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REFLECTION

Theories of Loss and Grief Experienced by the Patient, Family, and Healthcare Professional: a Personal Account of a Critical Event

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Abstract

When a patient is diagnosed with cancer, a number of losses and grief processes occur. Theories and models of loss, grief, and mourning are explored for the patient, her family member, and the medical treatment team, through a personal reflection when treating a patient undergoing a course of radiation treatment in a large cancer center. Reflection on this event can be used to guide health care facilities to assess and develop support systems for patients, caregivers, and health care professionals to cope with loss and grief processes in a healthy and meaningful way.

Keywords Cancer · Bereavement care · Loss · Grief

Introduction

A number of losses and grief processes commonly occur when a patient is diagnosed with cancer. The effects of loss impact not only the patient and their family members but also healthcare professionals (HCP) involved in the care of the patient. This is a personal reflection of the loss and grief process experienced while supporting a woman who was diagnosed with endometrial cancer as she underwent a course of radiation treatment at our cancer center. These reflections will be discussed and explored using several theoretical models of loss and grief as they relate to this event.

The Patient's Story

AB was a woman in her mid-seventies who was diagnosed with endometrial cancer. Her primary intervention was surgery followed by a course of radiation treatment for 25 days. She arrived at our large outpatient radiation therapy clinic with her husband who wheeled her in a wheelchair. During her surgery, she had suffered a serious adverse event resulting in temporary physical lower body weakness. She understood that this condition would expectantly improve over time and with physiotherapy.

My Experience and Reflection

During our initial contact, I felt AB and her husband directed their focus toward their imminent radiation treatments. Our conversations then proceeded to allow AB and her husband to talk about the losses they faced with the onset of AB's diagnosis and the aftermath of her surgery; the loss of ability to function independently; loss of identity as a wife and partner to her husband; her change in role definition from a well person to a patient. She expressed feeling exhausted and limited to the most basic activities of daily life. AB confided that she experienced shock and disbelief when she was first diagnosed with cancer, and this was now exemplified by the physical reality of the paralysis she was experiencing. I recall AB's husband saying that he saw his wife walk into her surgery only to see her being wheeled out in a wheelchair. Both AB and her husband described feeling anger toward the surgeon and with the ongoing situation after the adverse outcome of the surgery several months prior. They could not believe how they could be the statistic that added to the odds. These revelations made me feel

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uncomfortable. I felt I was there to support them and be their sounding board, but that I could not find the right words to give them the answers they needed. I tried focusing on the details of the treatment and the expected side effects, paying particular attention to even the smallest of details, so there would be no element of surprise. I even tried to encourage AB that with a positive mindset and attitude and continued physiotherapy, her lower body weakness would improve. She seemed to find solace in that. On that first day while I was treating AB, my thoughts were focused on the surgeon. The attachment, affectionate and "brother/sisterhood" bonds that we as HCPs feel with other interdisciplinary professions felt threatened, and I felt shock and disbelief about the consequences of this outcome of a routine surgery.

As AB arrived to our clinic for her treatments, I noticed that she was always impeccably dressed, with perfectly coiffed hair and make-up. She always apologized to the staff for needing their help to get her on and off the bed and into her wheelchair, emphasizing the loss of independence she felt. She described to me repeatedly her sense of gratitude for the overwhelming support she had experienced from her husband, who never left her side. It seemed that AB's husband's emotions of shock, yearning and flashes of despair were very evident, but most of the time he was not yet able to accept the reality of the diagnosis and the physical condition of his wife. It appeared he had submerged himself in the care of his wife, avoiding his own emotions and thoughts. AB often confided in me about her husband who was neglecting his own needs.

As we neared the end of AB's radiation therapy treatment, we staff still observed signs of grief in AB and her husband, who were oscillating between concentrating on the losses they both experienced and finding distractions from their grief by telling stories about their children. AB's husband displayed more ongoing signs of sadness, possibly because he remained mostly submerged in the care of his wife, rather than facing their loss of her mobility, cancer, and treatment. He still did not have social services or home care organized.

The medical radiation therapists (MRT) who treated AB often spoke about the outcome of her surgery and empathized with her loss; her imminent health and possible loss of future with her diagnosis of cancer, and the unfortunate adverse event that occurred in surgery that had placed her in a wheelchair. In the days following, our team of MRTs felt a sense of yearning and searched for answers about the complication that occurred during surgery. To some extent, we were left trying to process the anger, loss, and shock with the patient and her husband, because we were the next treatment team involved.

