Exploring Oncology Nurses' Grief: A Self-study

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A B S T R A C T

Oncology nursing, like many other nursing fields, often provides nurses with the opportunity to get to know their patients and their families well. This familiarity allows oncology nurses to show a level of compassion and empathy that is often helpful to the patient and their family during their struggle with cancer. However, this familiarity can also lead to a profound sense of grief if the patient loses that struggle. This self-study provided me the opportunity to systematically explore my own experience with grief as an oncology nurse, helping me to identify specific stressors and also sources of stress release.

Key words: Burnout, compassion fatigue, nurses' bereavement, nurses' grief, self-study

Introduction

As an oncology nurse, it has been my experience that we (i.e., nurses) interact with our patients over extended periods. Many of our patients are admitted frequently for chemotherapy, for complications related to neutropenia, or for pain and symptom management. The longevity of contact often allows us to get to know our patients well. Relationships develop between nurses and their patients and their families. In some instances, the patient becomes palliative. Palliative patients and their families rely on the same nurses that they have gotten to know during their treatment phase. When the patient dies, those nurses who have come to know the patient and their family experience loss but often have no formal opportunity to grieve. Those nurses still have other patients to care for and, within a short period, will be required to care for another patient who has is in the deceased patient's bed. Based on those realities, I was interested in examining the impact of grief related to patient death on oncology nurses and chose to start with myself.

Anderson and Anderson[1] defined grief as "a nearly universal pattern of physical and emotional responses to bereavement, separation or loss" (p. 516). The impact of grief on nurses has been examined in literature for decades.

Initially, the concept of grief in nursing was seen as a much broader concept than just the impact of grief, and it became referred to as burnout.[2,3] Other terms that have been used to describe nurses' grief or reactions/responses to nurses' grief include professional bereavement, secondary traumatic stress disorder, stress of conscience, moral distress, moral fatigue, compulsive sensitivity, disenfranchised grief, vicarious traumatization, and compassion fatigue.[2-6] The purpose of my study was to explore the impact of grief on oncology nurses. As the focus of this article was to analyze the grief related to the work environment of one nurse, with all these words to define similar concepts, it was necessary to decide on a term that best fit. For the purpose of this article, I will use the term "nurses' grief."

This article begins with a critique of literature into nurses' grief, with a particular focus on oncology nurses. This literature review is followed by a discussion of the self-study methodology, including data collection and analysis methods. Next, I discuss themes generated from the data, including situating those results in light of the existing research. Finally, I outline implications for practitioners and suggestions for future research.

Literature Review

This literature review was generated by searching the ProQuest, Nursing and Allied Health Source, PubMed, CINAHL, PsycInfo, and Google Scholar databases for terms associated with nurses' grief, specifically bereavement, burnout, chronic compounded grief, compassion fatigue, compulsive sensitivity, cumulative grief, disenfranchised grief, grief, moral distress, moral fatigue, patient death, secondary traumatic stress disorder, stress of conscience, and vicarious traumatization. Individuals respond differently to the same stressors. While stress and burnout are closely related, the concepts are not the same. Burnout was described in the literature as emotional exhaustion that occurred as a consequence of the relationship between care provider and recipient.[3] It had been said that nurse burnout was caused by lack of coping by nurses.[7] Burnout may result from prolonged exposure to high levels of work stress and can contribute to nurses leaving their specialized area of nursing or the profession altogether.[4] Stress may be decreased or relieved after a stressful situation has ended; however, there may be unhealthy after effects that can lead to burnout. Caring professions, such as nursing, may be more prone to burnout because of the variety of difficult circumstances and situations.[8]

