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Citation: Gee, E. & Yates, J. (2021). Lessons on life and death: a qualitative exploration of home carers' experiences following the death of a patient. *Home Healthcare Now*, 39(5), pp. 247-252. doi: 10.1097/NHH.0000000000001022

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Link to published version: <https://doi.org/10.1097/NHH.0000000000001022>

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Lessons on Life and Death: A qualitative exploration of home carers' experiences following the death of a patient

Emily Gee and Julia Yates

Abstract

The death of a patient can be a significant event for professional caregivers. Yet, little attention is paid to the emotional toll this can exert on carers, nor the support they need to cope during this time. The purpose of this study was to explore home carers' experiences following the death of a patient. Qualitative data collected through individual semi-structured interviews with six UK home carers was analyzed using interpretative phenomenological analysis. A central aspect was the merging of carers' personal and professional losses. Three key themes were: (1) there are no boundaries to loss (2) coping actions (3) a new understanding of life and death. These conversations gave carers a space to share their experiences of grief as well as lessons on their own life and mortality. Learning from these experiences will highlight the complexity of carers' loss and possible sources of support.

Introduction

Home carers play a fundamental role in caring for individuals at home and often develop close relationships with their patients (Boerner et al., 2015). When a patient dies, home carers can experience grief, yet this is often overlooked and recognized as a form of 'dis-enfranchised grief' (Moss & Moss, 2002).

There are limited qualitative studies exploring home carers' experiences following patient death. One study of home health aides in a New York City hospice setting reported emotional and grief responses, with coping through acceptance, meaning-making and social support (Ghesquiere & Bagaajav, 2020). In another study, home health aides working in New York City reported stressors surrounding the immediate loss of income and financial security; coping included self-reliance, faith and prayer, social support and education (Franzosa et al., 2019). Similarly, struggling with the loss of close relationships as well as their jobs was identified in another group study of New York health aides (Rickerson et al., 2005). While these studies share commonalities, the way in which home carers respond and cope with patient death may differ according to culture, personal beliefs and agency-level support.

With the number of people requiring home care in the UK predicted to increase (IBIS, 2020), paying attention to home carers' experiences following patient death is of growing importance. Gaining insight into the experiences of UK home carers following patient death and coping strategies may contribute to addressing needs to prevent loss of dedicated staff while maintaining high quality end of life care.

Methods

Research design

This study used a qualitative design to uncover the quality and texture of participant's experiences, through an interpretation, rather than to identify causal relationships. The study gained ethical approval from both the researchers' university and the care agency management team.

Sample

Six female home carers employed by a private home care agency in Luton, United Kingdom participated in the study. All had worked as a home carer for longer than four years (range 4-33 years) and all had experienced the death of a patient. The average age of participants was 46.5 years (range 29-64 years). The sample of six participants meets the suggested size for an Interpretative Phenomenological Analysis (IPA) study (Papadatou, 2000).

Data Collection

Upon securing ethical approval, the researcher shared a recruitment poster for the study via email with a group of carers, with details of how to contact the researcher. Six carers expressed interest to take part. The researcher screened volunteers for eligibility and sent further information about participation including consent. Semi-structured video interviews were conducted in June and July 2020. Questions included: *Can you tell me about a time recently when one of your patients died?* and *What do you find helpful to cope with the death of a patient?* Interviews lasted between 50-90 minutes and were recorded and transcribed verbatim.

Data Analysis

Transcripts of all audio data were analyzed using the interpretative phenomenological analysis guidelines of Smith et al. (2009). The first author listened to the recording of the first interview and read through the written transcript to ensure active engagement with the data. A line-by-line analysis of the data enabled an examination of the semantic content and language. This was used to develop an initial framework of themes and connections including patterns or contextual elements. This process was repeated with the remaining five interviews, including identification and prioritization of key themes. Reflective sessions with both authors were conducted on a regular basis throughout the study in line with best practice qualitative research (Ortlipp, 2008).

Findings

Three themes emerge from this qualitative research (1) there are no boundaries to loss (2) coping actions (3) a new understanding of life and death. These themes alongside relevant quotations are explored below.

There are no boundaries to loss

All carers described a personal impact of losing a patient. Although the death took place at work, carers felt their own 'personal grief' (Dolores) ripple across their own lives and memories of loss. Carers talked about *losing a piece of myself*, deaths that feel *too close to home* and the power of death to *re-awaken trauma*.

