


The Experience of Living With Breast Cancer and the Assessment of Needs and Expectations

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Maria Nikoloudi, MD¹, Florjan Thanasko, PhD¹, Efi Parpa, MA, PhD¹,
Sotiria Kostopoulou, RN, MSc¹, and Kyriaki Mystakidou, MD, PhD¹ 

Abstract

Living with a chronic disease constitutes a biographical reversal characterized by change and loss. The aims of this study are to conceptualize the meaning of breast cancer, of its burden, to explore the patient's needs and expectations while being admitted to a palliative care unit, and to evaluate the fulfillment of those expectations. Two semistructured interviews were conducted, audio taped, transcribed verbatim, and subjected to the qualitative method of Interpretative Phenomenological Analysis. The first interview was conducted at the first visit of the patient to the palliative care unit, and the second after 2 weeks of receiving palliative care services. Qualitative findings indicated that the meaning of cancer can be interpreted as a transition of fading away. The transition began with redefining cancer from "my difficult moment" to "fortunately to its final destination"; struggling with the paradox of "the will to see the development of yourself and your child" and "wishing to die" while being able to "adapt" to "a balanced" day to day leaving and preparing for death. The need for interdisciplinarity is expressed.

Keywords

cancer, interpretative phenomenological analysis, palliative care, fading away

Introduction

Palliative care is applicable, meaningful, and valuable throughout the disease trajectory (1,2). Many patients who could benefit from the palliative care services are not receiving them due to the existence of several barriers which undermine the patient's referral to a palliative care unit (PCU). Some well-described barriers to access to palliative care are the health care professionals' hesitation to discuss palliative care due to difficulties in recognizing the "key" moment in the illness trajectory (3), reluctance to refer, feeling unprepared to discuss end of life care (4), fear of destroying patients' hope (5), lack of resources to refer to, not knowing that resources exist, and ignorance regarding what palliative care is (6–8).

Breast cancer is the most common invasive cancer in women (9). It was the fifth most common cause of cancer death in 2020 (10).

Breast cancer is traumatic probably due to the threat that poses to the patients' lives, loss of bodily control, breast loss, hair loss, and weight gain (11–13). The lived experience of breast cancer can be shaped by the patient's identity and the role of culture (14). Kaiser argues that women with breast cancer make their own linguistic and conceptual

interpretations that represent their experience. Moreover, a "good" breast cancer story would acknowledge the long-term role of cancer in women's lives and their fears of recurrence. Assimilating breast cancer in life may lead the women to openly discuss their suffering and thus their pain (15).

In an interpretative phenomenological analysis (IPA) study with 3 female participants with breast cancer the issue of losing, regaining, and relinquishing bodily control had a major role in their experience (16).

Case studies with IPA can give insight into the personal life-world in the experience of breast cancer. An IPA case study found that the complications of the illness, lymphedema, and the short stretch bandaging affected her physical

¹Pain Relief and Palliative Care Unit, Department of Radiology, Aretaieion Hospital, School of Medicine, National & Kapodistrian University of Athens, Athens, Greece

Corresponding Author:

Kyriaki Mystakidou, MD, PhD, Full Professor of Palliative Medicine, Pain Relief and Palliative Care Unit, Department of Radiology, Aretaieion Hospital, National & Kapodistrian University of Athens, School of Medicine, 27 Korinthias St, 115 26 Athens, Greece.
Email: mistakidou@yahoo.com



and emotional functioning. The bandaging made her work and everyday life difficult while distracting her from her job role (17).

This is an IPA case study which aims to explore: (a) meaning making of a female patient about breast cancer, (b) expectations from palliative care, and (c) describe a “good” doctor.

Methods

Ethical Considerations

Ethical approval was gained from the Hospital’s Ethical Committee. The participant also gave her written permission for the recordings in compliance with the General Data Protection Regulation (GDPR, Eu regulation 2016/679). The interviewer explained to the participant the purposes of the study and informed her about her rights. Her name and other identifying information were changed. The participant is referred to as Elena.

Participant

At the time of the interview, Elena was 66 years old. Elena died some months after the interview. She was a college graduate in architecture, a married middle-class housewife, and had a son. Her relationship with her husband and son was very good characterized by mutual care. She has diagnosed with breast cancer 6 years ago with bone metastases, lymphedema in her right hand, and skin lesions. She had radical modified mastectomy surgery, chemotherapy, and radiotherapy in 2014 and in 2019.