Grief is well known and exists in many aspects of life; however, few people are equipped to deal with the loss associated with death without feeling a heavy psychological burden.[9] The concept of nurses' grief was described in the literature by Saunders and Valente[10] as "nurse's bereavement" (p. 318). The term nurses' grief was also used by Brown and Wood,[11] who, as a part of their compilation of literature on grief in oncology nursing, identified deficits in education, inadequate staffing, and suppression of feelings as reasons for burnout resulting from nurses' grief. In addition, Wilson and Kirshbaum[6] also described the more specific concept of disenfranchised grief, as originally defined by Doka,[11] as a "grief experienced by an individual but which is not openly acknowledged, socially validated, or publically observed" (p. 560). Alternatively, Sabo[3] described this emotional response as vicarious traumatization, or a form of stress that may result from continuous exposure to negative experiences of others. Further, Bush[12] stated that vicarious traumatization was often used interchangeably with compassion fatigue, but it was more a fine-balanced relationship between nurse and client with appropriate emotional boundaries.

Sabo[3] described "the stress resulting from helping or wanting to help a traumatized or suffering person" as compassion fatigue (p. 25). Joinson[13] defined compassion fatigue as including unique stressors that affect people in caregiving professions. Further, Wilson and Kirshbaum[6] described compassion fatigue as an emotional response by nurses who lost the ability to provide the same level of compassion to patients and their families as they had previously provided. Bush[12] concisely described compassion fatigue as a "complex phenomenon that escalates gradually as a product of cumulative stress over time, often when caregivers ignore the symptoms of stress and do not attend to their own emotional needs" (p. 25). Some have even suggested that powerlessness and frustration are almost a prerequisite in order for nurses to show compassion to parents of an ill or dying child.[14]

Challenges occur in many job settings. Burnout, fatigue, and grief can be used to describe challenges in several different professions. However, within the nursing profession, the term that appears to be the best fit is compassion fatigue. For example, Wenzel et al.[5] indicated that "nurses may relive and re-experience traumatic events repeatedly in their minds" (p. E272). Yet, nurses are expected to carry on as normal in these situations.[2] The nurses' emotional response could be referred to as grief when it occurs in isolation for a single patient; however, for multiple patients, throughout an individual oncology nurse's career, the literature seems to suggest that compassion fatigue may be a more appropriate term to describe the repetitive emotional response. Strategies

for reducing or coping with compassion fatigue include focusing on getting sleep, good nutrition, exercise, and relaxation.[15] Taking part in activities outside of work can help recharge and restore energy and focus.

Experienced nurses in the oncology specialty may develop attitudes, knowledge, and skills that enable them to better care for themselves and their own reactions in grief situations.[16] Oncology nurses have to deal with death and dying on a daily basis. Medland *et al.*[4] described stressors specific to oncology as including administering complex treatments, communicating with patients and families about treatment options, treatment failure, and dealing with death, ethical issues, and decision-making. In addition, interdisciplinary conflicts and complicated discharges become the responsibility of the nurse to resolve. Wenzel *et al.*[5] found that the daily activities of oncology nurses consisted of a large workload with little time for reflection. They also reported that the coworker support and the sharing of similar experiences reduced stress. Finally, Aycock and Boyle[2] identified that the close interpersonal contact between patients and oncology nurses can "result in physical, emotional, social, and spiritual adversity" for these nurses (p. 183). It is the variety of ways grief has been described in literature, as well as the potential career impact that grief can have on nurses – particularly on oncology nurses – that led me to want to explore the impact that grief had on my own practice.

Methods

The purpose of my study was to explore what impact grief has on oncology nurses. It was natural to begin this investigation with an exploration of my own experiences with nurses' grief. It was my hope that this study would form the foundation for my own future research of this subject. As such, my research question was:

What impact does the grief experienced when a patient dies have on an oncology nurse?

Given the goals of this research, a self-study methodology was appropriate. The self-study methodology I chose was loosely based on Callary *et al.*,[17] which was a study where the researcher systematically examined her own journey from student to future faculty member.

