The Suspended Self: Liminality in Breast Cancer Narratives and Implications for Counselling

Ifigeneia Koutri*, Evrinomy Avdi

[a] School of Psychology, Aristotle University of Thessaloniki, Thessaloniki, Greece.

Abstract

In the field of chronic and serious illness, meaning-making with regards to the illness experience has been shown to be a core process for patients. This study focuses on women's narratives of their experiences of living with breast cancer. Within the framework of narrative psychology, illness narratives are considered to provide the main means through which patients make sense of their illness experience and construct its place in their life story. In this paper, we present findings from a narrative study that aimed to explore the different meanings that breast cancer holds for Greek women. In the broader study, four basic narrative types about breast cancer emerged from the analysis. In this paper, we focus on one of these narrative types, in which illness is constructed as an entrance into a state of liminality and where the women's sense of self seems to be "suspended". The core features of this narrative type are described and arguments are developed regarding its usefulness. We argue that this is a narrative type that deserves further attention, particularly as it seems to reflect a socially non-preferred storyline, which might result in these women's stories being sidestepped or silenced. The implications of this narrative type for healthcare and counselling in cancer care are discussed.

Keywords: illness narratives, liminality, breast cancer, narrative identity

Introduction

Breast Cancer Narratives

Over the last few years, there has been an increase in both theoretical and research interest in the role of meaning-making in coping with serious negative life events, such as chronic illness (Crossley, 2000b; Frank, 1995; Kleinman, 1988). With regards to breast cancer, it is now generally accepted that for some, at least, women the diagnosis constitutes a threat that challenges many different aspects of the meaning of their life and their sense of self (Arman & Rehnsfeldt, 2003; Carter, 1993). Living with cancer can force women to revise important aspects of their life, values and priorities in a process of making sense of the illness experience and its place in their life story (Roussi & Avdi, 2008).

Several studies have examined breast cancer patients' quality of life at the time of diagnosis, during the acute phase and after the completion of treatment. Reviews of this literature have shown that the majority of women seem to adjust well to breast cancer, although some continue to report psychosocial needs even long after the completion of treatment (Knobf, 2011). More specifically, following the completion of medical treatment, some
women report improvement in their quality of life (Ganz, Kwan, Stanton, Bower, & Belin, 2011), whereas others report increased rates of anxiety, psychological distress and feelings of uncertainty about the future (Allen, Savadatti, & Levy, 2009; Knobf, 2011). Therefore, there seems to be a group of women who continue to experience psychological difficulties and concerns after the completion of medical treatment, and it has been argued that these needs need to be recognised and addressed by both healthcare professionals and counsellors (Cappiello, Cunningham, Knobf, & Erdos, 2007; Knobf, 2011). Although findings from quantitative studies on quality of life capture important aspects of the experience of breast cancer, we believe that narrative studies are able to illuminate more subtle meanings of women's subjective experiences, as discussed below.

In this paper, we discuss findings from a narrative study that explored the way that women with breast cancer made sense of their experiences within their life story and reflect on these findings, in relation to the provision of support services for them. After an introduction of narrative approaches to studying life with a serious illness, we introduce the notion of liminality, a fundamental concept in our study. Finally, we discuss the implications of these findings for counselling practice.

In recent years, narration has been recognised as a ubiquitous psychological and social process, and the study of narratives has been used to investigate the links between experience, meaning, social structure and cultural context (Polkinghorne, 1988). Narrative psychology has influenced the study of serious and/or chronic illness within different disciplines, such as health psychology, medical sociology, medical anthropology and nursing (Avdi & Karamba, 2010). In this literature, several researchers have focused on the function of illness narratives in the process of identity reconstruction that may be triggered by traumatic experiences, such as a life threatening illness (Bury, 1982; Charmaz, 1983; Crossley, 2000b; Mathieson & Stam, 1995). Illness narratives are considered particularly important, as they provide the means through which patients can talk about what it means to live with the illness, have their story witnessed by others, and make sense of the effects of the illness on their life (Hydén, 1997; Riessman, 1993, 2008). Therefore, several qualitative studies on the experience and meaning of breast cancer have focused on illness narratives as a key notion. Next, the main trends within narrative research on the experience of breast cancer are presented, as well as the main findings of this literature.

The majority of narrative research on women living with breast cancer has aimed to explore the meaning of the illness experience by studying women's stories through phenomenological methods of analysis; these studies aim to identify the main themes that emerge in the women's stories, as a way of gaining access to their inner experience (Elmir, Jackson, Beale, & Schmied, 2010; Jensen, Bäck-Pettersson, & Segesten, 2000). One important finding of this research is that the meaning of cancer changes over time. More specifically, breast cancer is often initially experienced as a threat to life and brings to the fore awareness of one's mortality and vulnerability, often fuelling the need to act in ways to preserve one's life. Later, after the acute phase, breast cancer is often represented in women's stories as an experience that has led them to a process of revising their life and priorities; at this point, several women recognise both positive and negative implications of the illness on their life and self (Arman & Rehnsfeldt, 2003; Berterö & Chamberlain-Wilmoth, 2007; Lam & Fielding, 2003; Sadler-Gerhardt, Reynolds, Britton, & Kruse, 2010). This process has also been studied through the concepts of benefit finding and post-traumatic growth (Bellizzi & Blank, 2006; Bellizzi et al., 2010; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Helgeson, Reynolds, & Tomich, 2006; Lelorain, Bonnaud-Antignac, & Florin, 2010).