Losing a piece of myself. Carers described a feeling of emptiness when a patient died, for their patients had become part of themselves. Carers used similar language, 'something lost in myself' (Zhita), 'something has been lost inside you' (Dolores). Rosa summarized:

Every death is like something is missing from you...there is one thing that is gone if they are gone

All carers treated caring as more than a job, not only to provide the best quality of care but also for their themselves, 'if it doesn't come from inside, you will not enjoy it' (Rosa). Such investment also increased carers' vulnerability to grief. Zhita recalled the loss she felt after a patient she had cared for 'just three weeks':

If you put your heart in what you are doing, you will feel it

Although looking after patients and their families was important, some carers tried not to invest too emotionally, 'not a personal thing, it's a job' (Cavell), perhaps for fear of losing themselves along the way. Bridget spoke about her personal life and a reluctance to give to someone romantically, for feeling like she will lose out anyway. She seems to also fear giving to her patients:

Why love somebody if they are gonna leave you?

'*Too close to home*'. Many carers struggled to cope with deaths which felt 'too close to home' (Dolores). Carers often identified with deaths which reminded them of their

own family. Dolores spoke about having young children herself and she struggled to accept younger deaths, for these challenged her beliefs about when it is someone's 'time' to die.

When we've had deaths when we've had younger, younger family members...somehow in your mind it doesn't really make sense, does it? you just kind of think, why, or, how, or for what reason is this?

Many carers empathized deeply with the family. Zhita imagined if it was her losing her mum, 'I put myself in the shoes of the children, especially the daughter. What if I lost my mother?'

Re-awakened trauma. For many, patient death stirred up emotions and memories of personal losses. Vilma struggled to contain the grief for her father from a patient:

I had just been through a death myself, my father in October and then now in February he is dying...I felt like it, he's also like my father who is dying, I couldn't cope

Carers' memories were often accompanied by intense emotions and conflicting feelings. Rosa was reminded of her own absence during her parents' death:

When my parents were ill I wasn't there (cries)...sometimes you get so you get so emotional and you feel guilty as well because you are not there to look after your parents

Despite the emotions that were stirred, Rosa described 'to compensate for it, you want to look after them well', seeming to channel her regrets to help her patients. Similarly, Zhita found it cathartic to be present with a patient on his last hours, 'rather than regret oh I should have looked after him when he was dying', for she was unable to do this for her own father.

Coping actions

All carers found their own ways of coping. This was not something that they were taught but it was 'instinct' (Rosa) and they found 'a way within yourself' (Cavell). Carers described a dual motion of *turning away from the loss* to avoid grief, whilst *turning towards the loss* to face grief at other times.

Turning away from the loss. All carers described the importance of setting aside their grief when at work. This helped them focus on their role, 'you can't let your emotions override your professionalism (Cavell). Keeping busy provided Dolores a distraction from the emotional charge of patient death:

I externalise myself; I almost feel a numbness to death. I don't feel much when I'm busy with what I have to do and its only afterwards when I think, or feel, or grieve.

Dolores creates an image of a bird flying over death, watching from above.

Externalising herself seems to create a temporary escape from the pain. Other

carers did not experience numbness. They felt their emotions deeply but learnt to control their expressions. Vilma learnt to relegate her emotions to a secondary position:

Even though you feel anger you cannot express it because at that moment you don't matter. The only thing that matters is the patient and their family

Carers also turned away from the loss by seeking distractions such as reading, swimming, going for walks or watching TV. Keeping busy seemed to help Vilma repress her own memories of loss:

Every time I feel sad and remember the person who died what I do, oh I have to play something, I have to do something, I have to make myself not think about it because then I will be sad, and I will just go into a depression

Turning towards the loss. All carers felt that they could begin to let the loss 'sink in' (Dolores) once they had finished their shift and were at home. Andrea was able to compartmentalise her grief:

Only when I come home, when I'm actually in my bubble, I deal with it

Many carers experienced an outpouring of grief at home. This was a whole-body experience, including emotional responses of 'distress', 'sadness', 'anger', as well as physical symptoms including 'exhaustion', 'headaches', 'loss of appetite'. Most

carers would enter a state of full immersion, often staying up all night or crying until the early hours.

While the grieving process was often solitary, carers also found solace in sources of support, such as family members and their manager. Vilma found it helpful to keep in touch with the patient's family, for it reminds her of what she did for them:

You feel in touch with the family it's like ohh we missed you, we missed the days when you were here

Although carers reached for support, many alluded to wanting more, including 'courses on end-of-life care' (Dolores) and 'courses about dying' (Zhita).

A new understanding of life and death

Following the death of a patient, all carers seemed to reach an existential appreciation of the fragility of life and the importance of acknowledging their own mortality. Death was a 'learning experience' (Vilma) and seemed to teach *lessons on life and lessons on death*.