As a frustration in my role, time does not permit lengthy in-depth consultations and counseling with our patients. MRTs treat up to 40 patients a day, and most of the time we feel our grief has to be repressed in order to be able to continue being supportive and efficient to the stream of patients we see in a day.

Application and Reflection of Theories/Models of Loss and Grief

To ground this clinical case in the theories of loss and grief, I note that Hall (2011) defines grief as the physical, emotional, cognitive, behavioral, and spiritual response to loss (the emotion of loss) [1]. Mourning is defined as the response to a loss, death or one's own terminal illness [2]. It is the individual's working through, the psychological processing of the loss and the social expression of grief [3]. Finally, bereavement is the individual and complex experience during the period of loss (suffering the loss/"being robbed") [4].

For most patients, family members and HCPs, the loss or grief is rarely completely forgotten, and the grieving process naturally evolves from acute grief into a state of integrated grief [5]. Lois Tonkin (1996), a grief counselor, describes this as "growing around the grief." Imagine drawing a circle on a paper, representing oneself. Then imagine drawing another circle within that circle, representing one's grief experience. Initially, the circle may be entirely shaded, as the grief is entirely self-consuming. However, as days, months, and years pass, the outer circle (representing the individual grieving), begins to grow bigger and the shaded area grows smaller, looking like a fried egg. The white represents the individual's life and the yolk represents the individual's grief [5]. This theory suggests that although the loss or grief may still be felt, be unprocessed, and may stay much the same, with time, new experiences, meeting new people, and finding moments of enjoyment and new life experiences result in the outer circle growing larger [6]. She suggests that the grief may never disappear and at times can even grow a little bigger, but the grief ceases to dominate the circle or the individual. Worden (2009), however, described working through the four tasks of loss: accepting, working through/experiencing the pain, adjusting, relocating/moving on; yet not everyone will carry out the tasks in this order, as was observed in AB and her husband [7].

Boss (2009) devised the term "ambiguous loss" for losses that lack clarity, with different possible assessments of what is being lost [8]. Wilson (2014) describes this as circumstantial loss stemming from illness and surgery [9]. AB's surgical loss was a complicated experience for her and her husband, as well as for the MRTs. It included the loss of the ideal perfect healer, the loss of hope, the potential of damage of treatment, and the loss of health. This resulted in many emotions of sadness mixed with anger and collective guilt even for the HCPs.

Kubler-Ross' (1969) [10] five stages of grief (denial, anger, bargaining, depression, and acceptance) has been criticized as being too linear, and not all people progress through each stage in the order that she described. AB and her husband experienced anger first, before showing signs of denial and may not even have experienced all of the stages of grief in Kubler-Ross' theory.

Bowlby's (1980) attachment theory, which suggests that a child comes into the world biologically pre-programmed to form attachments with others to help them survive, may be applied to this situation [11]. Four adult attachment styles were formulated from his theory: secure attachment, insecure anxious-preoccupied attachment, insecure dismissive-avoidant attachment and insecure fearful-avoidant attachment [12]. Bowlby (1980) theorized that an individual who had a secure attachment experience would likely possess an "internal representational model of attachment figures(s) as being available, responsive, and helpful" [11]. In contrast, someone with an insecure anxious-preoccupied attachment might depend on another, without the confidence that he could cope by himself and with the fear that the other would abandon him, resulting in attachment anxiety. Someone with dismissive-avoidant attachment may have come to the conclusion that the only person he can rely on is himself. Such an individual will feel very uncomfortable relying on others and often feels shamed and fearful at being dependent on others due to loss of health and function, such as mobility as we experienced with AB. AB's husband seemed to have an anxious attachment to his wife as he displayed signs of coping difficulties, still depending on his wife to tell him to do things such as ensuring rides to the clinic were arranged at appropriate times, external medical visits coincided with radiation therapy visits, etc. (observed by myself on several occasions while they attended treatment visits). It seemed he was dependent on his wife, lacking the confidence to take matters into his own hands. The threat of loss of security and affectional attachment to his wife caused AB's husband's emotions of shock, yearning and despair, in keeping with Bowlby's general phases of mourning. He was not yet able to perhaps accept his wife's diagnosis, the results of her surgery, the process of treatment and even the uncertainty of their future together. Bowlby's work overlaps with those of Parkes (1998) and reinforces the idea of phases, suggesting that grieving is a process and sequence of physical reactions and feelings going through phases of numbness, yearning, disorganization and despair, and finally reorganized behavior [13]. Thus, continual available support can help individuals who need it to grieve and mourn, so as not to be "stuck" in misery, isolation, anger and self-pity, but rather to work toward recovery and readjustment. If recovery is helped through relying more on others, those with insecure attachment will experience more difficulty in obtaining support and possibly more difficulty with the prospective loss of their loved one, their chosen attachment figure.

