What Is Hope For Breast Cancer Patients?

A Qualitative Study

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Abstract: This study explores the function of hope in the life experience of women diagnosed with breast cancer. Despite its relevance, hope is a psychosocial concept still not fully explored by the literature. Aim of the present contribution is therefore to conduct a qualitative examination of semi-structure interviews of women with breast cancer. In particular the connection between hope and eight domains (diagnosis, life events, supportive network, healthcare network, medical treatment, acceptance of the disease, ability to make projects and spirituality) associated with it is investigated. The analysis of the interviews of four breast cancer patients met during their hospital staying reveals that hope is an essential aspect of the ability to cope with the illness. Furthermore, our analysis confirms that hope can be placed on a continuum between Cognitive and Emotional dimensions, from the intersections of which four possible scenarios (Despairing Space, Fleeting Space, Hesitating Space and Hoping Space) can be identified.

Keywords: hope, breast cancer, qualitative research, cognition, emotion.
INTRODUCTION

Hope has traditionally been mostly addressed by theology and philosophy, despite the fact that it seems to represent a very important resource for cancer patients (ESMO, 2011; Weir & Brint, 2011). Furthermore, most of the psychosocial research has examined hope in palliative and end-of-life settings (Greisinger, Lorimor, Aday, Winn, Baile, 1997; Johnson, 2007; Richard, 2009). The literature agrees that it represents a key element of the human experience (Lynch, 1987). Hope has been described as a feeling that allows to find strength while coping with difficult situations and events. It has been described as a projective trust towards the future, in spite of afflictions and suffering of the present (Short & Casula, 2004). From a psychological perspective, hope represents a valuable resource to face critical moments in life. It develops from the power of imagination and anticipation of the future as a time of improved well-being (Farran, Herth & Popovich, 1995). One key aspect of this construct is the perception of something missing at the present time: this belief supports the individual to look at the future as a time of greater functional outcomes (Korner, 1979). However, these anticipated results remain tentative because of the uncertainty of the human condition (Bloch, 1970). It therefore follows that uncertainty is a core element of hope, since both a positive attitude and apprehension characterized it (Liotta, 2004). Based on this consideration, hope represents a feeling that is placed on a continuum at whose extremes we find a positive emotion (the anticipatory expectation to realize what is hoped) and a negative emotion (fear of not being able to realize what is being hoped). These thoughts and feelings can be experienced when a person is diagnosed with a serious illness, like cancer. This type of diagnosis is often unexpected and destabilizing for the individual, as treatments compromise many aspects of life and threaten the sense of psychological and physical continuity. Moreover, the social representation and the emotional experience associated with this illness challenge (in certain cases destroy) the patient's life; since cancer often represents a breaking point with everything existing before and after the diagnosis (Author, 2009).

Hope has a close connection with the future and has some similarities with growth and resilience. As the possibility to turn a critical and disruptive event into a starting point that allows communities, groups and individuals to reorganize their lives in a positive way (Cyrulnik, 1999), resilience has been recently examined in its connection with illness and traumatic events.
Resilience can be considered as the ability to deal with a potential traumatic event, maintaining appropriate levels of physical and psychological functioning (Bonanno, 2004). In line with this definition, hope represents a prerequisite of resilience (Casula & Short, 2010). From this perspective, cancer can either represent a tragedy, which is a condition completely separated from health (Author & Cigoli, 2009), or the beginning of new life projects.

The present study is aimed at exploring the construct of hope among women diagnosed with breast cancer. The choice of this type of cancer is motivated by the fact that breast cancer, in addition to the consequences of treatment, forces a woman to face a deep analysis of her sense of self (starting from her body image), and to activate complex decision-making processes. The ultimate goal was for us to clarify cognitive, emotional and structural elements of hope. More specifically, authors were interested in exploring the existence of a connection between hope and resilience (Herth & Cutcliff, 2002; Hickey, 1986; Korner, 1970; Kubler-Ross, 1969; McLeod & Carter, 1999) by identifying elements that both promote and inhibit hope in the early stage of the cancer care continuum.

