

Professional compassion fatigue: what is the true cost of nurses caring for the dying?

Christina S Melvin

Abstract

Background: Emerging evidence describes some of the heavy tolls that health professionals experience as they deal with the continual loss of patients. Each patient and family has particular needs (physical, psychological, social, and spiritual) and is deserving of expert end-of-life care, and it is this intensity of need that places nurses at risk of professional compassion fatigue (PCF). **Aim:** This pilot study aimed at further exploration of the prevalence of PCF among hospice and palliative care nurses, as well as the nature of its effects and any coping strategies that nurses adopt. **Methodology:** A descriptive qualitative study was undertaken using semi-structured interviews with six highly experienced, purposively sampled nurses from a home health agency in northeast USA. **Results:** All six of the participants recognised the risks of developing PCF, and one was clearly experiencing PCF at the time of interview. Signs and symptoms were described and strategies for avoiding and alleviating PCF were discussed. **Conclusion:** There are clear physical and emotional health consequences for nurses who provide hospice and palliative care over extended periods of time. Further research is needed into the extent of the problem, specific causes, and coping strategies.

Key words: Accumulated loss phenomenon ● Professional compassion fatigue ● Nurses ● End-of-life care

anxiety, intrusive thoughts, apathy, and depression (Slatten et al, 2011). Chang et al (2007) and Lim et al (2010) studied work stress and its effects on acute care nurses, cancer nurses, and emergency care nurses; however, few studies have examined these effects in nurses working in hospice and palliative care.

Demographic statistics indicate that the proportion of older adults in many developed countries is set to increase dramatically; thus the demand for expert end-of-life nursing care is only going to increase (Anderson and Hussey, 2000; US Census Bureau, 2008). Emerging challenges facing health-care systems around the world, including in palliative care services, will become very apparent within the next 20 years (Canadian Institute for Health Information, 2008). Hence, there is a pressing need to learn more about the prevalence and extent of PCF in health professionals, including nurses providing palliative care, as well as techniques for dealing with the problem. This study aimed at furthering the understanding of PCF and its effects on nurses who care for the dying over extended periods of time.

Pioneers in hospice and palliative care Florence Wald, Dame Cicely Saunders, and Elizabeth Kubler-Ross emphasised that those in need of care at the end of life 'merit the most competent, expert, evidenced-based care provided in a way that embodies compassion, respect for dignity, and an appreciation for the whole person and family' (Ferrell and Coyle, 2006, p16). One of the underpinnings of end-of-life care is the provision of exquisite symptom management, in which nurses play a crucial role (Ferrell and Coyle, 2006). At the same time, 'exquisite care' places unprecedented demands on the individuals providing it.

The terms professional compassion fatigue (PCF), burnout, and accumulated loss phenomenon have all been used to refer to the cumulative physical and emotional effects of providing care over extended periods of time. These include

Background

Professional compassion fatigue

The term compassion fatigue was first introduced by Figley in 1983, who defined it as a 'state of tension and preoccupation with the cumulative impact of caring' (Figley, 1983, p10). Figley identified that PCF is experienced by those who help others in distress. He reasoned that nurses were at particular risk for compassion fatigue because compassion and empathy are core values of nursing. Nurses are often routinely exposed to considerable pain, trauma, and suffering (Coetzee and Klopper, 2010; Hooper et al, 2010), and hence they may be predisposed to being 'wounded by their work' (Stebnicki, 2000, p23). Although it is a privilege to care for those in need, 'there is a cost to caring' (Boyle, 2011, p1).

LaRowe (2005, p21) described PCF as 'a heavy heart, a debilitating weariness brought on by

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repetitive, empathic responses to [the] pain and suffering of others'. He further described PCF in nursing as 'nurses absorbing and internalising the emotions of clients and sometimes co-workers' (LaRowe, 2005, p21). Showalter (2010, p239) stated that healers 'collect bits and pieces of their [patients'] trauma by exposure to their lives'. Many professionals carry these bits and pieces as images in their minds and intense feelings that affect them physically and emotionally at the end of their working day. According to Showalter (2010, p239), 'Those who are strongly empathetic may be most at risk.' Such experiences frequently result in health professionals leaving the field (Aycock and Boyle, 2009).