While often most associated with teaching and teacher education, the self-study methodology is starting to be used by other disciplines.[18] According to Hamilton *et al.*,[19] the self-study methodology, like narrative and autoethnography, "privilege self in the research design, recognizing that

addressing the self can contribute to our understanding" (p. 17). Further, Mooney[20] argued that a self-study is not interested in the experience of the self, but what occurs between the practice one is engaged in and its impact on the self. Bullough and Pinnegar[21] indicated that the balance between the two is often grounded in the focus on formal data that are collected.

Lunenberg *et al.*[22] indicated that "an important characteristic of self-study research is the focus on the *I*" (p. 1281, emphasis in original). Further, Hamilton and Pinnegar[23] argued that the self-study methodology was useful for researchers interested in the ability to "navigate through this intimate examination of our [i.e., their own] practice" (p. 167). Some have even suggested that the systematic nature of the self-study methodology is useful for establishing the "authority of experience."[24] In this particular study, I was interested in that intimate examination of my own practice, at least as it related to the grief I experienced as on oncology nurse when a patient died, and what I might be able to contribute to both my own and others' understanding of the issue.

Data collection

The data for this self-study consisted of reflective journal entries that I recorded following the death of patients under my care. Whenever I was caring for a patient and that person died on my shift, I took a few minutes in the moment, or at the end of the day, to dictate an audio memo. In this memo, I addressed my relationship with the patient and their family (e.g., how long I have known the person, how long I have cared for the person, what I may have done for the patient's family), how I felt, how the patient's family reacted to the death, how the family responded to me, and how my coworkers responded. Following my shift, I transcribed these memos. The initial data collection began on Monday, March 11, 2013.

By the end of April, I realized that there were times when I felt grief that were not specifically associated with the actual death of a patient. For example, I cared for a young man with lymphoma who I had come to know quite well, I even administered his initial treatment. He was very hopeful and determined and eventually did go into remission. Almost a year later, his name was on our admission board; I instantly felt a sinking feeling in my chest. At his 6-month follow-up with the oncologist, tests showed he now had leukemia. He was admitted to our unit with the same drive and determination to get well, but I could not help but feel sad and uneasy about the difficult time this man and his young family had already undergone and the challenges that now laid ahead for them.

Because of the observation that I experienced patient-related grief at times other than at the moment of death, I modified my data collection plan to allow for the inclusion of audio memos from these instances of grief. Research with the broad and exploratory goals that I outlined above is often associated with naturalistic inquiry, a type of research where the design "is usually not fully established before the study begins but emerges as data are collected, preliminary analysis is conducted, and the content becomes fully described" (p. 66).[25] Following this guidance, I felt comfortable in expanding the data collection to better address my research question. I began collecting these additional data in May 2013. Data collection concluded at the end of July, which provided a total of 14 weeks of data collection.

Data analysis

I analyzed my data using an inductive analysis approach;[26] specifically, I used the constant comparative method of data analysis.[27] The constant comparative method focuses on identifying categories and on generating statements of relationship. To undertake this process in a more systematic fashion, I used Microsoft Word® as a tool for qualitative data analysis.[28] Ruona outlined a four-stage process for using a table format and the search and replaced features of Microsoft Word® to conduct a systematic analysis of qualitative data. During Stage 1, I prepared the data by transcribing each audio memo. Stage 2 calls for the researcher to become familiar with the data, including listening to the audio files, reading and rereading the transcriptions, and jotting notes of initial observations (i.e., memoing). During Stage 3, I coded the data, and in Stage 4, I began to generate themes to uncover overall meaning. Walker[29] stated that there was no consistent manner in which to determine saturation in qualitative research; thus, researchers may use many different strategies to do so. Hence, after reviewing the data multiple times in the coding process, data saturation in this study was reached when redundancy in codes occurred or no new codes were identified.[30]

To ensure rigor of the data analysis, I undertook a process of peer debriefing.[31] Throughout the analysis phase, I consulted with my advisor and other senior colleagues who were knowledgeable about nurses' grief, throughout the thesis process. My advisor, along with her colleagues, explored the phenomena of compassion fatigue in oncology nurses.[32,33] It was her background in the broader topic of nurses' grief, specifically in the field of oncology, which made her a suitable knowledgeable critic. Similarly, I had access to several colleagues, including a nurse practitioner who specialized in palliative care and wrote her thesis on vicarious traumatization, as well as four of my oncology nursing colleagues who I also consulted. These colleagues provided feedback on the results as part of peer debriefing for study rigor.