**MATERIALS AND METHODS**

The present study is a phenomenological examination of the life experiences of women diagnosed with breast cancer. Given the exploratory nature of the research study, a qualitative methodology using in depth semi-structure interviews was identified as the most appropriate approach (Creswell, 2013). By assuming a phenomenological perspective it was possible to focus on the experiences of the study participants while limiting the impact of researchers biases (Kvale, 1996). A phenomenological methodology, aimed at describing the meaning of the lived experiences of individuals around a specific concept or a phenomenon (Creswell, 2013), contributed to the understanding of the subjective experiences of the participants. While conducting a phenomenological study it is necessary to pay particular attention to the selection of participants, preferring qualitative to quantitative criteria. In the present study the choice of the patients was conducted in agreement with their physician, by considering socio-demographic characteristics and their attitude about the cancer experience. Study participants were four women in their fifties (mean age was 54) and
with a low level of education. Three of them were married and one was a widow. Three had children. All the women were treated in the Breast Cancer Unit of a metropolitan hospital in Northern Italy. The study protocol was approved by the Scientific Committee of the participating institution. Participants were interviewed during the 48 hours following surgery for breast cancer (either lumpectomy or mastectomy). The interviews were completed individually in order to allow maximum freedom of expression to the women. All the interviews were recorded, after consent was given, and then transcribed verbatim.

According to the previous exploration of the literature about emotional and cognitive aspects of coping with cancer and inspired by Johnsonís work (2007), eight were the themes considered by the researchers:

- Diagnosis: the patients narratives about the moment in which they received communication of the diagnosis is classically considered relevant for the activation of hope. The literature indicates that the modality in which the diagnosis is communicated to the individual influences his/her look to the future (Girghis & Sanson Fisher, 1995; Weir & Brint, 2011);
- Life events: a relationship exists between the way in which subjects faced problematic events in the past and their ability to cope with the current experience of cancer (Baffigi, Pettorossi & Author, 2009);
- Supportive network: the presence of a supportive network of close relationships is considered a fundamental psychological aspect to cope with the disease (Goldberg, 1981; Bukberg et al., 1984; Sinsheimer and Holland, 1987; Broadhead & Kaplan, 1991; Harrison & Maguire, 1994; Pinder et al., 1994; Torta & Mussa, 1997);
- Healthcare network: the literature indicates that aspects of acceptance and assistance next to the modality of treatment provision from the entire healthcare team are significant to promote a positive outlook in the patient (Girghis & Sanson Fisher, 1995);
- Medical treatment: the type of treatment can affect the ability to look at the future. Invasive and painful therapies involving physical and daily changes have been found to limit the ability to develop hope (Harrison & Maguire, 1994; Torta & Mussa, 1997);
- Acceptance of the disease: as outlined by Kubler-Ross (1976), the ability to accept one's own destiny is a pre-requisite to cope with the implications of the disease. On the contrary, denial activates dysfunctional defences, for example the choice to stop treatments;
- Ability to make projects: who is able to look concretely to the future is also able to show hope (Snyder, 2000);
- Spirituality: it is defined as the search for meaning, purpose, and connection with self, others, the universe, and the ultimate, however one understands it. This may or may not be expressed through religious forms or institutions (Sheridan, 2000). Among the theoretical frameworks underlying spirituality, the Bio-psychosocial-Spiritual Model of Care focuses on the relational nature of life and illness is considered a disturbance in these relationships (Reese, 2011; Altilio & Otis-Green, 2011). Since hope has been historically intertwined with faith (Sandrin, 2014), is thus legitimate to assume that the two aspects are connected.

