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“We look beyond the cancer to see the person”: the healing path of female cancer survivor

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Abstract

The purpose of this study was to understand the lived survivorship experience of Portuguese women with gynaecological cancer. A phenomenological hermeneutical method, inspired by Ricoeur’s theory of interpretation was employed. Ten women cancer survivors were recruited. An iterative process was carried out to identify themes and interwoven them into the four existentials of life world to lend structural meaning to the lived experience. Female survivors reported stories of positive and negative change complete with doubts and fears, as well as renewed relationships and altered priorities. Assisting clients with finding their ‘new normal’ and embracing its possibilities is critical to their long-term success.

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1. Introduction

Gynecological cancer is the third most commonly diagnosed cancer and the fourth leading cause of cancer death in women worldwide (Globocan, 2008). Since the 1970s, the death rates of women with gynecological cancer have significantly declined. As a result, there have been a growing number of survivors who are forced to cope with the consequences of the disease and its treatments (Aziz, 2007). Although survivorship is considered the most important outcome of a gynaecological cancer experience, it is understudied, and thus, the least understood aspect of the disease (Holland & Reznik, 2005). Researching how gynaecological cancer survivors actively construct their lives and the meaning of cancer to better understand the process of adjustment following the disease is of particular interest.

To date, little or no qualitative research has been undertaken in Portugal that offers in-depth insight into the gynaecological post-cancer experience from the perspective of female survivors. It is also important that the specific supportive care needs of gynaecological cancer survivors are understood to better tailor health care initiatives and services to assist the physical and emotional recovery of women diagnosed with this disease. This knowledge may...
help health care staff to better understand the depths of these experiences and thus be able to meet the women in a more holistic way.

2. Method

A phenomenological hermeneutic interpretation inspired by the French philosopher Ricoeur (1976) was used to unveil the meaning of the women’s lived experiences of living with gynaecological cancer.

Using this method, the researcher tries to explain and understand the meaning of experience by interpreting interviews with narrated stories fixed as a text. According to Ricoeur, people disclose much about themselves when telling about their lived experiences.

2.1. Selection of participants

In accordance with a phenomenological research perspective, the researcher used theoretical or purposeful sampling, in which the researcher selects a participant according to the needs of the study. To be eligible for inclusion in the study, firstly, the participants needed to self-report a cancer diagnosis and self-define survivorship, and then they were selected for inclusion in the study based in following criteria: women > 18 years of age who had experienced the diagnosis and treatment of gynaecological cancer (ovarian, vaginal and uterine) and were now in the post-treatment phase of cancer (for at least 6 months), and who are able and willing to communicate their perception regarding the cancer experience.

Ten women participated in the study and were seen as co-researchers (Riessman, 2002). The participants represented a variety of professions, their socioeconomic situations were heterogeneous, and the style of living varied markedly within the sample. The ages of participants ranged from 33 to 70 (median= 55) at the time of the study, all the women had undergone surgery and had received additional treatment – chemotherapy and radiation therapy.

2.2. Ethical concerns

Confidentially procedures were followed, and all women participated in an informed, independent and voluntary basis. A consent form was signed after the provision of written information about the project from the researchers. Consent forms were kept in a secure location and destroyed after data collection. The purpose of audio-recording the stories was fully explained to participants and those recordings would be destroyed after transcription. They were also informed that the data would be anonymous.

2.3. Data collection and Data analysis

Data were collected through in-depth interviews, and were conducted by the first author. Three in-depth conversational interviews were conducted with each participant over a period of 2 to 6 months. The interviews took place in the participant’s homes and they lasted from 1 – 1 ½ hour. They were tape-recorded and transcribed verbatim. In qualitative research the researcher’s analytic and observational activities run concurrently, because there is temporal overlapping of observational and analytic work (Riessman, 2002).

The interviews were undertaken between December 2011 and July 2012. Data collection and analysis in this study reflected an evolving dialogue between the researcher and the participants. The researcher approached the participants with a very broad question that concentrated on the description of the lived experience of cancer, i.e., Can you tell me of your personal experience of having cancer? In the first interview the participants were allowed to tell their stories. During the dialogue or interaction with the participants in subsequent interviews the researcher asked questions that in direct response to the participant’s descriptions to arrive at a deeper level of understanding,
to reflect and to validate. It was through this intersubjective interaction or dialogue that the participants and the researcher constructed the essential description of the lived experience of having cancer.

Phenomenology of praxis proposed by van Manen (1997) guided the data analysis and transformed personal experiences into disciplinary understanding. Van Manen’s four fundamental existential of lived space (spatiality), lived body (corporeality), lived time (temporality), and lived other (relationality) describe the humans experience the world. These life world existentials acted as guides for reflection and were used to guide the analysis of the data.

3. Results

Results from this study indicate that women who were diagnosed with gynaecological cancer were faced with tremendous changes and challenges as a result of their illness.

3.1.1. Lived body

The hope of being a normal person underscores the pragmatic nature of the Portuguese culture and its values of conforming to the societal norms of being productive. Several women defined normalcy in terms of their ability to do paid work and social activities. Work affirmed who these women were and who they are: optimistic, independent, strong and confident.