Doka's (1999) theory describes a time limit given to us as medical professionals to deal with grief and suggests that we have to move on, in order to continue our work [14]. Similarly, Faulkner (1995) suggests that grief has to be blocked out due to workplace demands and immediate workplace responsibilities, causing suppression of our feelings [15]. Similar to Tonkin's (1996) model, HCPs avoid their grief and focus on finding new experiences and meeting new people, not forgetting their grief but growing around their grief [6]. More recently, however, a significant advancement in our understanding of grief processes is the dual process model developed by Stroebe and Schut [16]. This process may be more appropriately applied to HCPs response to grief, oscillating between loss-oriented and restoration-oriented phases allowing time to remove oneself from their experiences of loss.

With very little research focusing on grief of HCPs, Danai Papadatou (2001) conducted several studies, and through semi-structured interviews with nurses and physicians found that HCPs recognize their grief, but their reactions fluctuate between experiencing and avoiding feelings of grief [17]. She reports this is a healthy and adaptive way of giving meaning to the dying and death of each patient, and the losses can be integrated into their lives. She found that when HCPs are able to be reflective and in touch with their distress, they respond to grief at an emotional, cognitive, behavioral, and physical level. This would be a very good reason to incorporate interdisciplinary reflective practice, especially in oncology. Papadatou's (2001) research compared pediatric nurses in Greece and Hong Kong and found differences in expressions of grief/mourning that may have been related to religious differences and beliefs. Some suppressed their grief, immersing themselves in their workload, and others demonstrated anger and injustice toward a God who should be protective of the innocent [18]. Similarly, Stroebe and Schut (1988) indicated that different cultures have different ways of coping and expressing their grief, "the expression, manifestations, duration of grieving and ways of coping with loss are shaped by cultural factors" [17]. Within our own multicultural team, our reactions varied, as some members avoided interactions with AB and her husband, suppressing their feelings and actively engaging themselves in their clinical duties and tasks of the day.

Implications for Service Delivery

Evaluation and reflection of this experience reveals the need for HCPs in radiation therapy at a large cancer center to be proficient in offering primary level supportive care and to be able to refer when necessary. HCPs need to be aware of the multidisciplinary supportive care programs available. Updated educational forums in continuing education for HCPs in radiation therapy are necessary to promote the ability to recognize and assess distress, including signs of grief in our patients as well as ourselves and other colleagues, and to know when to offer referral. Staff would benefit from understanding different types of grief and patterns of mourning and from knowing how to facilitate healthy grieving and mourning. This support would help patients and family members deal with the losses associated with their cancer diagnosis and treatment.

From the first contact during new patient teaching prior to treatment, patients could be encouraged to open up by the MRTs asking what they have been told about their disease and what feelings they have experienced or are experiencing. By allowing the patient and family to talk about losses and normalizing associated feelings, we may dispel some fears and help patients and family members going through treatment and caregiving to start on the path toward acceptance and resilience, whatever the prognosis. This could happen hand in hand with sharing information about the treatment regimen and potential side effects of the treatment. It would create an environment of trust and open communication for patients to feel free to talk about their feelings, including grief and other complex emotions such as sadness, fear, guilt, anger, and blame.

This personal reflection on the experience of grief and mourning in one patient, her husband, and the radiation therapy team provides some pointers on how to improve service delivery and patient and family experience. It emphasizes the importance of the cancer center supporting patients, families and also their HCPs. Validations of emotions, effective team, and organizational communication and continuing education on supportive care for all front-line workers are all possible and important. Treating MRT teams need to look within the confines of their treatment areas and identify the different emotional reactions to their patients' loss and grief, as well as their own coping and processing of grief and loss. Instead of denying or not processing the grief and loss they witness, they need to reflect, mourn, oscillate back and forth and integrate these experiences with others.