A revised version of Giorgi framework for phenomenological analysis was used (Giorgi, 2009). This methodology includes five steps, which are presented below. After being transcribed, interviews were read with the goal to gain the holistic sense of the patients' experience; then, interviews were analysed again to understand the units of meaning. Later, these units were examined for redundancies and differences, placing them in relation with each other and with the holistic sense. Then a depth reflection about units of meaning lead to the identification of the themes. Finally, a consistent description of the patients experience was formulated. Coding was conducted by different researchers, who worked according to the principles of triangulation to verify the interpretation.

RESULTS

This exploratory analysis of the interviews conducted with women coping with breast cancer confirms most of the thematic areas identified when preparing the interview.

Diagnosis

Four are the categories identified when analysing the experience of women about the communication of the diagnosis.

- Emotions: all the participants reported to have experienced feelings of distress, fear, despair, loss, anger after the communication of diagnosis, highlighting the potentially traumatic nature of the news (“It was a very bad shock, I remember that I was angry”);

- Ruminant thought: all the interviews indicate an intense imaginative activity in relation to the diagnosis. The moment of its communication is described in detail (and is often re-experienced by the women);

- Communication strategy used by the healthcare professional: the
way the news was communicated to them is often re-examined by the patients, trying to identify implicit meaning in the communication (“When I spoke with the physician, a very humane person, I realized… thanks to his attitude, he explained everything to me and told me that I should not worry and that everything would be fine”);

- Setting: a more positive experience of the communication of diagnosis was associated with aspects of acceptance, availability, openness, patience and understanding of the hospital setting.

Life Events

The discussion of life events can be summarized in two categories, critical events and resilient attitude.

- Critical events: all patients referred back to previous difficult or stressful events faced before the cancer diagnosis (“Before the surgery, my life was quite eventful(…), to the point that I believe the cause of my sickness was a past traumatic events”);

- Resilient attitude: patients underline their own ability to cope with difficult situations.

Supportive Network

Among our participants, the supportive network is identified among primary support persons like partners, next of kin, and friends. Two are the types of support identified:

- Practical help, which refers to concrete actions of care and support, especially during the post-surgery period.

- Emotional help represents a significant source of motivation for the individual, as healing is perceived as something to achieve for themselves and for others (“My husband, my sister, my daughter …they all reacted to my disease! They support me and give me lot of energy and understanding”).

Healthcare Network

Although the healthcare environment was initially experienced as the setting where the communication of diagnosis was received, two other aspects are highlighted by the analysis of the transcripts: acceptance and
communication with the team.

- Acceptance is experienced by the women as a consequence of kindness, trust, peace, security, informality, and the welcoming attitude of the nursing staff (“I am fine in this hospital, all the staff is so kind and patient which is very important for me!”);

- Communication: a clear and explicit communication, without being excessively formal, is reported as preferable from the participants and beneficial to clarify the current situation as well as the possible prognosis of the disease. This result highlights how the evolution and change on the registry used to refer to the cancer represents the starting point to develop a sense of hope (“they know what to say and how to approach you …and this is also important for you in order to be confident, because it is a brand new situation for you”).

Medical Treatment

For the women interviewed as part of our study, medical treatment was associated with uncertainty and anxiety.

- Uncertainty: women had not clear understanding of the kind of treatment they would have received as part of their care and expressed uncertainty about this next step. Our finding can be also due to the time when the interview was conducted. Since participants had undergone surgery only 24-48 earlier, they haven’t had a chance to focus on the following treatment.

- Anxiety: the uncertainty experienced about their treatment triggered in the study participants anxiety and fear. In particular they express concern for the physical impact of chemotherapy and the following impairment of the body image (“The only thing that scares me is chemotherapy… I am afraid about it, I know that it is very aggressive, but if I have to do it I will do, trying to face it with courage and strength”).