Some of the additional symptoms of PCF include anxiety and intrusive thoughts, similar to traumatised patients (Slatten et al, 2011), as well as apathy and depression, hypertension, errors in judgment, difficulty sleeping, and nightmares (Jackson, 2003). Sabo (2011) stated that the care provider's declining ability to provide empathy in a therapeutic relationship is considered a key factor in PCF. These symptoms have the potential to create negative long-term health effects in nurses and indeed anyone who continually cares for people who are seriously ill, wounded, traumatised, and/or dying.

Dean (1998) described how, since the mid-1970s, hospice specifically has been considered 'stressful' (p151). She stated that not only do hospice workers deal with repeated and ongoing loss, but they also work with families at a time of immense emotional strain. This strain is often preceded by months or years of treatment, physical care, immense worry and stress, and anticipatory grieving prior to the time the hospice team becomes involved. Problematic family dynamics added further stress for nurses.

Research questions

This pilot study set out to answer the following questions:

- Are nurses whose job it is to deal with death and dying on a continual basis at risk of developing PCF?
- What are the consequences (both physical and emotional) of hospice and palliative care nurses continually dealing with death?

Methods

Design

This was a descriptive qualitative study. According to Sandelowski (2000; 2010), the goal of qualitative descriptive studies is a comprehensive summary of events in the everyday terms of those events. Qualitative descriptive designs are

Box 1. Semi-structured interview guide

1. How many years have you worked in hospice and palliative care?
2. Describe how you cope with ongoing patient deaths and the families following these deaths.
3. Professional compassion fatigue is described as having the potential of causing negative effects for those who continually care for patients who are seriously ill, wounded, traumatised, and the dying.
 - a. What are your thoughts about this?
 - b. Do you have some feelings around this concept?
 - c. Have you ever experienced any distressing symptoms related to this work (nightmares, difficulty sleeping, intrusive thoughts, depression, etc)? If so, please describe.
4. Has your view of death changed since you began this work?
5. Describe your coping strategies.
6. Describe any boundaries that you use to protect yourself.
7. What role does your supervisor play in supporting you in this area of practice?
8. When you return from vacation, are you refreshed, rejuvenated?
9. How would you know if you needed a break from hospice and palliative care?
10. Do you have any recommendations for other nurses working in this area of practice which might allow them to continue over long periods of time?

typically an 'eclectic but reasonable combination of sampling, and data collection, analysis, and re-presentation techniques' (Sandelowski, 2000, p334). Burns and Grove (2005, p44) described the purpose of descriptive research as an 'exploration and description of [a] phenomenon in real-life situations'. This method is used to generate new knowledge about topics where limited or no research has been previously conducted.

Participants

Data was collected via one-on-one personal interviews with six hospice and palliative care nurses. All six nurses were female and purposively selected from a population of registered nurses employed at a community home health agency in the northeast region of the USA. The home health agency is affiliated with the researcher's institution. There were approximately 20 nurses who worked in hospice and palliative care at this home health agency; volunteers were solicited from this group based on their having a minimum of 10 years of experience. The participants' experience ranged from 11 to 33 years. Each participant willingly agreed to participate; none was selected because they were exhibiting any signs or symptoms of PCF.

Data collection

The researcher developed a semi-structured interview schedule (Table 1). According to Polit and Beck (2012), the interviewer's job is to encourage participants to speak freely about the

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identified topics, while allowing them to provide as many illustrations and explanations as they would like. This technique ensures that the researcher will obtain all relevant information. Any ambiguous comments by the participants were clarified during the interview.

Each interview was audio-taped behind closed doors in a conference room at the home health agency and lasted approximately one hour. Implied consent was obtained from each participant. All participants were informed about the purpose of the research and assured of anonymity. At the beginning of the interview, the researcher asked the first question from the questionnaire and then probed further as needed. The researcher then moved to the second question, and so on. Each interview was then transcribed verbatim and was analysed concurrently with the ongoing data collection. Analysis included a line-by-line process using themes generated in the literature.