Lessons on life. On one hand, the death of a patient encouraged carers to slow down and 'get quiet' (Andrea). Death provided the opportunity for carers to reflect on their own lives and what truly matters to them. Andrea talked about the lack of time she had in her previous career to reflect on such things, 'I just had to perform, perform'. She described death like a mirror:

It brings me to a point of reflection in me and reminds me how important life is and the value of life, having family, friends and loved ones

Andrea seems to enter a state of stillness, in which death reveals the authenticities of life and the importance of living in the present. For many, these lessons on life helped them 'grow' (Cavell) on a personal level. Sheryl spoke about her struggles with depression and the privilege of her work, 'a lot has opened up to me...if it wasn't for the caring, I don't think I would have been here.'

However, patient death also seemed to propel carers into a state of urgency to make the most of life. For Dolores, witnessing her patients die reminded her of the temporality of life:

One thing I have learnt from this job is that life is very short. You just have to be thankful for what you have every single day

Many carers described a feeling of duty to do the things they enjoy. This seemed to stem from the ability to separate themselves from the patient, to realize that 'if your patient will die, just prepare yourself that you still have life.' (3).

Lessons on death. Carers not only sought to live more fully in the present, but also to prepare for the future, and their own mortality. Dolores had not thought much about this before:

It's something that you would never ever think about if you had not experienced death or thought about it or seen it because, who thinks about that?

Carers learnt from the way their patients died and form their own wishes, when their time comes. Vilma noted:

I told myself that if I ever, if I ever, if I'm ever going to die, I would just like to be sleeping and not wake up. I wouldn't want to be suffering

Many carers took practical steps such as what type of death they would want, medication plans, planning their funeral and communicated this to their family. Witnessing repeated deaths seemed to distil carers' fears, instead, death became an inevitable part of life. Dolores could no longer ignore death:

No-one wants to talk about death its, not a great subject. But I do think it's important to talk about...I think that death wouldn't have to be so terrible if it was something that was spoken about more

Discussion

The first theme in this study highlighted the interface between carers' personal and professional losses. Like a gas leak, carers' memories of personal loss seeped into their work with their patients, corroding the space that separated the grief for the patient from their own personal losses. Previous studies suggest that home carers

might benefit from attending grief groups to process the stress of their work (Ghesquiere & Bagaajav, 2020). Yet, carers also suppressed their personal grief to keep up with death in their day-to-day work. Given that unresolved loss may contribute to burnout (Anderson, 2008), home carers might also benefit from opportunities to process personal loss, alongside strategies to contain this from patient loss.

The second theme revealed that with experience, all carers found their own coping actions. Individual coping strategies were used both personally and professionally as each carer learned to regulate their emotions where and when it felt appropriate. The motion was similar to that described in Papadatou's (2000) model of 'experiencing' versus 'repressing' grief. Yet, this model emphasizes the importance of learning to grieve from others such as co-workers. Carers in the present study grieved privately and learnt these ways themselves. Further research is needed to explore the importance of shared group grieving, versus individual coping. Further, almost half of participants alluded to a lack of formal training and education on ways to cope with patient death. Offering training would offer support to carers alongside supervisor support.

The final theme showed that patient death awoke existential questions. Carers were deeply touched by the loss of a patient and they integrated these experiences into their relationships with others, their approach to life and their relationship with their own mortality. Post-traumatic growth (PTG) has also been observed among nurses (Vishnevsky et al., 2015). To the authors' knowledge, this is the first study to identify PTG among carers. Such lessons on life and death should be shared with junior carers, to highlight opportunities for enrichment through their work and possibly a source of light when things seem too tough.

Limitations

The sample was made up of a small group of female carers from a single care agency in the UK which might impact the generalizability of findings. Second, while efforts were made to acknowledge reflexivity, such as keeping a reflective diary, as with any qualitative study, the researcher's personal experiences are likely to have played a role in the interpretation. Finally, the participants were known to the head of the care agency which might have impacted the 'validity' of responses, given they might have had concerns about expressing their experiences and confidentiality.

Conclusion

This study provides qualitative evidence of the complex interplay between home carers' personal and professional grief following patient death. In doing so, it extends previous studies which show the depth of carers' grief. The study indicates the possibility for positive life changes and views. Future studies that evaluate interventions to help carers process their grief, both personally and professionally, promote emotional health and prevent caregiver burnout may be beneficial. Acknowledging the complexity of carers' grief alongside offering formal education and support systems is crucial to their wellbeing and ability to provide quality care.

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