Results and Discussion

Four themes emerged from the data: feelings of sadness or grief, the eminence of death and end of life, positive effects of communication, and the role of patients' families. First, the most common recorded emotions I experienced were sadness and grief. This theme was evident in my data as the word sad or sadness was included in each entry at least once. For example, I described feelings of grief when a patient I had things in common with died and when a coworker shared with me that she was "having a hard time" dealing with the passing of two patients in a short period. Another time I felt grief was after interacting with a dying patient's family who were at her bedside, I wrote that "he was crying a lot, he would leave the room and their son would start to cry." I also reported feeling grief when I described my experience with a patient who died suddenly without a do-not-resuscitate order and I initiated the attempt to resuscitate. I noted that "I returned to her room and she wasn't breathing. I did a sternal rub… yelled for help and called the code blue… I started compressions and kept going until the code team arrived." Once I was relieved by another team member, I remember there was a wave of emotion, I held back tears but the feeling of grief was overwhelming.

Fatigue was mentioned twice in my entries. The first was when a coworker told me she was feeling exhausted although my data did not reflect the reason for this exhaustion. The second instance was one where I personally felt fatigue during a weekend when I had worked three 12-h day shifts in a row. When I arrived on the morning of my third 12-h day, I learned that a patient had died overnight. This patient was not one I had cared for directly, but I had interacted with this patient when I assisted another nurse. In my data following this shift, I described myself as "more mentally exhausted than physically." This lends creditability to Bush's[12] definition of compassion fatigue that described it as a phenomenon that gradually increased due to stress experienced over time when caregivers did not focus on their own emotional needs. Three days caring for the same people contributes to the relationships that develop between nurses and patients and thus the gradual realization of compassion fatigue.

Other emotional descriptors that were reported, many only once, included: Frustration, concern, compassion, comfortable, shock, nervousness, bad, uneasiness, and anger. For example, "I was very frustrated because I knew she needed something more for pain and agitation, I asked the doctor and she basically dismissed me." I was trying to make a patient more comfortable and the on-call doctor did not agree with my assessment and would not prescribe any further medication. On another occasion, I looked at pictures of a patient before she had cancer. At the time, I wrote that "it made me feel very uneasy to see how happy she was and what a young family she had." Essentially, this additional information of what this patient had been like before she was terminal created a sense of emotional adversity in me.[2] Finally, there was an instance when I reported feeling angry when a doctor told a patient and her family "she had about 2 weeks to live" and then she died after only 2 days of the conversation. This woman's family was left with the impression they still had time remaining to be with her. I remember feeling there had to have been a better way to prepare these people for the potential unknown aspects of what was to come.

While I have chosen to use the term nurse's grief in this exploration, the sense of fatigue that I also felt in the first example in the previous paragraph was closer to Sabo's[3] description of compassion fatigue as opposed to it being an example of "grief." This lends some credibility, at least based on my own limited data set, that these two concepts – while related – may be describing two different phenomena (is there a citation from your thesis that suggests this?). In addition, Vachon[34] found that bereaved nurse reported feelings of anger, depression, frustration, helplessness, and hopelessness. All of these were consistent with the emotional descriptors that appeared in my own data set. This would lead me to believe that I was experiencing some form of compassion fatigue.[6]