Another body of narrative literature on the experience of breast cancer focuses on the structure of narratives and often utilises the notion of biographical disruption. This is a term that is initially introduced within the context of
chronic illness (Bury, 1982) and refers to the catalytic effects of chronic or serious illness on an individual's taken-for-granted beliefs, assumptions and behaviours. Biographical disruption is thought to implicate a need to reconstruct one's life story and repair narrative identity. Findings from studies with breast cancer patients that make use of this concept confirm the hypothesis that breast cancer can lead to biographical disruption, particularly in the initial stages (Karamba, 2009), although these effects may also be discernible many years after the diagnosis (Thomas-MacLean, 2004). On the other hand, there is evidence that not all women construct the meaning of their illness in terms of a biographical disruption (Hubbard & Forbat, 2012; Karamba, 2009; Thomas-MacLean, 2004).

Another group of studies that focus on structure of narratives use the concept of narrative types. According to Frank (1995), a narrative type refers to “the most general storyline that can be recognised underlying the plot and tensions of particular stories” (p. 75). Central to this concept is the view that, although the stories that patients narrate are deeply personal and reflect their individual story, they are constructed through the cultural and linguistic resources that are available in the person’s particular sociocultural context. Frank (1995) identified three main cancer narrative types in industrialised Western societies, which he termed: restitution, chaos, and quest narratives, respectively. Restitution narratives represent illness as a temporary disruption to life and emphasise the return to health, to “normal life” and to one’s pre-illness identity. Chaos narratives lack structure and temporal ordering of events, are thought to be associated with non-integrated or traumatic experiences, and often express vulnerability and futility. Quest narratives construct illness as an opportunity for personal development and growth and are currently culturally preferred core narratives. Research using this typology to study the experience of breast cancer is limited, but the studies that have been conducted from this perspective have generally confirmed these narrative types in breast cancer patients’ talk, although the need for further investigation has also been emphasised (Howard, Bottorff, Balneaves, & Grewal, 2007; Karamba, 2009; Thomas-MacLean, 2004).

Furthermore, some narrative research has approached illness narratives primarily from a sociological perspective. These studies have illustrated an important shift in the social representations of breast cancer, as a result of increased awareness about the illness and of cancer-related activism; this shift entails a change from the construction of women as “victims” to that of breast cancer “survivors” (Klawiter, 2004). Notwithstanding the many positive effects of this cultural shift, it has been argued that the focus on survivorship may itself be limiting and may function to conceal the hidden losses and difficulties associated with the illness (Kaiser, 2008). At the same time, there is evidence that former social representations associated with the stigma of cancer still exist (Thorne & Murray, 2000); this may be particular pertinent in Greece (Anagnostopoulos & Spanea, 2005), as compared to other European countries, given the relatively limited presence of cancer-related activism, as well as the fact that cancer healthcare is very much centred in biomedical approaches.

Finally, there is a handful of narrative studies where the experience of living with breast cancer has been investigated in relation to the notion of liminality. In our opinion, this concept deserves further attention, as it captures the complexity and tensions of the experience of living with cancer, from the initial stage of diagnosis to years later. As we will discuss later, we also consider it a useful concept for healthcare workers, counsellors and policy makers. Before turning to our study, we introduce the notion of liminality.

Liminality: Life in Between

Liminality is a concept originally developed within social anthropological research on rites of passage. More specifically, Van Gennep (1960) proposed that in traditional rites of passage, the person passes through a three-phased process: separation entails a distancing from the rest of society and is a phase during which the person
is prepared by purification; in transition the person has left his former status behind, but has not yet entered the new status. This is the liminal phase. The final phase, aggregation, refers to the process during which the person is accepted into his social group as a member of the new status. So, liminality reflects the cultural processes through which a person moves from one social position to another, within a local context.