Data Collection

This is a case study. A case study is intended to demonstrate the existence, not incidence (18,19). Single case studies simply show us that how something is, unfolding it in an

insightful manner (18,19). The interview was performed at a PCU in Greece. Two semistructured interviews were obtained in this qualitative study. The first interview was conducted in the patient’s first visit to the PCU and had a duration of 50 min. The main questions were: (1) what does your illness mean to you? (2) What are your needs and expectations from palliative care? The second interview was conducted 2 weeks after receiving palliative care services in the PCU and lasted 25 min. The main question was: how was your experience in our PCU?

Data Analysis

The interviews were conducted in Greek and transcribed verbatim. IPA was applied. We followed the 6 proposed steps of IPA analysis as those have been described by Smith et al (18). IPA is a qualitative research method focused on exploring how people understand the experiences that play an important role in their lives (5). Investigator triangulation was employed in the data analysis analyzing the data in order to promote transparency, to present different perspectives on a complex phenomenon, adding breadth to it (5–7).

Results

The analysis of the interview transcript revealed 3 superordinate themes: (a) living with Breast Cancer, (b) the joint contribution: home, communication, care, and death, and (c) the good doctor: expectations and palliation (see Table 1).

Living With Breast Cancer

Elena experiences breast cancer as a progressive and constant descent to the final destination, death. Through this path, Elena experiences somatic pain, the changes in functionality, while trying to adapt to the multiple losses of her future, goals, and roles.

Diagnosis: Agony and Fear. When Elena received her diagnosis she immediately felt agony about her future: “Will I make it through this?” and the prevalent emotion was: “Fear. Fear of what I have to face.”

My Difficult Moment (the Meaning of the Illness). Breast cancer for Elena: “means my difficult moment that I have to cope,” and “Position A and position Z. From position A when cancer was diagnosed to position Z which is the end I will try to get through it as best I can.” Elena redefined the meaning of cancer throughout her illness trajectory over time. Position A used to be “It means a difficult time that I have to face” implying that for a given period of time efforts can be made to treat the disease; position Z means “Cancer is a disease that you know it has an end” acknowledging the changes and decline in health and the shift from hoping to overcome the illness to realizing the ending nature of it. In this descent, the feeling of “fear” emerges.

Table 1. Superordinate Themes and Themes.

Superordinate theme 1: Living with Breast Cancer	Superordinate theme 2: The Joined Contribution: home, communication, care, and death	Superordinate theme 3: The Good Doctor: expectations and palliation
Themes (a) Diagnosis: agony and fear (b) My difficult moment (the meaning of the illness) (c) Symptoms and Relapses (d) The next day: balances and losses	(a) Open communication and care (b) To calm down, to calm down: the Descent into My Death	(a) Accessibility and reference to the Palliative Care Unit (b) Expectations and palliation from the healthcare workers

Symptoms and Relapses. The disease is perceived as a state of consecutive relapses and decreases in functionality. Breast cancer, bone metastases, lung metastases, and skin lesions have caused Elena a great deal of “fatigue.” Furthermore, she has completely lost the functionality of her right hand, “which causes me to be even sadder.” However, her “biggest problem is located here in this part” (in the skin lesions), because “every night, every night I do this cleaning over here, I feel, incredibly awful,” and wishes “at least the skin lesions got better.” This wish is so powerful that Elena can “get used to the pain” in contrast with the issues on the skin. She feels the bad and unpleasant smell coming from her own body and realizes her inner biological problem “by bad smells” and “bleeding.” This immediately and constantly observable stimulus is a trauma for her as it is an indication of the difficult situation in which she has to cope. Elena associated her breast cancer with fatigue, pain, skin lesions, swollen arm, bad smells, and death.

The Next Day: Balances and Losses. Elena has been living with cancer for 6 years and has managed to find her “balance,” in which there are changes that turn in different directions, struggling with paradoxes: “it is a bit contradictory what I say.” On bad days, pain is one of the directions that threatens the balance: “all this pain drives you crazy” and makes Elena to succumb to vanity “why do I have to go through all this torment,” wondering whether “does this prolongation of life has meaning?,” and despair “please, let me die.” On the contrary, on good days Elena mentions “when I wake up and things are a little better, in terms of pain, that is when I say life is nice,” and dares to gaze into the future founding the “will to see the development of yourself and your child.” Elena has acknowledged the changes in everyday life as she mentions: “man adapts.” “Many things in my life have been altered, things that used to give me joy, I am deprived of now, that is, and this is even more painful,” and “for the first time in my life I was jealous of going to the sea.” “I feel like I’m trying day by day to see improvements or at least to maintain stagnation.” Elena has found meaning by tolerating the altered everyday life and tries to adopt an attitude of living “I’m fine so far, I’ve tasted life.” The distressing bodily symptoms: pain, swollen arm, fatigue, and bad smells have restricted Elena from her household and leisure activities. Having goals gives meaning in living day to day: “this occupation (architecture) made me forget, and kept me getting up in the morning,” but now “I do not feel that I have something to say as a goal, something to occupy myself. Yes, it makes it easier to have something to do.”