Ethical considerations

This study was approved by the University of Vermont Human Subjects Research Committee.

Data analysis

Data analysis commenced after the first interview and was ongoing throughout the study. The interviews were transcribed verbatim and the researcher undertook a content analysis of each transcription. Qualitative analyses were conducted according to the guidelines of Patton (1990). The researcher became immersed in the data in order to understand the frame of reference of each participant. The transcripts were read and reread, and notes were taken about the overall impression of the interview. An inductive approach was used to develop codes, categories, and patterns. Definitions were written for each code that emerged. The data was analysed using a constant comparison analysis, categorising and sorting the text. The codes were then grouped into clusters and the clusters were then organised into categories. The categories were thematically organised and named and are discussed in the results section.

Trustworthiness

Various strategies and attributes enhanced the trustworthiness of the study.

- **Credibility:** the audiotapes were transcribed verbatim, a search for confirming evidence was conducted, peer review/debriefing took place, and the accounts contained thick, vivid description
- **Dependability:** the audiotapes were transcribed verbatim and were read and reread, and notes were made on the overall impression given by the interviews

- **Confirmability:** documentation was done carefully and a search for confirming evidence was conducted
- **Transferability:** the taking of field notes was done carefully, a search for confirming evidence was conducted, thick, vivid description was obtained, coded data were used, and consistent themes were found
- **Authenticity:** comprehensive field notes were made, interviews were audiotaped, transcription was verbatim, and impactful, evocative accounts were given (Lincoln and Guba, 1985).

Results

The overarching theme that emerged from the study was that, without adequate coping strategies, the participants were at risk of developing PCF. One participant was clearly experiencing PCF at the time of the interview, and she identified this herself. Each of the other participants had experienced some aspects of PCF and had developed strategies for coping and remaining healthy. Each stated that they were aware of the need to maintain healthy coping strategies to ensure their ability to continue to provide end-of-life care.

The individual themes that were derived from the data analysis were as follows:

- Risk for PCF in exposure to repeated deaths over extended periods of time
- Physical and emotional costs of providing hospice and palliative care
- Setting boundaries/healthy coping strategies.

Risk for PCF

Although all of the nurses interviewed indicated that providing hospice and palliative care was a privilege, each had experienced some of the symptoms of PCF. The participants described their feelings and responses to recurring exposure to death. They described the need to put into perspective the experience of caring for the dying while not letting the experience totally consume them.

‘I think that hospice and palliative care nursing is very challenging ... it takes a person being willing to be introspective to really understand and to be honest with themselves about what they are feeling and why they are feeling that ... I think that when I began to see that ... I could identify all that I was doing and still not feel that I could come up with an acceptable solution for me to cope in that setting. That helped me to make the decision that it was time to leave palliative care. [This participant moved from an inpatient palliative care service role to a hospice residential home.]’ Participant 3

'We do develop a separation ... an abstraction ... You can be very present with the family and very present with the patient ... you then step away and know to let go of ... as much as you can ... but you never want to totally let go. But you let go a lot ... I really encourage it to leave when it's time to leave ... that stress, that emotion, that sadness, that intensity.' Participant 3

'So there seems to be a theme of doing stuff [roles] for 3 to 4 years and then kind of changing what I do or where I do it; so I don't have to leave the field completely but it's kind of a reset moment.' Participant 4

'I just felt that at that point I was working too much, feeling too responsible and it was reinforced by [telephone] calls at home ... I was not giving people my number, but they would look it up in the phonebook ... I was starting to feel it [hospice and palliative care] was who I was instead of what I do and I felt like I was starting to lose a bit of me.' Participant 4

Physical and emotional costs of caring

Each participant also reported associated physical and emotional costs to providing hospice and palliative care. One participant stated that when she was working in a community home health hospice, she felt nearly sole responsibility for patients and would worry about them after she went home at the end of the day. She later transferred to a residential hospice home where at the end of her shift there were other nurses to assume responsibility for the patients.