To date, the notion of liminality has been studied in relation to the experience of physical disability (e.g. Harrison & Kahn, 2004; Murphy, Scheer, Murphy, & Mack, 1988; Willet & Deegan, 2001), the experience of chronic illness, such as kidney disease (Molzahn, Bruce, & Sheilds, 2008) and chronic pain (Honkasalo, 2001), and in the context of prevention screening for cervical cancer (Forss, Tishelman, Widmark, & Sachs, 2004). In these studies, the notion of liminality highlights the way people find themselves in spaces where ambiguity is prominent and can result either in alteration of their social status, or in social isolation. Within the literature on the experience of cancer, liminality was first proposed by Little, Jordens, Paul, Montgomery, and Philipson (1998), in their attempt to interpret their findings with regards to patients diagnosed with colon cancer. They suggested that patients with a serious or chronic illness enter into a state of liminality from the moment of diagnosis, and that this state can continue for the rest of their lives. They describe liminality as a process which initially is an individual’s attempt to deal with the disruption of life after the illness incidence and, later on, a continual adaptation to illness by constructing its meaning through narrative. They suggest that people diagnosed with a chronic or life threatening illness do not necessarily pass through three clear phases, as described originally by Van Gennep (1960), but rather that liminality is experienced as an enduring state. Little et al. (1998) found that individuals with a serious and or chronic illness enter a state of liminality, which tends to proceed through two phases: that of acute and of sustained liminality. Liminality was seen to be reflected within three narrative themes, namely “cancer patientness”, “communicative alienation” and “boundedness”. The authors argued that, although the specific features associated with each theme change over time, liminality remains as a fundamental aspect of life with cancer, throughout the patients’ life. More specifically, cancer patientness refers to the immediate impact of the cancer diagnosis and its main features relate to confrontation with mortality and an associated urgency to act. At a later phase, cancer patientness is reflected in a persistent identification as a cancer patient, regardless of the time elapsed since treatment. Communicative alienation is initially reflected in the belief that others, who have not been diagnosed with cancer, cannot really understand or empathise with the patients’ situation, especially the associated physical pain and the traumatic aspects. At a later phase, this theme is related to a broader state of alienation, which can take the form of distancing from others and alienation from social settings as the result of being a cancer patient. Finally, boundedness in the acute phase of liminality refers to a need to change one’s life in order to follow medical treatment and the subsequent relinquishment of important social and professional roles; this is often associated with a sense of loss of control. At a later stage, boundedness takes the form of existential constraints as the patient experiences uncertainty about the future and fear of death. Liminality describes an experience characterised by ambiguity, conflict and tension, and is in contrast to the societal emphasis on positivity and the need to return to normalcy after cancer (Little, Paul, Jordens, & Sayers, 2002; McKenzie & Crouch, 2004).

Based on the research to date, it is not clear whether the experience of liminality in breast cancer is chronic, i.e. that one’s sense of self remains “suspended” forever, as Little et al. (1998) have suggested, or whether individuals eventually shift into another state beyond liminality (Blows, Bird, Seymour, & Cox, 2012). A few studies provide evidence for such a shift to return to ‘ordinary life’, without the ambiguity of liminality (Crouch & McKenzie, 2006; Scott, 2014). Also, it is not yet clear whether liminality is associated with specific demographic or illness factors (Scott, 2014). More generally, although the concept of liminality is useful, in expressing the ambiguity and uncer-
tainty that is often experienced in cancer, these are issues that remain unexplored in the limited number of relevant studies.

Summarizing, in breast cancer experience, creating a narrative about ones' life enables the person to attribute meaning to their experience. The majority of narrative studies tend to find that the construction of breast cancer meaning is a dynamic process and is often characterised by tensions and contradictions. For some women, the illness acquires positive connotations, whereas for some others is associated with negative changes in identity. Also, the biographical disruption that occurs as a consequence of the illness is evidenced in most illness narratives, but there are findings that imply that for some patients this is not an issue. Furthermore, a small number of studies have proposed that the illness experience may be better understood as a continual process of living in liminality. Thus, although there is an increasing interest in exploring the meaning of breast cancer through a narrative framework, there are several issues that need further investigation and theoretical elaboration. This study aims to explore the ways that women diagnosed and treated for breast cancer made sense of their experience through construction of illness narratives.

**Method**

Fifteen women, who had been diagnosed with breast cancer at least one year earlier, participated in the study. Inclusion criteria included a diagnosis of breast cancer at Stages I-III and no recurrence at the time of the study. The women were invited to participate in the study by the first author at a large urban hospital in Greece. The research material was collected through narrative interviews. The interview guide was based on the protocol presented by McAdams (1993, as cited in Crossley, 2000a) and aimed to facilitate the creation of a narrative about the participant's whole life (Crossley, 2000a; Lieblich, Tuval-Mashiach, & Zilber, 1998). The following instruction was initially given to each participant: “Let's start thinking about your life as it was a book. Could you divide this book in chapters and give a title to each one? There is no right or wrong answer. I am interested in the way you see it.” The construction of one's self narrative in the form of a series of chapters in a book was selected, as it provides the researcher with information about the place that an event, in this case cancer, has in the participant's whole life story. This was decided following a series of eight pilot interviews, in which we noticed that the women's talk focused almost exclusively on medical details of their illness. According to Crossley (2000a), narrative interviews, like the one selected, enable the interviewee to place her life story in a temporal dimension and accentuate the important events in every phase of life, as represented by each chapter. Moreover, it is assumed that the process of narrating one's life in a temporal order can enhance the narrator's sense of personal continuity and narrative coherence, thus potentially helping the person process his or her experience. It could be argued that such a method of data collection may artificially “enforce” order in the self-narrative produced and this indeed may be the case. In our corpus of data, however, we noticed that several women did not produce overly ordered narratives and several narratives were characterised by tensions, conflicts and contradictions, as discussed below.