Acceptance

About this theme, participants expressed awareness of the need to deal with many changes, both concrete and existential. Furthermore, women highlighted that these changes were not predictable, since accepting the disease meant for them the ability to set, day after day, new goals.
Ability to make projects

The explorative analysis reveals that women in our study experienced both an interruption and resumed interest in their ability to make projects:

- Interruption of the ability to make projects: two participants reported how the disease "paralyzed" their thought process and therefore their planning ability. In two other passages, due to personality traits (strong anxiety) and past experiences, participants clearly indicate their preference for not making long-term projects, focusing mostly on the present ("I don’t have concrete projects yet, because sometimes, in spite of everything, I think I could not do it");

- Progress of in the ability to make projects: in two interviews patients revealed an inclination to think about future goals, even long term ones such as travelling. These thoughts are perceived as essential to positively cope with the illness ("I am able to look forward, it is one of my strengths; I have never lived day by day… I will always look forward!").

Spirituality

Finally, when considering spirituality, it is possible to affirm that all the participants shared a belief in God and the beneficial aspect of spirituality in thinking about the future. It is this belief that activates a feeling of hope. In particular, Christian principles, prayers and rituals are described as supportive tools that allowed them to reach inner peace ("I believe in God and this helps me to look forward because it represents a support that gives me peace of mind").

DISCUSSION

In the present study we investigated the role of hope in the life experiences of women diagnosed with breast cancer with the goal to identify cognitive, emotional and structural elements of this concept. Authors were also interested in exploring the existence of a connection between hope and resilience by identifying elements that both promote and inhibit hope in the early stage of the cancer care continuum.

The literature seems to identify two different dimensions of hope: a cognitive and an emotional one (Staats, 1985). In line with this
conceptualization and building on the findings of the present study, a theoretical model of hope can be introduced. This model is organized around two Cartesian axes (Fig. 1). The x-axis refers to the Cognitive Dimension (whose extremes are Delirium and Adherence to Reality) while the y-axis represents the Emotional Dimension, which ranges from Fear to Serenity.

Figure 1. Theoretical Framework of Hope.

If we consider the Cognitive dimension, Delirium seems to constitute the pathologic extreme of detachment from reality (Galimberti, 2006), while Adherence to Reality refers to the correct functioning of a reality exam, although rigidity and resistance may still be present. On the Emotional dimension the two extremes are Fear and Serenity. The first one is a primary emotion of defense triggered by dangerous situations (either real, anticipatory, or imagined). On the opposite side Serenity can be described as
an emotional condition characterized by inner and outer peace, calm and patience. From the intersections of these two axes, four possible scenarios are then created: the Hoping Space, the Despairing Space, the Fleeting Space and the Hesitating Space. The Hoping Space (HoS), placed in the quadrant between Adherence to Reality and Serenity, is characterized by the serene acceptance of the disease as critical moment that can be faced by referring to personal and/or environmental resources. The Despairing Space (DS) presents cognitive and emotional difficulties (like denial and strong negative and paralyzing feelings) that hinder the patient’s ability to look at the future. It is placed between Delirium and Fear. In the Fleeting Space (FS) a constant movement between denial of reality and serenity exists. This inability of the individual to select a course of action creates inconsistency, uncertainty and fragility. Finally awareness of the present situation and the fear associated to possible negative outcomes can be identified in the narratives of patients that can be placed in the Hesitating Space (HeS), which is located between Fear and Adherence to Reality.

This theoretical model is supported by the analysis of the interviews, which reveals that patients position in one of these scenarios isn’t static and immutable, but yet a dynamic process. Movement and changes to other spaces, next to moving back to previous scenarios, are possible due to the interaction between these dimensions.