Second, in all seven entries, the patients' poor prognosis or eminent death was mentioned as evidenced by statements such as "only a day or two to live" and "deteriorating rapidly." Interestingly, even though I had initially expected it, there were no instances where I reported experiencing grief when caring for a patient who was not at the end stages of their disease. I also noticed that I used the phrase "passed away" many times in the data to refer to death. My record revealed other words such as "died," "death," "palliative," and "end-of-life" when describing patients. Reflecting on the usage of "passed away," I feel that I may have used this to give the death more peace or more compassion. Death is what elicited all of my emotional responses; I wonder if this was one of the ways in which I was trying to suppress or deflect my feelings.[35]

Vachon[34] reported that in one of her studies, nurses felt they were unable to discuss their feelings with coworkers about patient's death. Personally, I did not find this to be the case. In my own experiences, nurses talked more to coworkers who had similar experiences and even reached out to colleagues for support during difficult times. For example, while I sat in our break room after the death of my patient following a code, my fellow nurses took turns coming in to check on me, to make sure that I was okay. Further, it was also not uncommon for a large group of the oncology nurses on my floor to get together outside of work at a restaurant or bar to "let off steam." Having worked on a neurology and neuroscience unit, as well as two different medical floors before working on this oncology floor, this social outlet was something that was unique to my oncology colleagues.

Beyond the ability to talk with my colleagues, I did note that the nurses I worked with in the oncology setting were primarily concerned with comfort and holistic care. This included ensuring the needs of the family is being met, as well as the patients' needs. Essentially, my colleagues and I often got caught up in the significant demands of being an oncology nurse that – at least during the work day – there was little time to reflect on our grief.[5] Even the patient I recorded as not being nice to the nurse, I reported that "showing him compassion felt very deliberate," whether it was instinctive or deliberate, the patient was treated with respect. This seemed to be an inevitable consideration of most oncology nurses, at least according to Brown and Wood.[35] Knowing a patient was dying greatly affected the way nurses care for that patient and their family. The untimely death of a patient creates a highly emotional situation for both the staff and the patient's family.

Third, there were only a few mentions of communication in the data. However, when communication did occur, it had a positive effect on my grief. Most of the communication described was between a nurse, primarily myself, and a patient and their family. For example, I found that families that talked to and supported each other, and patients that made their wishes clear to their families, were much better at relaying their feelings to each other. A 42-year-old patient told her husband and parents "she didn't want her children to see her dying," and because she had expressed these wishes they honored her decision. Based on the data that I recorded at this time, in these instances, I appeared to experience less grief. There was one patient who refused to communicate with anyone, including his family, friends, doctors, or nurses. I described his death as being sad because "he died alone not knowing if there was anyone who cared about him." There were also a few

instances of communication between a nurse – again usually myself – and fellow nurses, nurse practitioners, and/or doctors. Only one incident was reported that demonstrated negative communication between the nurse and physician. Other interactions with the multidisciplinary staff were positive in nature. It was clear to me that communication had a positive effect on the way I was able to deal with grief.

Interestingly, Wenzel et al.[5] reported that participants in their study believed nurse–patient relationships actually helped the nurses' ability to put their work into perspective. Further, the positive feedback from patients and their families reinforced the nurses' motivation to provide the best care possible. Debriefing with coworkers was also described as a resource for nurses to help them deal with bereavement. These positive aspects of communications between nurses and their patients, patients' families, and coworkers were consistent with the primarily positive communications' experiences in my own data. Further, nurses who reported feeling a sense of support from their coworkers had a wider variety of coping skills.[4] When a nurse was able to turn to other members of the team for guidance and support, the ability to deal with the various stressors increased.

Finally, patients' families were discussed in each of my entries. Caring for each of the patients involved getting to know a little about the family and the dynamics among their relatives. For example, the patient from my data who died unexpectedly, I did not have the opportunity to meet her family, but saw pictures and spoke to the patient about her children. In another instance, there was a husband, son, and daughter who stayed at the bedside almost all the time, and part of my time caring for that patient was committed to talking to them about how they felt, answering their questions, and making sure there was nothing they needed from me. Finally, the last patient I recorded on was alienated from his friends and family. In describing my experience in this instance, I commented on how rare I thought it was for a patient to be alone and not have any loved one present.