Several different analytic concepts were used to analyse the women’s narrative in terms of both their content (i.e. in terms of the main themes that comprise the stories) and their structure. Based on Crossley's (2000a) narrative analytical method, we explored the narrative tone, i.e. if a story is optimistic or pessimistic, and also reflected on the place of the illness in the narrator's life course. We also used the holistic content analysis, proposed by Lieblich et al. (1998), to identify the recurring narrative themes in each story and the holistic form analysis to identify the main plot in each narrative. Next, narratives with similar plots and themes were grouped together and we explored
the main narrative types, drawing upon Frank's (1995) work. In the final stage of the analysis, we constructed a “meta-narrative” (Riessman, 1993), in other words our own narrative about the meaning of the experience of breast cancer, based on the women’s stories.

In brief, the analysis pointed to four basic narrative types that women constructed when talking about their illness experience. In the first narrative type, breast cancer is represented as a challenge and an opportunity for significant personal change, and consequently, the women’s sense of self is improved or expanded as a result of their illness. In the second narrative type, breast cancer is represented as a parenthesis in the women’s life and they talk about returning to their former “normal” self. In the third type, breast cancer is represented as introducing women to a state of liminality, and the women talk about their sense of self oscillating between a return to prior state and a new state after the cancer illness. In the fourth narrative type, the story of the women’s illness does not occupy an important place in their life narrative, but instead, is integrated into the broader context of their life story as one of other life events; correspondingly, their sense of self remains untouched by the illness. In our sample, no narrative type emerged as dominant; more specifically, the first, second and third narrative types were used primarily by four participants each, whilst the fourth was typical in three participants' talk (for a full discussion of the findings, see Koutri, 2013).

In this paper, we focus on the third narrative type, associated with entrance to a state of liminality. The main reason that we decided to focus on this narrative type is that only a few studies have discussed or explored the utility of liminality as an interpretive concept in breast cancer experience, leaving several issues unexplored (Blows et al., 2012). Moreover, we would argue that recognizing and understanding this particular narrative type is very important for counselling women with breast cancer, as liminality is a socially non-preferred meaning (Little et al., 2002); this means that women whose stories take this form face the risk of finding themselves alienated or silenced. Next, we present the main features of this narrative type and then discuss its implications for healthcare and counselling.

Results

Four participants, Areti, Helene, Efstathia and Stephania1, constructed their illness as an event that led them to a state of liminality. The main plot in these narratives is that breast cancer leads to disruption in the women’s life and brings to the fore the need to reconstruct their life story and identity, in order to restore order and coherence in their life narrative. The distinctive feature of these narratives, in contrast to other narratives that were associated with biographical disruption, is that the process of biographical reconstruction is characterised by a constant tension and contradiction between the feeling that life continues as normal and the feeling that the illness is still very much present in their lives. We investigated whether specific factors (such as age, time since diagnosis, cancer stage and life context) are associated with this particular narrative type, but were unable to find any clear association. Future research exploring the role of demographic, cancer-related and life context-related factors on the construction of this narrative type, would be useful.

In this type of narrative, women’s efforts to place their experience of breast cancer into their past are not effective because of concerns that remain even years after diagnosis. In this study, these concerns were associated to the altered body following mastectomy and the fear of cancer recurrence. Although the women reported that their
health had been restored after treatment and that this amounted to a return to the normal flow of life, the two aforementioned issues appear in a way that renders full restoration of normalcy impossible.

Below, we use excerpts from two participants’ accounts to illustrate these findings. Interviews were conducted in Greek and the following excerpts have been translated from the original text.

**The Altered Body: “I Am the Same, yet Different”**

The importance of the altered body, following treatment for breast cancer, in creating a sense of identity, continuously oscillating between a prior identity and a state after illness, is evident in two women's accounts. Helene and Areti had both undergone mastectomy and had not proceeded to breast reconstructive surgery. A point made by both women is that the loss of their breast remains a source of discomfort years after the surgery and that reconstruction (i.e. fully returning to one's previous self) remains an “open” issue. Similar findings have been reported in other qualitative studies on the experience of breast cancer (Avdi, Ziliaskopoulou, & Roussi, 2012; Ziliaskopoulou, 2010).

In the extract below, Helene – 52 years old, married and diagnosed with cancer Stage III two years previously – refers to her feelings of when she had to appear in public for the first time after the mastectomy. She states that losing a breast is like losing a part of oneself; feeling different, ashamed about her differentness and fearful of being stigmatised, are dominant issues in her talk. As is shown in the following extract, Helene compares herself to people with visible disabilities, who have lost a part of their body.

Why does someone with a leg missing, an arm missing,
Come out in public?
I am the same, too!
Say that I have a missing arm or leg.
This is how I thought about it,
Yes.
I did not pay any attention to anything and to anyone.

After that I went out, normally.