Similarly to previous results reported in the literature, the present analysis shows how the communication of the diagnosis constitutes a potentially traumatic event, characterized by strong and negative emotions (Barraclough, 2001). This moment is often re-experienced over time focusing both on the communicative strategy used by the physician and to the feelings elicited by the context (Baile, Buckman, Lenzi, Glober, Beale, & Kudelka, 2000). Thus, as confirmed by the model proposed by Kubler-Ross (1976), the diagnosis can lead to Despair (DS) because the patient feels emotional and cognitive disturbances that can hinder the ability to look ahead with a positive attitude and trust. These difficulties are similar to those experienced during other dramatic life events and seem to be mitigated thanks to the support received by caregivers (Author, 2009) and the healthcare network (Alici, 2011). These two aspects seems to promote feelings of wellness similar to those experimented during spiritual experiences, which support the transition of the individual in the Fleeting scenario (FS). Although denial is considered dysfunctional, it is from this suspension of anguish that an optimistic and resilient attitude can emerge. This ability leads to like acceptance of changes (Author, Molgora, &
Fenaroli, 2011), the activation of project ability (Snyder, 2000) and can be inspired by positive memories of past live events (Grassi, 2003).

If we consider the Cognitive dimension, it’s possible to receive information related to the disease and its cure that allow to move towards an improved adherence to reality (Cousson-Gelie et al., 2008). The illness, although life-threatening, can be considered a life event, which can represent the first step of a new journey (Randall, 2005). When presented with clear communicative modalities, the patient may be able to shift towards a Hesitating scenario (HeS).

The patient’s ability to look ahead seems to be linked to individual capacities of resiliency (Bonanno, 2010), next to relational and contextual aspects. Each of these three aspects should be addressed extensively, but we focus here on contextual aspects because of the wealth of contributions regarding the other two (Randall, 2005; Schofield et al., 2003). Particular attention has to be given to the medical sphere, which can lead the patient to two different scenarios. Invasive and painful therapies, that involve physical and daily changes, may limit the ability to develop hope (Harrison & Maguire, 1994; Torta & Mussa, 1997) and contribute to increased sense of anguish, fear and denial of reality. However, medical therapies are also a very important healing tool and they can guide the patient towards feelings of peace and trust. This is achieved through the communicative patterns of the healthcare team, which promote awareness of reality and positive patient outcomes (Schofield et al. 2003).

The encounter with the diagnosis and the new condition of being a patient occur in the hospital setting, which has both physical and symbolic connotations. The data analysis revealed the pivotal role of the context (referring to structural and physical aspects of the setting and to the entire healthcare staff) for the patient’s activation of a hopeful attitude. Next to the diagnosis and healthcare network, the comfort of the primary network plays an essential role in order to promote hope. Family members and friends, in the role of caregivers, represent a bridge between past, present and future that allows the patient not to feel alone during the treatment phase. Their involvement ranges from practical daily life support (for example, management of the household or economic support) to emotional aspects/care (Carpiniello et al., 2002).
CONCLUSIONS

Finally, our findings indicate that spirituality is a critical resource for women coping with breast cancer. Participants expressed the importance to being able to rely on a set of values, practices and rituals that allow to detach themselves from the current physical suffering. Our results are consistent with previous studies that had demonstrated a helpful relationship between spirituality and well-being (Meraviglia 2006). Furthermore, spiritual and religious forms of coping are helpful for cancer, especially since spirituality can be consider a predictor of less mood disturbance (Romero et al. 2006).

In conclusion, the experience of the diagnosis, its communication from the health care professional, the support of the healthcare network and from the primary supportive relationships, next to a sense of spirituality emerge as key elements for the movement of patients towards a Hoping scenario (HoS) characterized by acceptance of reality. Itís possible to affirm that the disease is included in the life experience of the individual (his/her own story), but also in the emotional relationships established with significant people (including the healthcare staff) (Author & Astori, 2009). Such story can be metaphorically compared to a piece of tapestry: patient’s thoughts, emotions and the characteristic of significant relationships all contribute in determining the resulting pattern (Cigoli, 2002). Summarizing, the present qualitative study highlights the existence of a positive link between hope and other specific domains related to cancer. In particular, these findings emphasize the need to approach patients and their experience with the disease according to a multidimensional framework, as suggested by the Bio- Psychosocial Model (Engels, 1977, 1980; Schwarts, 1982).

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