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Women's Studies International Forum

journal homepage: www.elsevier.com/locate/wsif



Meaning of life after cancer: An existential-phenomenological approach to female cancer survival



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ARTICLE INFO

SYNOPSIS

Available online 21 June 2013

Cancer survivors actively construct their lives and the meaning of cancer to better understand the process of adjustment following the disease. The aim of this study was to understand the significance of lived relations (relationality) for cancer survivorship. The methodology used was a qualitative, phenomenological lifeworld perspective focused on the stories of the participants' lived experiences as gynecological cancer survivors. Data was collected through semi-structured interviews of ten female cancer survivors. A phenomenological hermeneutic method was used to interpret the transcribed interviews. The findings revealed three main themes: mediation between the subject and the world, between subjects, and between the subject and herself. Survivorship can be best attained when individual strengths are the focus of intervention and help guide positive outcomes. Health practitioners should be aware of the potential for positive changes in their patients following trauma and adversity.

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Introduction

Cancer is a major cause of premature mortality and a public health crisis (Baum & Andersen, 2001). Research has focused on etiology, treatment, and prevention. Researchers and clinicians have paid less attention to psychosocial aspects and to the processes of adaption and reintegration following cancer diagnosis or treatment (Ferrell, Smith, Cullinane, & Melancon, 2003).

Various morbidities – psychological issues, body image concerns, and relationship problems – can emerge in the context of gynecological cancer, which stress the importance of assessing unmet supportive care needs. There is a growing body of research focusing on psychosocial aspects of gynecological cancer. However, the survivorship trajectory of women

with gynecological cancer is just recently being studied (Sekse, Raaheim, Blaaka, & Gjengedal, 2010). Intrusive medical procedures and aversive treatments often lead survivors to experience negative outcomes, including decreased psychosocial adjustment, negative changes in life perspective, decreased physical function, and other psychosocial disruptions (Arman & Rehnsfeldt, 2003; Bloom, 2002). As a result, researchers have primarily investigated negative psychosocial sequelae. More recently, psycho-oncology research has focused on positive psychological changes to the experience of cancer. The aim of the present exploratory qualitative study was to ascertain how gynecological cancer survivors (re)construct the self and shift their thinking about others and the world, particularly positive changes that elucidate new benefits or meanings to life.

Gynecological cancer is a life-altering random event, precipitating crisis and chaos for most diagnosed women. We addressed the changes experienced by affected women, in particular the occurrence of quantum or epiphanic change and meaning-making in the lives of survivors. For the purpose of this study, the term epiphany was adopted because it focuses more distinctly on the consequences of major crises (i.e.,gynecological cancer) rather than stress level. Moreover, it

[†] Conflicts of interest: The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.

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embraces a comprehensive approach to post trauma changes because it implies that growth can coexist with psychological distress. Although not all change is positive, there is evidence that cancer diagnosis causes benefits and consequently changes lives (Miller, 2004). Specific questions were considered: (a) how do cancer survivors define themselves in relation to their cancer trauma?; and, (b) how does cancer influence or lead to a transformation of life or worldview? This knowledge is crucial given that intra- and interpersonal relations are central to the task of identity renegotiation¹ during the pathological drama of cancer and trauma recovery. According to Roux and Dingley (2011), understanding the experiences of individuals as they live with chronic illnesses, such as cancer, may guide care by identifying survivors' needs and potentially improving health outcomes. Furthermore, clinicians should avoid creating expectations, but rather foster a search for new benefits to life or positive meaning-making by the patients.

In the next section, we introduce the topic of survivorship and discuss the psychosocial issues raised by the cancer experience, as well as the theoretical framework for undertaking this research. We also outline the methodology of the study, including a detailed description of the sample population, recruitment process, data collection, management and analysis. Rigor and ethical considerations will also be addressed. Finally, we present a brief overview of our findings, focusing on the significance of relationality for cancer survivorship. Implications for social work and clinical practice are discussed throughout.