This extract illustrates some elements of the experience of embodiment in breast cancer. We approach embodiment from a phenomenological perspective, in the sense that we use the term to denote a perspective through which the body in illness is considered not only as a material object that suffers from a disease but as a fundamental part of identity (Yardley, 1997). Moreover, the body is associated with cultural messages; for example, the integrity and symmetry of a body is associated with what is culturally considered as “normal”. Within this framework, an altered appearance has a direct impact on one’s identity and status. From our point of view, Helene's feelings of difference and stigmatisation are embodied experiences, as her experience of an altered body, lacking integrity and symmetry, is not just a matter of change in physical appearance (“how do I look?”), but also a matter of change in embodied identity, as expressed through her physical appearance within her social world (“who am I now that I have this body and how do others see me?”). This is in line with others findings in phenomenological studies.
that have shown that the experience of mastectomy affects the woman’s embodied identity, and tends to be specifically associated with feelings of differentness with regards to sexuality, femininity and disability (Avdi et al., 2012; Thomas-MacLean, 2005).

Over time, Helene seems to have constructed an identity of a woman like other women and found ways to negotiate her stigmatised status, such as, for example, through humour [e.g. later in the interview she states “I don’t care about going out, ... at some point I even started to joke about it”]. It seems that the meaning of breast loss was transformed over time for Helene as she became increasingly able to integrate it in her identity (Yoshida, 1993). This process, however, seems to be incomplete, as Helene expresses her difficulty to find a new identity in her sexual relationship with her husband, as illustrated in the extract below:

After –

The first ye–

Since last year and until now, thank goodness everything is fine,

There was no problem, no –

A problem that I have,

It is the theme –

Sexual contact.

Hmmm, since the surgery

I have had contact with my husband only once.

I feel so uncomfortable,

I feel so –

While all day I say to myself “Tonight!”

Mmm, then, I stop.

My only problem is this.

In the above extract, Helene’s account about her breast loss seems to be related primarily with her sexual identity, rather than her whole bodily self, as in the first extract. However, it seems impossible for Helene’s life to be exactly as it was before. Breast loss for Helene seems to be associated with an inner conflict and a sense of confusion. This is reflected in her talk in the above extract, which has many pauses and hesitations that make it difficult to follow. In the above extract, her desire to return to her prior self is inhibited by a tangible and visible material fact, which is the loss of her breast. This conflict around sexual activity seems, however, to be the only issue she is still facing as a result of mastectomy.

We would argue that the disruption in her sexual identity and the continuity of identity in other areas of her life lead the narrator to a contradiction. She experiences herself like a “half person”, as she herself states, but at the
same time, she sustains that she can experience herself as a “whole person”, a “normal person”, in social settings. It seems that Helene is oscillating between different meanings concerning her bodily appearance and her sense of self as a woman, depending on the context (Manderson & Stirling, 2007; Thomas-MacLean, 2005). Therefore, her narrative reflects a tension between a representation of the illness as something that has not changed her identity, on the one hand, and as something that has led to a radical transformation in her sexual identity, on the other.

Other narrative studies on the experience of mastectomy report similar findings regarding contradictions, conflicts, ambivalence and complexity in the construction of the meaning of breast loss (Crouch & McKenzie, 2000; Manderson & Stirling, 2007; Thomas-MacLean, 2004, 2005), without, however, making use of the notion of liminality. For example, Thomas-MacLean (2004), in her study of women's narratives who had undergone mastectomy but not breast reconstruction surgery, concludes that the notion of a restitution narrative seems misplaced in the case of mastectomy, as the body is never the same after cancer. The author suggests replacing the term "restitution narrative" with that of a “reconstruction narrative”, as the latter reflects more accurately the complex meaning of women's experience of mastectomy. We would suggest that findings regarding such contradictions in meaning and identity with regards to mastectomy are better conceptualised by the notion of liminality (Ziliaskopoulou, 2010).

The Fear of Cancer Recurrence: “If I Live Next Year…but I Do Make Plans”

The uncertainty associated with the unpredictable and life-threatening trajectory of breast cancer is something that arguably characterizes this illness (Arman & Rehnsfeldt, 2003; Knobf, 2011). Although some women find it relatively easy to address their concerns about possible recurrence, for others, the uncertainty associated with the possibility of recurrence makes return to normal life impossible. In our study, two participants’, Stephania and Efstathia, accounts represent their illness as a point of entrance into a state of liminality, as they talk about the issue of the uncertainty of illness and the deeply seated association between cancer and mortality. Below, we present a characteristic extract from Stephania’s account (Stephania is 58 years old, married, diagnosed with breast cancer Stage II two years previously, and had undergone breast conservation surgery).

At the moment

Thank God!

Thank God!

I am as I was before surgery.

I still haven't got over the fact that I am faced with a d_

I am faced with a deadline, so to speak,

I haven't got over it.

Inside me nests… the fear,

The doubt.

A little later in the interview, she goes on to explain the meaning of “doubt” for her:

Now it is the dou–, the–, the doubt.
That you do not know what will happen to you.

The uncertainty,

That is the thing that kills you,

The uncertain progression of the illness.