'In the 1990s, I worked in an AIDS inpatient unit. It was a 35-bed unit. They [patients] were young men and they weren't ready to die. And so, it was like being in a war zone. Out of the 35 beds, we probably had a death every 24 hours ... You can't have enough [emotional] support in that situation. And I made multiple changes within the facility because I was burned out.' Participant 1

'... you are seeing a death ... you are seeing one, two a week, and maybe you just happen to be here [residential hospice home] when those deaths occurred. But it can also eat away at you—multiple losses. And how can you not get attached to people because they are just lovely, and you go in and spend time with them, and then they die? And so, if you don't do something in your life to make that better or cope with that, then eventually you burn out.' Participant 1

'I used to be able to go on vacation and come back feeling relaxed, refreshed and excited and I have really noticed in the last 2 years that it is not happening. I just returned from a week's vacation. I came back feeling only a quarter full ... I am not recovering. I'm not doing well ... I am really struggling both mentally and physically. In the last 2 years, even coming back from a weekend I'm still feeling heavy, really heavy on the shoulders.' Participant 2

'The last couple of years, the paperwork has quadrupled. I come home after working 10 hours and I have 3 to 4 hours of paperwork to do ... I still enjoy it but the recovery piece is not happening ... the recovery of me.' Participant 2

'Particularly cases where things are going really quickly like this fellow who was in a swimming pool ... last Sunday and Wednesday he was admitted to hospice. Saturday morning, he died. I was physically and emotionally exhausted. And I think that it does compound synergistically in a negative way ...' Participant 6

Setting boundaries/healthy coping strategies

Each of the six participants described the need to set professional boundaries in order to maintain their ability to work in end-of-life care.

'I think the boundaries make me not less of a compassionate person but I think it preserves me ... I think that it helps preserve you from burnout ... it preserves yourself to allow you to do this work.' Participant 4

The participants identified certain strategies as key in supporting their work in end-of-life care:

'... talking with colleagues, reflection, physical health [regular exercise], a supportive partner and supportive supervisors. I feel like without these ... I would not be doing this work.' Participant 5

'I do physical [exercise] ... I have a full life outside of work. And when I get into trouble is when work is so demanding that I'm so exhausted when I get home that I have no time to even think. All I do is paperwork and fall asleep ... If I do this on an ongoing basis, I can certainly start to unravel. If I can't go sailing or the weather is bad, or I'm too tired or other things interfere, I can get sort of frantic ... I will either find myself teary or angry at somebody ...' Participant 6

'The participants identified certain strategies as key in supporting their work in end-of-life care ...'

‘Nurse managers have a unique ability to assist nurses who are distressed as a result of repeated exposure to patient and family trauma and suffering.’

Discussion

This study supports previous research indicating that PCF does indeed exist among nurses providing hospice and palliative care. The study confirmed that there is potential for significant negative physical and emotional effects of providing such care. Signs and symptoms of PCF were clearly evident in one participant, and all of the others recognised the risks. Those nurses who were functioning well had developed healthy coping strategies, which included boundary setting.

These findings support those of Coetzee and Klopper (2010), who conducted a concept analysis of PCF, and Hooper et al (2010), who conducted a cross-sectional survey. Hooper et al’s (2010) study suggested that nurses who deal with the seriously ill, wounded, traumatised, and those facing the end-of-life over extended periods of time are at particular risk of PCF effects. The results from the present study also support those of Showalter (2010), who suggested that PCF erodes a professional’s ability to function at an optimal level.

There is no global recognition of the potential negative effects of hospice and palliative care on the care providers (Aycok and Boyle, 2009). Several of the participants in the present study spoke of the need to change roles periodically, while remaining in hospice and palliative care. These findings support research conducted by Showalter (2010, p240), who described the concept of ‘Krumpled Kleenex’. She discussed how, when health-care providers are not adequately supported, they have ‘remnants that become stuffed’ (Showalter, 2010, p240); in other words, the nurse continues to provide care despite the depth of his/her physical and emotional pain, not allowing the pain to be visible to others. Further, she stated that many professional caregivers report that, in addition to the everyday work stressors, ‘there is a sense that one never has time, or recognition of the need to “refill the well” in their personal life’ (Showalter, 2010, p240).