Cancer treatment can change the way a woman feels about herself and her body image. The majority of women reported that the changes in their physical appearance did not affect their self-identity; the loss of their reproductive organs was insignificant if it meant they could live: Our life is what is most important. Diagnosis and treatment of gynaecological cancer can negatively affect a woman’s self-image as scars and physical changes can be constant reminders.

For all of participants, they had looked death in the eye during the time of their diagnosis, but most had pushed the thoughts of dying aside as they became farther away from diagnosis and active treatment. For this reason, women indicate that there is a need for psychological assistance.

3.1.2. Lived other

At the heart of this existential experience, emerges the term “cancer survivor epiphany” which describes the process of women who discover and reveal their newfound situation after gynaecological cancer. The survival trajectory was characterized by intense self-analysis, the result of which was a major new insight or change in perspective. The content of the new insight or change in perspective was deemed to be highly significant to the participant’s life, so much so that it radically altered their perceptions of themselves and of their world. For many of the participants, some means of obtaining social support would have been advantageous. Health professional support can help the cancer survivor navigate in their changed world; help them to feel safe and reassured in their epiphanic journey. Through pain and suffering they have developed deep personal insight that has enabled them to connect much more deeply with others (e.g. parents, friends and other survivors). They have also each developed their own unique forms of psychospiritual growth, which has enabled them to connect much more deeply with the world around them.

3.1.3. Lived space

The oncology care setting provided a "home from home" for some participants, and creating feelings of security and safety, comfort and easiness, which contributed to feelings of at-homeness. For all of women, going home is the ideal pathway to which all treatments of grave and lengthy illnesses in hospital eventually converge. At home, people can be expected to have a stronger sense of autonomy and control than elsewhere, they can be expected to be more comfortable, and they may have the protection and security of relatives.

3.1.4. Lived time

Cancer journey extends across past, present, and future. A key finding in the present study was the importance of relationships as a temporal anchor in participants’ present lives. Family of origin provided an historical connection,
whereas present day family and friends provided a connection with the present here and now. When looking to the future, participants reconsidered their personal, social and community relationships. Firstly, participants learned the limits of their boundaries with others. Some wished to: be more tolerant of people than I am. Secondly, the wish to become a good person (Morton, 1996) involved redefining one’s boundaries for oneself.

4. Discussion

The research literature addressing the psychosocial aspects of cancer continues to expand, with narratives occupying a prominent position because of growing appreciation of their relevance in identifying and meeting the needs of those affected by cancer.

The current research investigation of the lived experiences of gynaecological cancer survivors considered their stories about their cancer diagnosis and treatment and how they changed during the time following. Consistent with the posttraumatic growth literature, the participants demonstrated areas of positive growth in their lives. Reappraisals of what was important, renewed spirituality, increased sense of purpose, and a desire for altruism were confirmed by the survivors’ stories of change. Part of the meaning making of any life-threatening illness such as gynaecological cancer involves taking a look at the possibility of dying. All of the participants had considered their own mortality in some form during the recovery process.

The major areas of growth whereby people often experience positive psychological change after trauma include changes in self-perception, changes in relationships with others, and changes in one’s general philosophy of life (Tedeschi & Calhoun, 2004). According to Taku, Cann, Calhoun, and Tedeschi (2008), changes in perception of self include an increased awareness of personal strength, resiliency or autonomy, as well as creating new opportunities. Changes in interpersonal relationships consist of greater compassion, closeness in relationships, or altruism. Changes in philosophy of life involve a greater appreciation of life or spiritual/existential development. These post trauma changes have been variously labeled as meaning focused coping (Folkman, 2008), positive reappraisal or benefit finding/reminding (Tennen & Affleck, 2002), positive personal growth (Kayser & Sormanti, 2002), post-traumatic growth (Weiss, 2004), inner strength (Roux & Dingley, 2011) and epiphany or sudden transformation (Miller, 2004). These terms have been used interchangeably within the literature to describe the growth reported by people after various adverse events.

Given the small number of studies investigating the lived experiences of the woman with gynaecological cancer, this study expands the theory and knowledge of what that experience is, and what the women themselves consider important about changes in their lives after a gynaecological cancer diagnosis. The positive changes described by women who have managed the disturbances associated with gynaecological cancer include improved relationships, new possibilities for one's life, a greater appreciation for life, a greater sense of personal strength, and spiritual development.

The findings from this study provided invaluable insights to aid oncology social workers and other psychosocial providers to assess these women’s needs, anticipate potential problems, facilitate their internal “positive and strong” frame of coping as well as support the development of culturally appropriate psychosocial and supportive care services to maximize adaptation and recovery. The findings open various new possibilities for future research and intervention relating to identity following diagnosis, as well as the impact this can have on women themselves and significant others. Future studies will hopefully assist women who experience gynaecological cancer to cope with the many challenges and changes of treatment and post treatment effects. Further qualitative study is therefore needed to be replicated in different populations to establish how women re-evaluate and reconstruct their identity. Quantitative study can help determine the extent to which the themes that emerged in this study are representative of women’s experiences.
5. Conclusion

In conclusion, by providing the opportunity for women to share their unique experiences of their cancer, pathological drama, healing path or letting their voices be heard, this phenomenological study contributed to a richer and more detailed understanding of the sensitivity of challenges faced emotions experienced and meanings attributed to the gynaecological cancer experience.

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References