Background

Cancer survivor identity

Little, Jordens, Paul, and Sayers (2001) studied the phenomenon of survivorship identity. They stated that illness is something understood in the stories of our culture, and people with cancer have a legitimate illness identity. Others know how to relate to them, because there is acceptance and understanding for someone who is ill. However, survival alters and disrupts the person's personal identity, the sense of personhood that defines our position and roles within the social context. Research on surviving trauma suggests that part of successfully navigating the experience of trauma is a new sense of self. It was once believed that self-concept was static, but now it is understood that sense of self is not only dynamic, but a guiding force for our lives (Neimeyer, 2006).

The term epiphany emerges at the core of the cancer survivor's experience. The sociologist Denzin (1990) defines epiphanies as interactional moments that leave a mark on people's lives and have the potential to create transformational experiences for the person. In other words, epiphanies are sudden and abrupt insights and/or changes in perspective that transform the individual's concept of self and identity, usually because of the creation of new meaning in the individual's life.

Examples of positive findings from survivors include a reappraisal of life and its meaning (Sears, Stanton, & Danoff-Burg, 2003), a renewed or increased recognition of the importance of spirituality (Bloom, 2002), new self-transformation (Carpenter, Brockopp, & Andrykowski, 1999), reordered goals and priorities (Bellizzi & Blank, 2006),

improved sense of purpose, positive self changes, enhanced intimacy in relationships (Weiss, 2004), new self knowledge and awareness (Taylor, 2000), improved health behaviors (Manne et al., 2004), and a new focus on altruism (Nelson, 1996). However, not all survivors identify positive growth after their experience. There are often physical sequelae from the surgical and medical interventions, which produce altered body-image, draining fatigue, financial strain, relational stress, and an uncertain future (Manne et al., 2004; Taylor, 2000). Along with the physical effects are fears of recurrence and fears of dying, the two most outstanding and commonly verbalized concerns of women with cancer (Vachon, 2001).

Such viewpoints are crucial in shedding light on the human aspects involved in coping with and managing cancer. The support of close, caring others is crucial during the recovery from a traumatic event such as the diagnosis of cancer. Core experiences of psychological trauma are disempowerment and the feeling of being disconnected from others. Recovery is, therefore, largely based on the empowerment of the person and ability to reconnect or create new connections with others. Others can help to provide a healing environment through advice, moral support, providing assistance as required by the person, and showing affection and care, but they cannot mend what is hurting. Only the person can do this within themselves over time. No intervention that removes power from the person can aid in their psychological recovery (Neimeyer, 2006).

Little or no qualitative research has been undertaken in Portugal that offers in-depth insight into the gynecological post-cancer experience from the perspective of female survivors: how they see themselves in relation to their social world. This study aims to interpret the particular life experiences of Portuguese women in a way that recognizes the ever-present cultural contribution to individual perception and action. Moreover, given that cancer trauma is overrepresented in the country, this understanding is particularly important within this national context, which is shaped by the cultural factors of fatalism. The marianismo, and religiosity.

We adopted an alternative conceptual, methodological, and analytical framework, shifting the focus from the injury event itself to a consideration of the cancer-journey's aftermath: healing and reconstruction of self and worldview in the meaning-making process. In so doing, we advocate a new discussion about cancer trauma in the Portuguese context that favors the subjective viewpoint.

The lifeworld perspective

Lifeworld refers to the world of lived experience or the phenomenological world, and implies that human beings are part of a historical context that they share with other human beings. For a healthy transition in cancer survivorship, the ability to interact with others in order to share experiences is crucial and contributes understanding of self and the lifeworld. Dahlberg, Dahlberg, and Nyström (2008) describe the lifeworld as a social world, and understanding as an internal dialog, taking place within the person, and an external dialog, taking place between the person and their surroundings, including the social environment. Prior to any description we might make of our existence, we are already

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