The Joint Contribution: Home, Communication, Care, and Death

A key point in Elena’s life is the creation of her family. The open communication in the family reinforces Elena to

express her fear, uncertainty, despair, and paradoxical feelings. She feels the care from her family. Elena expresses concerns for the well-being of family members and friends. Moreover, she acknowledges the effects of the illness and burdens on family members, friends, and self. Finally, Elena is ready to talk about her death.

Open Communication and Care. Elena’s illness, thoughts, and feelings have been extensively discussed within the family and there is “excellent communication and support” with “no false reassurances.” Elena feels the presence of her family as “a gift” because she has “company all the time.” Open communication is a channel for conveying thoughts and desires for decision making. The desires of the family members are opposed to Elena’s desires: “when sometimes my son tells me: mom you will do this and that and your illness may go on for 10 and 20 years and this is what we want; we want you here. I tell him this is a wish and a curse, if the years are many and painful I do not want them.” Elena seems to accept that the role of the mother that holds in the family will be gone much sooner than what the members of the family do expect. Elena’s family members try to show their interest by taking care of her on a daily basis. This care includes assistance with daily living activities such as bathing, preparing breakfast, and hanging out. Elena tries to show her care towards her family by reducing the impact of her disease burden on her family’s day to day living “fortunately, my husband stands by me, but there are moments that I feel like I am manipulating his goodwill,” and she does “not want to upset them all the time”; hence “I cannot become the whole world’s focus of attention. Yes, I deserve some extra care, but if my son does not go to work, if my husband does not go to work, if my friend does not do her chores, her shopping, what will happen? That is, I try with logic to cope with the negative things.” Elena acknowledges the “extra care” and her dependence in terms of her daily routines: “a dysfunctional arm cannot cook, and clean” as indicative of the burden experienced by family and friends caregivers while encouraging them to take time for themselves and focus their attention elsewhere. Moreover, Elena redefines herself as her capacities are diminishing while making efforts to lessen the burden to her family members: “as long as my mentality remains intact, to be able to communicate, to walk, to get up. I want to go the toilet at night to be able to get up. I have found a trick when they sleep in order not to wake them up, I sleep on the sofa, and next to it there is a small table so I put my foot on it in order to be able to get up, so no one needs to pick me up. I get up just fine and say as long as it’s like that its fine, I will keep doing it.” Elena breaks down tasks into manageable ones in her attempt to cope with the changes in her functionality.

To Calm Down, to Calm Down: the Descent into My Death. Elena has begun to wish withdrawal and thoughts about preparing for death are emerging. She seeks peace from the negative stimuli in her attempt to come in terms with herself and

her death: “to calm down, to calm down,” “it (the pain) hunts me constantly” and “this (the cancer) has now taken its final form, fortunately.” Furthermore, Elena begins to think that she is ready to separate from the positive aspects of life as well: “that is if I die today it is fine, the people around me will be fine after me.” Elena tries to comfort her loved ones in their preparatory lament realizing the difficulties in this endeavor: “Sometimes when I beg for death to come, they (her family) say no, no, we want you here and I strive not to say it many times, because I know I upset them, but I have to express myself about how I feel when the situations overcome me.” Furthermore, she describes her lived experience of the deaths of her beloved parents from cancer: “I remember that your own patience runs out, so I do not want to bring my family to that point” leading her to reconsider about how much of a burden her illness must be to her family. Elena had the “endurance” to let them die at home. This experience made her more resilient in discussing her own imminent death: “I remember (my mother) telling me I want to die at home. I wish I would too.” Our participant had the “endurance” to accept her parents’ wishes to die at home. As for her family members she mentions: “I do not want to lead them to that,” to experience the “endurance” which she lived. Elena repeatedly describes her desire “to die at home,” but no concrete preparations were ever carried out for that, maybe due to acknowledging what that some “extra care” that she “deserves” means for her family members. Unfortunately, Elena experienced what she constantly feared; the “scaring image of dying alone at the hospital.”

The Good Doctor: Expectations and Palliation

Accessibility and Reference to the PCU. Elena explicitly and repeatedly reports the difficulties in accessing the PCU: “I have a complaint, that is, the access it is not easy,” “the access is very difficult, this creates an extra stress for me,” and “I considered it as a private initiative.” Elena was not referred to the PCU by her physician, but “by circuitous form of actions, by a mere chit chatting with a psychologist in another hospital.”