If I had any other illness,

A heart condition,

You have surgery,

You say “I had surgery,

From now on I will do what my doctor says

And I’ll be just fine”.

But now it does not depend on me!

The progression of the illness does not depend on me!

It’s not something that I can do, and I’m not doing.

That’s it!

In Stephania’s account, breast cancer is contrasted to other life-threatening illnesses; she points out that what makes cancer different, in comparison to other chronic illnesses, is the association of cancer with death and mortality (Titter & Calnan, 2002). The phrase “uncertain progression” implies that uncertainty remains, regardless of the absence of illness “at the moment”. The above contradiction in her account, between the absence of physical illness and the presence of fear of recurrence, implies the existential disruption, i.e. a disruption of the sense of continuity of identity (Little et al., 2002).

It is interesting to note the role of medical perspective on managing uncertainty and her “doubts” about the future. The medical discourse appears in Stephania’s account, both more broadly and specifically in relation to her fear of recurrence, as shown below.

He [the doctor] said to me

The first three years are the most dangerous.

“Of course”,

He tells me,

“The first year is the most dangerous”,

... as time passes,
We remove –

Of course, to be 100% sure,

Five years need to have passed.

Medical knowledge is used as a guide for Stephania to navigate her life, given the uncertain illness trajectory and provides her with some sense of control. The temporal horizon of five years provides her with a perspective that this situation will end at some defined point. In other words, she uses it as a way of managing the uncertainty and the disruption of her identity in relation to her future (Little et al., 2002). Until the time marker of five years, Stephania continues to live, but lives with a “deadline” in mind, uncertainty about the future and existential anxiety. In the above, the concept of “boundedness” in time (Little et al., 1998) is prominent. Therefore, it seems that the biographical reconstruction is characterised by a fundamental inconsistency, where returning to normal flow of life coexists with the constant presence of illness in the women's life.

Similarly, another participant, Efstathia seems to have succeeded, as she says, in restoring biographical continuity, to a certain extent. However, the restoration of a sense of continuity coexists with the uncertainty associated with the very nature of cancer. Efstathia is 55 years old, married, was diagnosed with breast cancer Stage II five years previously, and underwent mastectomy and breast reconstruction surgery. The following excerpt from her account illustrates this:

In the early years –

Since the surgery and after that –

I didn't want to make plans for the future.

I used to say “I do not know what tomorrow will bring to me”

Now I do make plans,

But deep inside my mind I try to hold back

Because the time com–, the time comes when I say:

“If I live next year”

Do you understand?

While ...but I do make plans.

Based on the extract above, we can see a tension between two opposing forces in Efstathia's account, a force that pulls her back into life and one that constantly reminds her of the possibility of death. Similarly to Stephania, “boundedness” in time (Little et al., 1998) is an issue that arises for Efstathia too. Fear of recurrence seems to be a barrier in reconstructing her time orientation to the future and so, the process of making sense of the illness is in a sense impeded, leaving the woman in a state of liminal or incomplete meaning with regards to the future (Little et al., 1998). Little et al. (2002) argued that in cancer survivorship, existential tensions are present and often are associated with the disruption of “future memory”. They use the term “future memory” to describe an element of personal identity, which involves an act of imagining ourselves in the future, taking into account all our past
experiences; this memory is profoundly disrupted in cases of extreme experiences, such as cancer diagnosis (Little et al., 2002). In other words, the disruption in Efstathia's ability to project herself to the future, may be interpreted as a disruption in future memory that puts restrictions to her future planning, but simultaneously, calls for an attempt to repair this disruption, as evidenced in her statement "but I do make plans". This is a representative quote of the existential tension involved in the experience of herself in a liminal state, as fear of recurrence, alongside with the issue of mortality, continually disrupts her attempts to restore her time orientation to the future.

**Discussion**

The findings of our study suggest that liminality may be considered as a new narrative type, in the context of breast cancer research. This narrative type differs from others that have been described in previous studies on cancer experience (Frank, 1995; Howard et al., 2007; Karamba, 2009; Thomas-MacLean, 2004) and centres on the recognition that women with breast cancer may enter a new state of identity following diagnosis and for several years later. In this state, their sense of self oscillates between a return to prior state and a new state after the cancer illness. We believe that the recognition of this narrative type is important for our understanding of the meaning that breast cancer holds for individuals, as it seems to capture an element of the experience that other narrative types, in the literature to date, seem to leave out. This particular experience illustrates that for some women a completely return to previous “normal” life trajectory is impossible, as the illness remains implicitly present, even for years after diagnosis. This finding is in line with and can elaborate on findings of previous research, as discussed below.

In Thomas-MacLean's (2004) research, some of the participants who had undergone mastectomy described an experience where they simultaneously felt the same as before, and different. They specifically referred to the loss of their breast, which was impossible to undo or disguise through wearing a prosthesis or through breast reconstruction surgery. Ziliaskopoulou (2010), in her phenomenological study with Greek women who had undergone mastectomy, suggests that the state of identity characterised by a sense of differentiation and disability after breast loss may be better interpreted by the notion of liminality. In another study with breast cancer survivors, some women asserted that a return to “normal life” is impossible, as they have permanently changed, because of the fear of recurrence (Allen et al., 2009). In general, we suggest that liminality is a notion with potential to encompass all narratives characterised by ambivalence, contradiction and oscillations between past and present aspects of self.