The participant in the present study who was clearly experiencing PCF described how she was not recovering from her work stresses in the way she used to. This finding is consistent with those of Showalter (2010), who suggested that when health professionals suffer with PCF they become physically, mentally, and spiritually exhausted, yet they continue to provide care for their patients. Many have described this syndrome as ‘being sucked into a vacuum that slowly brings them down’ (Showalter, 2010, p240).

Each of the participants described the importance of setting boundaries in order to maintain a personal–professional balance and

ensure their ability to continue providing palliative care. According to Showalter (2010, p241), ‘Professional caregivers must learn to live a balanced life, allowing their professional life to enhance their personal life, not compromise their well-being.’ The participants’ personal strategies for coping with PCF included getting adequate sleep, good nutrition, regular exercise, and relaxation. Techniques such as meditation, deep breathing, self-reflection, use of humour, and massage assist the health professional in maintaining a work–life balance (Rourke, 2007). Engaging in non-work activities often rejuvenates and restores a person’s energy commitment and focus.

Yoder (2008) described work-related strategies for addressing PCF. These include time off from work, changing assignments, developing supports, personal awareness, rituals, and changing jobs. Nurses also need permission and support to deal with these emotions. It is only through careful planning, recognition of these effects, and intervention when needed, that it can be assured that nurses will be able to continue to provide such care. Two participants in the present study described the importance of supportive supervisors. These results are in line with the work of Jezuit (2003), who described the role of the nurse manager in identifying and assisting distressed nurses. Nurse managers have a unique ability to assist nurses who are distressed as a result of repeated exposure to patient and family trauma and suffering. They must create a safe environment in which a nurse may express his/her distress and discuss methods to treat it.

The author believes that there is an inherent dichotomy between providing emotional support and subsequent evaluation. In many cases it would be more appropriate for a third person to intervene. Colleagues, medical social workers, advanced practice registered nurses, psychologists, and members of the clergy may be more appropriate for this type of intervention. Beck (2011) described ambulatory care gynaecologic oncology nurses who organised a compassion fatigue support group that met monthly for 1 hour before work, led by a social worker. These nurses found the group highly supportive of one another and beneficial.

Recommendations

Strategies for dealing with nurses’ ongoing exposure to patient deaths must continue to be developed. Several recommendations can be made from this study:

- The role of the nurse manager needs to be further studied to develop strategies for providing support to hospice and palliative care nurses

- Additional scholarly work in the area of PCF would add to the body of knowledge of this phenomenon and increase the understanding of the effects of repeated exposure to patient deaths
- Early identification needs to be made of nurses experiencing PCF and strategies must be developed to better assist distressed nurses.

Strengths and limitations

This study demonstrates the strengths and limitations of qualitative research and is consistent with the emergent nature of such research. Strengths of the study include:

- The hospice from which the participants were selected has a very strong history of providing expert end-of-life care
- The descriptive qualitative study design allowed unlimited rich data to emerge.

Limitations include:

- The small sample size limits generalisability
- The participants were selected by purposive sampling, which may have limited the information that they were willing to share.

Future research

Further research exploring PCF among hospice and palliative care nurses is needed. For example, current literature suggesting numbers or percentages of hospice and palliative care nurses experiencing these symptoms is limited. Future research questions might therefore include:

- How prevalent is PCF among hospice and palliative care nurses?
- What strategies might an employer use to protect this population of nurses?
- What potential effects may changing world demographics have on PCF among hospice and palliative care nurses, and what effects might this in turn have on care delivery?

Future studies should include a larger sample of hospice and palliative care nurses as well as health professionals from other disciplines.

Conclusion

The projected significant increases in the proportion of older adults in many developed countries will only increase the need for health-care resources, including hospice and palliative care. It is therefore becoming increasingly critical to keep nurses healthy in order to provide expert end-of-life care. By learning more about PCF, hospice and palliative care nurses can be better prepared to identify signs and symptoms in themselves or their colleagues and seek assistance as indicated. This pilot study substantiates the need for further research in an effort to preserve the hospice and palliative care nursing workforce. 

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