A common mission and vision across healthcare organizations is to incorporate the patient's experience, values and voice into their person-centered care. This involves the commitment to provide resources, education, nurturing physical space and design for patients, families and employees to be able to communicate about values, choices, and loss and grief with dignity and respect [19]. Patients depend on front-line workers for continued support. Halkett and Kristjanson (2007) found that breast cancer patients felt a sense of emotional comfort from their MRTs by forming relationships [20] (which Klass et al. (1996) [21] described as continuing bonds) with them and being provided information about their care. In contrast, a second study by Halkett et al. (2010) found that MRTs reported a lack of training in emotion-focused communication with patients and did not feel confident about having conversations with patients about psychosocial issues [22]. MRTs would therefore benefit from inter-professional workshops with Supportive and Palliative Care to discuss and share experiences of loss with other HCPs to help with the process of healing [21, 23].

Boss (2004) proposed a therapeutic strategy by psychosocial services to reduce uncertainty for patients and their families while offering social support and meaning to their loss using a structured setting of meetings in a safe environment, sharing as much information as possible about the diagnosis, with opportunity for reflection and discussion [24]. Further strategies using dialog, writing/journaling or art therapy through meaning-centered meetings or workshops can be offered to better understand the circumstances and emotions surrounding the grief and loss and building meaningful connections together to reduce ambiguity [25, 26]. This can also be done individually or in structured groups through rituals which help to contain and express emotions and allow for families and the community to bear witness to the loss [27].

End of active treatment for some patients also marks the transition from being a "cancer patient" to a "cancer survivor" [28]. During the intense period of daily contact during 25 consecutive days of treatment, as was the case in AB's treatment plan, she and her husband formed supportive relationships and attachment bonds with their MRTs. When active cancer treatment ends, anxiety or depression can occur in patients, and feelings of sadness, loss or distress need to be discussed. Patients may suffer a sense of loss of continual support, daily interactions with their medical team and a routine they have grown accustomed to during a period of high stress and need. At the end of treatment, the patient may feel tired, sick, experience mental and physical changes caused by the cancer treatment, and now the patient is expected to find her new normal without the same level of support.

In June 2014, the American Cancer Society published prostate cancer survivorship guidelines for primary care clinicians on how to deliver the best possible care to their patients after cancer treatment [29]. Patients with a written follow-up care plan should discuss with their primary care doctor which provider (oncologist, primary care doctor, or other specialist) will be in charge of cancer-related issues and other medical care issues. Providing telephone support or even monthly support group sessions for patients with similar cancers would be a constructive way to cultivate patient-centered care.

Unfortunately, there is little education, communication, validation or provision for the oncology HCPs' grief and loss, especially in the field of radiation therapy. Research on job stress and burnout has sparked medical teams in Oncology to critically examine support systems in the workplace. Several studies found that helping patients and families by providing emotion-focused patient care and communication could be a major source of job satisfaction in all groups. However, an increasing workload and trying to provide emotion-focused care without skills, training, and support could also be a major stress [18, 30, 31]. Although most patients comment on and validate the support provided during treatments by therapists, it is understandable if some HCPs feel uncomfortable addressing grief and loss with the patient and their families. This emphasizes the importance of educating staff on how to recognize and be aware of the signs of loss and grief, how best to support patients and families, and of ensuring they know about hospital and community resources, so they can direct the patients to the formal and informal support services available to patients and their families.

Conclusion

Loss and grief are felt and experienced by cancer patients, their families, and the HCPs involved in their care. There is growing awareness that we should move away from the notion of suppressing or denying grief or loss, and that we should be working toward maintaining continuing bonds, supporting and allowing a healthy grieving process for all concerned.

Personal reflection about this lived experience of treating and supporting AB and her husband made me want to learn more about loss and grief and share this experience, reflection and knowledge. Discussion of the theoretical models of loss and grief as applied to this patient, her husband and the staff and the description of my experience of AB's care throughout her radiation treatment with her husband can improve our understanding of the types of grieving and loss experienced by all in our radiation suites. Any intervention must respect unique qualities, social and cultural differences, the circumstances of the loss experienced and promote validation and, when desired, safe processing of difficult emotions and the development of strong meaningful relationships.

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