We would argue that findings from research on breast cancer survivors' quality of life generally support our argument about the usefulness of the concept of liminality. For instance, several studies have reported that, although the overall quality of life for breast cancer patients improves after the completion of treatment and tends to reach levels similar to the general population, references to physical problems related to the cancer treatment and fear of recurrence remain high for years (Mehnert, Berg, Henrich, & Herschbach, 2009; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005; Vickberg, 2001). This is in line with the concept of liminality and the observation that for some women life can and cannot be the same after breast cancer, as they are able to repair certain aspects of their (narrative) identity, but not others. In addition, liminality can be used to provide an integrative, interpretative and more holistic model of the experience of breast cancer.
The concept of liminality, as developed in this paper, has some similarities with other notions developed in the fields of disability, chronic health and mental health issues, and primarily, with the recovery being associated with a process of “living with” one's symptoms. Further theoretical and empirical work needs to be done in order to clarify the relationship of liminality and similar concepts. However, based on our analysis, we would argue that certain elements of the experience of breast cancer are unique, in comparison to other chronic conditions, primarily the existential anxiety and fear of death, which emerged in our data through reference to uncertainty about the future and the fear of cancer recurrence.

Finally, we would like to stress that, although this narrative type is characterised by constant contradictions, it retains its coherence. It is for this reason, that we did not identify these narratives in our analysis as chaos narratives, as described by Frank (1995). We assume that the situation described as liminality is not associated with incomplete meaning or a lack of meaning (a situation which would probably leave women in a state of chaos), but that it constitutes a different way to talk about illness experience. One of the strengths of narrative psychology is that it allows us to recognise that a situation characterised by contradictions does not necessarily reflect problematic meaning making or a chaotic narrative (Frank, 1995).

Implications for Counselling

Despite the small number of studies that utilise the concept of liminality, it is a notion that seems useful in understanding cancer patients' experiences in complex and subtle ways (Blows et al., 2012). It is important to stress that it reflects cancer patients' state that has not yet been represented within mainstream cancer discourses. The suspended self, between the need for continuity and the call for changes embedded in extreme experiences, such as the incidence of cancer, is usually not included in the preferred cultural narratives (Little et al., 2002). Frank (1995) argues that one of the constraints of illness narratives is that they highlight the concept of rehabilitation and promote a narrative based on the return to one's previous “normal” life. This “moral imperative” may function to suppress the emergence of issues related to uncertainty, which is a major concern for many patients during the period after treatment (Cappiello et al., 2007; Holland & Reznik, 2005). Thus, there is a group of people, named by Frank (1995), the “remission society”, who are affected by serious illness, have subsequently been treated for it, but are not cured, in the sense that the illness continues to somehow be present in their lives. This continuous presence is reflected in mild physical symptoms associated with the illness itself or the side-effects of therapy, as well as in the form of fear of recurrence. Indeed, several studies point to the suggestion that contradictions and tension is a key feature in cancer experience that should be taken into account in the cancer survivor discourse (Allen et al., 2009; Kaiser, 2008; Little et al., 2002).

Moreover, the limitations imposed on patients by our society's emphasis on the shift towards positive thinking has been argued to amplify the experience of liminality in cancer survivor's narratives (McKenzie & Crouch, 2004). Patients may come to feel a moral obligation to emotionally protect others from being confronted by serious illness and the prospect of infirmity, dependence or a limited time-span, and consequently, construct their illness narratives in such a way as to avoid dealing with issues concerning death. This has been described as patients being led to play the role of emotional caregiver to closed ones, trying to alter their own feelings, remain optimistic, master their negativity and present a “normal” self, in order to preserve their intimate relationships. This, however, conflicts with feelings of anxiety or frustration that accompany the uncertainty and anxiety associated with illness. As a result, they often feel unable to maintain the desired positive attitude and may come to feel alienated and lonely (McKenzie & Crouch, 2004).
The knowledge that breast cancer patients, after the completion of treatment, may enter into a particular state of liminality may be extremely helpful for professionals in counselling in several ways. Most importantly, the recognition, on behalf of healthcare professionals, of the contradictions inherent in the meaning of cancer for some women, which lead them to feel “suspended” until the five year marker or even beyond that, can play an important role in facilitating communication between patients and professionals and in forming a healthcare system oriented towards patients’ needs (Blows et al., 2012). Studies on patients’ views about what is helpful for them in their contact with professionals show that patients identify the creation of conditions that enable them to tell their story, attribute meaning to their illness experience and feel that this is acceptable, even if it differs from the meanings expressed through the dominant breast cancer discourses (Collie & Long, 2005). Furthermore, the finding of four different narrative types in our broader study that emerged from the participants’ stories leads us to the conclusion that the promotion, by health professionals, of a specific meaning for the illness is limiting, restrictive and possibly misguided. In contrast, in our opinion, health professionals need to keep a critical attitude towards the implicit view that it is necessary for patients to reach a positive outcome as a result of the process of meaning-making of their breast cancer experience.