Expectations and Palliation from the Healthcare Workers.

Excellence in communication is the main component of a good physician, according to Elena: “information is very important, no matter how difficult or strange it may be.” Prior to receiving services from the PCU, there was complete unawareness about the PSU’s purpose: “I do not know what I am hoping for.” Elena’s basic request was: “to experience it as painlessly as possible,” “maintaining my mentality is important for me.” More generally, Elena expects from the health care professionals, in terms of treatment, to act as an interdisciplinary team: “the advice of doctors sometimes disappoints me, because I would expect another treatment, that is, more holistic,” and “when the problem is more complex, to feel that these people cooperated with each other, I do not

feel this happening regarding my treatment at the hospital.” After her first visit Elena mentioned: “I felt relieved” from pain and other somatic symptoms. Furthermore, “I am very happy, because I feel that you listen to me throughout, throughout my history very kindly (cries). This is something rare to find. I wanted to state that,” and “I do not give up and this helps my psychology. I see with how much compassion you hear me.” Finally, Elena’s last main concern was: “I do the following thought, that I will not have the (physical) strength to come (to the PCU), so I will lose contact.”

Discussion

Based on the purposes of this research, we will structure the discussion around the following two topics: (a) the conceptualization of the meaning of the breast cancer experience; and (b) the conceptualization of the expectations of palliative care, and the description of a “good” physician.

The Conceptualization of the Meaning of the Breast Cancer Experience

The participant’s lived experience of breast cancer can be conceptualized as a transition of fading away. This transition began with the end of life as used to be (2–4). Studies have shown that the transition of fading away consists of 7 dimensions that are inextricably linked to one another: redefining, searching for meaning, living day by day, contending with change, struggling with paradox, burdening, and preparing for death (2–4) consistent with our findings. More specific all your patient, in her own linguistic and conceptual interpretations as also Kaiser argues, redefined her journey in living with cancer from the traumatic “difficult moment” and wondering whether “Will I make it through this” to shifting it into living “a balanced” “nice life.” Elena managed to “adapt” to the changes in everyday living while struggling with the paradox of gazing into the future while at the same time wishing to die. Our findings about the adjustment to the changes that Elena experience are in agreement with other studies (11,12,17). Adjustments to change include: (a) somatic symptoms, (b) relapses, (c) decreases in functionality while implementing feasible alternatives in breaking down various tasks in everyday life, (d) losses in activities, goals, and roles, (e) and realizing the shift from living with cancer to dying from cancer.

Our participant was aware of her dependence, in terms of care, from family members and friends. Furthermore, she acknowledged the burdening that her family members and friends experience, through a reflective process in which she described us herself as a caregiver to her parents who died from cancer. However, Elena encouraged and reinforced her family members and friends to spend time on their own, and to drift away from their focus of attention from her from time to time. These efforts were made in order to minimize as possible the burden experienced by family and friends

caregivers due to the “extra care” that Elena needs. The patients who had redefined themselves in a more realistic way as their functionalities diminished were more accurate in their perceptions of burdening (2) consistent with our findings. However, in our study, the attention was placed on the burden experienced by the patient, by reflecting what that “extra care” that Elena “deserves” means to her and consequently to others. This reflexivity process has its unique restrictions and may have played a key role in not making the preparations for Elena to “fortunately” “die at home.”

A good death is a complex issue. This decision is influenced by the way health care professionals inform patients about the disease, the degree of awareness of the situation, the trust and perceived adequacy of caregivers, the patient’s desire, the management of symptoms, and the timing of the decision (10,11,13). The relatives’ trust in their own adequacy for the delivery of care at the end of life plays an important role in choosing the place of death, often feeling unprepared for the provision of such care (10–13).

The Conceptualization of the Expectations of Palliative Care and the Description of a “Good” Physician

There is total unfamiliarity with the purpose and scope of palliative care similar to other studies (4–8). This study is significant in highlighting the personal need for assessing and receiving palliative care.

Patients define a good physician as a good listener, honest, willing to communicate, and able to alleviate them from distressing symptoms (8) consistent with our findings. Something that impressed us was that Elena expected a “holistic” “cooperation” “for more complex problems” by her physicians prior to the PCU visit. This was one of her most strong motivations. She essentially described the need for interdisciplinarity, for which concept she did not know anything; she just felt that gap in her treatment in the hospital and the need for palliative care in our country.

Limitations and Strengths

The present study focused on a case study based on one cancer patient; therefore the results cannot be generalized (15). The strength of this study stems from the transparency and coherence of the data presentation as we present many extracts from the textual data. Finally, the implementation of investigator triangulation on data analysis offered multiple perspectives on the exploration of the phenomenon presented in this article (5,7).