Peters et al.[7] discussed how stressful situations arise from a variety of family dynamics. Families may have difficult times dealing with the impending death of a loved one, and the changes that go along with the loss of a family member. This, in turn, is a potential stressor for nurses as they identify coping problems by family members or difficulty communicating their feelings to loved ones. I spent with one patient's family, discussing with them their own emotional stressors and ways that I might be able to assist them, "I could see in his eyes, he was very frustrated, he was upset about losing her, he didn't want her to suffer, and he was beside himself trying to make sure that he was

doing the right things for her." The kind of grief that this situation arose from was quite consistent with Wilson's and Kirshbaum's[6] description of disenfranchised grief – again provided some evidence of the similar, yet subtle difference between these various terms.

Finally, while not a general theme in the data, there was one instance in my data where it happened that there was time between the death of a patient and a new patient occupying the room that is worth mentioning. In the data, my description of the experience indicated that "I felt much more comfortable than on days when the bed has been cleaned right after… and report is being called for the new admission before it is even complete." In this particular instance, Wilson and Kirshbaum[6] concept of disenfranchised grief was again evident. The loss of a patient may not be recognized by other members of the healthcare staff as having an impact on an individual nurse. Some of those health care staff may even see the loss of a patient as part of the nurses' job, with an expectation that they should be able to move on with their work. These individuals fail to recognize that the event may have been a loss for the nurse as well as the patient's family.

Conclusion

The concept for this self-study came from my own feelings of grief after experiencing the loss of several patients I had come to know. As an oncology nurse, over the past 4 years, I found patients demise particularly difficult after getting to know them over the course of their treatment. Due to these experiences, I began keeping a journal of times when I experienced grief over a 14-week period and analyzed those entries using a constant comparative data analysis method. My findings reflect my own personal thoughts about death and feelings of sadness and helplessness when patients die. Yet, while sadness or grief was the most common emotion I experienced, I did express a wide range of other emotions throughout the data (e.g., fatigue, frustration, anger). Rarely did I have the opportunity to communicate with others the emotions I was feeling, but when I did get that opportunity, it helped my grief (as did a single instance where the room that a patient died in was not immediately occupied by another patient). Finally, it was interesting that patients' families were included in each of my data entries (even more than the patients themselves). It should be noted that there are significant methodological limitations to these findings. The first limitation was that this is a self-study; the findings are based on a single perspective. The second limitation was the limited data that were collected (i.e., only seven entries over a 14-week period). It is important that this study be understood in light of these limitations.

However, even considering these limitations, there were several implications for practice that can be made. First, this self-study has also given me a better sense of identifying grief in my coworkers, which enabled me to be a better source of support for them by acknowledging their experiences and encouraging them to talk to me if they feel the need. Further, on a personal note, I believe that journaling my thoughts and feelings after a patient death was therapeutic in and of itself. I am inclined to continue to do so as a way of debriefing after such an event. In fact, this is a suggestion that I would make to my fellow nurses that they keep a journal to write about how they feel after a loss of a patient, not necessarily to share with anyone, but to allow themselves to express their feelings privately.

There are several avenues for future research based on this self-study. The first, and most obvious, avenue for future research would be a more extensive study of this specific topic. This could be accomplished in two ways: The first way would be to conduct another self-study where data were collected over a longer period (which would increase the overall amount of data collected). The second way would be to conduct a study that included several oncology nurses, again to increase the amount of data available, as well as to provide multiple perspectives regarding the research question. Beyond replication studies, within my own work context, there was a nurse practitioner who organized a service of remembrance for several patients who died on our unit recently. It would be worthwhile to explore if this kind of public memorial had a positive impact on nurses' grief.

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Conflicts of interest

There are no conflicts of interest.

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