Moreover, recognizing the experience of liminality is important as it foregrounds the central role of bodily experience in illness. Embodiment is often sidestepped in narrative studies of illness, which generally focus on issues of identity and context (Frank, 1995; Kleinman, 1988; Little et al., 1998). In this paper, we discussed the way mastectomy may affect women’s identity through the changes it causes in their physical appearance. Therefore, counsellors may need to work towards enabling women to share their concerns about their new self in an altered body or about sensitive topics, such as sexual functioning.

Also, our findings indicate that liminality is intimately linked to existential concerns regarding death, as fear of recurrence is closely associated with mortality. In such cases, we suggest that counselling oriented or addressing existential issues might be particularly helpful for patients. This may be particularly important, given the difficulty many patients experience in sharing such feelings and concerns with the important people in their life, a situation that can lead to a sense of alienation and loneliness (Arman & Rehnsfeldt, 2003). Moreover, it is worth mentioning that when examining the meaning of liminality through a broader cultural context, it has been argued that the reference to such experiences as problematic is the product of modernity. Several authors have argued that in recent times, in the West, illness is represented as an aberration in one’s life course, often experienced as an intrusion by some untoward force rather than a part of life (Little et al., 1998). It has been argued that in pre-modern societies, people counterbalanced the risk and uncertainty of life by relying on certain aspects of social life, such as tradition, religion and family ties (e.g. Crossley, 1999; Giddens, 1991). The weakening of these cultural resources is arguably associated with a cultural shift which frames liminality as problematic. It is interesting to note that from an existential perspective, liminality is considered the “right” way to live one’s life, as the anxieties of death and non-existence can motivate the person to live his or her life with authenticity (Little et al., 1998).

Furthermore, the attempt to highlight the complexity of meaning-making in breast cancer through narrative research can contribute to creating healthcare policies which focus on the psychosocial needs of cancer patients in Greece. The focus of this study on participants’ perspectives of living with illness reflects their perceptions about what it means to live with breast cancer and highlights the different ways that patients talk about this. Drawing on our findings, it seems crucial that the biomedical community considers cancer as a psychosocial problem that concerns not only physical health but also affects, to a greater or smaller degree, women’s identity on multiple levels. The impact of illness on one’s life seems to start with the diagnosis and can continue for several years after the com-
pletion of treatment. Therefore, this research underscores the importance of planning appropriate counselling intervention programmes for patients with breast cancer, with an aim to foster the meaning-making process, whenever needed. The design of women's support programmes aimed at facilitating the process of meaning-making through the use of narrative techniques may prove useful. In Greece, this need is even more pressing, as breast cancer patients' psychosocial care is in its infancy compared to other European countries.

Conclusions
The findings of our study suggest that liminality can be considered as a new narrative type in breast cancer. Notwithstanding the insights that this study has provided, it is worth noting its limitations. Firstly, there is a limit to the generalisations that can be made, that is based on a relatively small sample. Designing quantitative studies with bigger samples would enhance these initial findings. Also, future research concerning women's experience of liminality would benefit from an exploration of factors that may be implicated in the construction of illness in this particular way. Another limitation of our study relates to the fact that participants were interviewed only once, and this makes it impossible to examine the way that the meaning of illness changes over time. Similarly, this study design cannot shed light on issues around the duration of sustained liminality (Crouch & McKenzie, 2006; Little et al., 1998). Further, several questions about the utility of the notion of liminality in understanding the experience of other types of cancer with different prognosis, need to be answered. We hope that this study would trigger further exploration of Greek women's experiences of breast cancer, as the relevant research is still limited (Avdi & Karamba, 2010; Avdi et al., 2012; Karamba, 2009).

Finally, based on our findings, the development of counselling programmes for women with breast cancer may help them integrate their illness experience into their lives, even when there are contradictory and ambivalent meanings. It is crucial for counselling psychologists to understand that liminality is an alternative narrative type, which reflects women's illness experience that is not contained within dominant cancer discourses. Furthermore, we believe that accepting the fact that liminality is not an "abnormal" state of self, but a way of living with breast cancer, would contribute to the development of more patient-centred care.

Notes
i) Pseudonyms are used to preserve participant anonymity.
ii) It is worth noting the interviews were transcribed using a method proposed by Gee (1986, 1991); this transcription method aims to capture and reflect the poetic features of language use and is used to provide the "feel" of talk in a vivid way. Briefly, changes in tone and the pace of the narrative are used to divide the text into lines, which are then placed into a stanza, i.e. a larger unit of analysis concerned with a specific topic. This method is often used in structural narrative analyses (Riessman, 1993, 2008).

Funding
The authors have no funding to report.

Competing Interests
The authors have declared that no competing interests exist.

Acknowledgments
We are indebted to all the women who participated in the study.
References