Conclusion

The conceptualization of breast cancer from the perspective of a patient involves: (a) symptoms management, (b) redefining of illness meaning, (c) breaking down tasks into manageable ones in the attempt to cope with the changes in

functionality, and (d) open communication between patient, family, oncologist, and the palliative care team, indicating the interdisciplinary need. Future research should be aimed at raising patient awareness of available palliative care services.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.


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Ethical Approval

Ethical approval and permission for this study was granted by the Aretaieion hospital Ethics committee. The participant gave her written permission for the recordings in compliance with the General Data Protection Regulation (GDBR, Eu regulation 2016/679) regarding the protection of personal data. The Hospital’s Ethical Committee approved the study protocol.

ORCID iD

Kyriaki Mystakidou  <https://orcid.org/0000-0002-5236-1014>

Statement of Human and Animal Rights

All procedures in the study were conducted in accordance with Arataieion hospital-approved protocols.

Statement of informed consent

Written informed consent was obtained from the patient(s) for their anonymized information to be published in this article.

References

1. WHO. Definition of Palliative Care. Geneva, Switzerland: World Health, Organization; 2015.
2. Hui D, Kim SH, Roquemore J, Dev R, Chisholm G, Bruera E. Impact of timing and setting of palliative care referral on quality of end-of-life care in cancer patients. *Cancer*. 2014;120(11):1743-9.
3. De Vleminck A, Pardon K, Beernaert K, Deschepper R, Houttekier D, Van Audenhove C, et al. Barriers to advance care planning in cancer, heart failure and dementia patients: a focus group study on general practitioners’ views and experiences. *PLoS ONE*. 2014;9(1):e84905.
4. Hancock K, Clayton JM, Parker SM, Wal der S, Butow PN, Carrick S, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med*. 2007;21(6):507-17.
5. Pfeil TA, Laryionava K, Reiter-Jheil S, Hiddemann W, Winkler EC. What keeps oncologists from addressing palliative care early on with incurable cancer patients? An active stance seems key. *Oncologist*. 2015;20(1):56-61.
6. Tapera O, Nyakabau AM. Limited knowledge and access to palliative care among women with cervical cancer: an

- opportunity for integrating oncology and palliative care in Zimbabwe. *BMC Palliat Care*. 2020;19(1):20.
7. Hirai K, Kudo T, Akiyama M, Matoba M, Shiozaki M, Yamaki T, et al. Public awareness, knowledge of availability, and readiness for cancer palliative care services: a population-based survey across four regions in Japan. *J Palliat Med*. 2011;14(8):918-22.
 8. De Lima L, Pastrana T. Opportunities for palliative care in public health. *Annu Rev Public Health*. 2016;37(1):357-74.
 9. McGuire A, Brown JAL, Malone C, McLaughlin R, Kerin MJ. Effects of age on the detection and management of breast cancer. *Cancers (Basel)*. 2015;7(2):908-29.
 10. Ferlay J, Colombet M, Soerjomataram I, Parkin DM, Piñeros M, Znaor A, et al. Cancer statistics for the year 2020: an overview. *Int J Cancer*. 2021;149(4):778-89.
 11. Arman M, Rehnsfeldt A. The hidden suffering among breast cancer patients: a qualitative metasynthesis. *Qual Health Res*. 2003;13(4):510-27.
 12. Fang SY, Chang HT, Shu BC. Objectified body consciousness, body image discomfort, and depressive symptoms among breast cancer survivors in Taiwan. *Psychol Women Q*. 2014;38(4):563-74.
 13. Morris BA, Shakespeare-Finch J, Scott JL. Posttraumatic growth after cancer: the importance of health-related benefits and newfound compassion for others. *Support Care Cancer*. 2012;20(4):749-56.
 14. Williams F, Jeanetta SC. Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: qualitative study. *Health Expect*. 2016;19(3):631-42.
 15. Frank AW. Why I wrote... The wounded storyteller: a recollection of life and ethics. *Clin Ethics*. 2009;4(2):106-8.
 16. Gorven A, du Plessis L. Corporeal posttraumatic growth as a result of breast cancer: an interpretative phenomenological analysis. *J Humanistic Psychol*. 2021;61(4):561-90.
 17. Sun Y, Armer JM. A nurse's twenty-four-year journey with breast cancer-related lymphedema. *Work*. 2019;63(1):21-31.
 18. Smith J, Flower P, Larkin M. *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage Publications; 2009.
 19. Yin RK. The case study method as a tool for doing evaluation. *Current Sociol*. 1992;40(1):121-37.