post-caring. Carers described an innate sadness following the death of the PWD while in their post-caring void. During this 'wind down' period, carers undertook closure activities however struggled with the lack of routine and abundance of free time now available to them. Another role transition occurred reconstructing life and reinventing the self in the post-caring phase. Blandin & Pepin (2017) term this state of transition as liminality and while the end result may be positive, the process is unstable and ambiguous. Assistance is required in the pre-death period to help carers plan for their post-caring lives while still caring (Larkin, 2009) such as maintaining leisure activities and undergoing education and training to develop skills. Several carers in this study engaged in online courses on computer literacy and care skills. Equally, it is imperative that those healthcare professionals who had contact with carers during their caregiving career, continue this relationship with follow-up visits in the post-death period. This facilitates former carers discussing the challenges associated with the post-caring phase and reduced the incidence of complicated grief.

According to Shear (2010) complicated grief results after a loss and is defined as a severe form of grief which includes intrusive thoughts, separation distress and the inability to resolve a loss. 20% of dementia caregivers suffer from complicated grief following the physical death of the PWD (Holland, Neimeyer, Boelen, & Prigerson, 2009; Blandin & Pepin, 2017). Dementia caregivers with high levels of pre-death or dementia grief are more likely to have post-death complicated grief (Schulz et al., 2006). Therefore adopting interventions to lessen stress and caregiver burden, decreases the level of post-death depression and complicated grief (Blandin & Pepin, 2017).

Strengths & Limitations of the study

This is the first study to examine the experiences of carers who provide end of life care to those with late stage dementia at home in Ireland and the findings add to the limited

knowledge base on this topic. Methodologically, an IPA study involves a highly detailed analysis of the participant's verbatim accounts, which relies on the researcher's skill to reflect on and make sense of the participant's sense-making of their experience. The findings presented here have addressed the need for sufficient extracts providing evidence of the two themes.

The findings are limited to the West and North-West regions of Ireland and may not have widespread international application. However, given that the majority of participants were recruited by gatekeepers of national dementia and health related organisations, it is reasonable to assume that the experience is not uncommon to other carers who may share many of the same experiences and issues. This study had a sample size (n=23) which could be perceived as a limitation, however, IPA studies typically have small sample sizes which result in rich data. The age of participants ranged from 30 – 79 and years spent caring ranged from 0 – 19 years. However all PWD were in the late stage of dementia, and all carers lived in the West or North-West of Ireland, thus increasing the homogeneity of the study.

Conclusion

This study highlights the challenges faced by carers who provide end of life care for a PWD living at home. The supports carers require to provide care were outlined, providing valuable clinical insights for healthcare providers and organisations working with this cohort of people. Carers want to provide care for the PWD at home until the time of death. The support currently available has been described as inadequate and not addressing the specific needs of Irish carers or the PWD. Enhanced support is required in this area at both individual and community level and the findings should be considered when developing carer support services and education programmes to meet the needs of carers as well as the PWD. Findings from this research can additionally inform future research which could include larger samples of carers, comparing the caregiving experiences in different countries, or different cultural groups.

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Author Contributions

LD conceived and conducted the study. MD, PL, and KM supervised the study. LD wrote the first drafts of this paper. All authors contributed in critiquing and proof reading this paper.

Declaration of Conflicting Interests

The author(s) declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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