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Social Work, Cancer Survivorship and Liminality: Meeting the needs of young women diagnosed with early stage breast cancer.

Introduction

Breast cancer is the most commonly diagnosed cancer in women with an estimated 1.67 million diagnosed cases in 2012, but ranks 5th as the cause of death because of the relatively favourable prognosis (Ferlay et al:2015:386). A woman who has been diagnosed with breast cancer, like other people diagnosed with a life-threatening illness "often experiences the diagnosis of cancer as a near-instantaneous destruction of the basic premises underlying her life: that she is healthy, that she is safe; that the world is, pretty much, a place where she can get up in the morning and go out into her day and count on coming home the same person at the end of it" (Auchincloss,1995:2118). A traumatic event challenges people's beliefs that the world is a meaningful and comprehensible place, and studies suggest that long-term survivors can experience posttraumatic effects as a result of their cancer experience (Sumalla et al, 2009, Schaefer and Moos, 1998). Tomich et al (2002) comment that traumatic events can shatter an individual's sense of invulnerability and a diagnosis of cancer may permanently threaten perceptions of invulnerability, because after treatment finishes, the threat of recurrence still remains.

In order to ameliorate the profound effect that cancer has an individual it is necessary to explore how the illness has affected the individual as a whole. The predominant therapies that tend to be used in cancer interventions are the cognitive and behavioural approaches. These approaches are usually symptom focused and fit well within the medical system's philosophy of identifying and treating what is wrong in the present. Many patients however, may be able to cope with the immediate and function in a way that does not give rise to any obvious distress. As patients proceed through treatment however, many experience distress about issues that they never bring to their physician, and their distress continues beyond treatment (Andrykowski et al: 2000, Baum & Posluszny: 2001, Kangas et al:2002). The concept of denial developed from psychoanalytical roots with the emphasis on the pathological nature of the phenomenon to become a comprehensive expression of an adaptive strategy for protection against distressing events or feelings (Vos & de Haes, 2007). One of the major tasks of survivorship is to regain the ability to carry on, having faced one's mortality and lost the comfort of previous existing adaptive denial because although death is a reality for us all, adaptive denial enables individuals to get on with their lives and put that reality out of their minds (Auchincloss,1995). A cancer diagnosis however, destroys the adaptive denial and can leave the person with overwhelming anxiety, and difficulty in carrying out everyday activities. Bury (2001) discusses the concept of biographical disruption, where the diagnosis of cancer is unexpected and forces people to question their assumptions about their health and mortality. All of the women in this study were young women and all considered themselves healthy.

The adjustment to living with, or having had, cancer is multidimensional, involving emotional, cognitive, behavioural, physical and social features and this paper will discuss the implications for patient's as they traverse the liminal space from treatment to survivorship. The term liminality was first introduced to anthropology by van Gennep in 1909 when describing rites of passage. The concept of liminalty in this context refers to the quality of ambiguity or disorientation that occurs in the middle stages of rituals, when participants no longer hold their pre-ritual status, but have not yet begun the transition to the status they will hold when the ritual is complete. Stanton et al (2005) uses the concept of liminality when discussing people as they transition from 'cancer patient' to 'person'. Stanton et al uses the term ‘re-entry’ phase to describe the transition point from cancer patient to person, and point out that the challenges faced during this re-entry phase were often unanticipated, and many individuals feel unprepared to deal with them. Taplin (2016, p. 160) also describes the concept of liminality as a useful framework in order to further understand the dynamic processes of accommodation and adaptation that a person with cancer may be required to undergo.

This paper describes and discusses the findings of a PhD study and will explore the role of social workers in assisting people to traverse the liminal space from treatment to survivorship. Using the definition of psychosocial care as being “a whole-person approach to cancer care” (Turnbull Macdonald et al, 2012) this research is psychosocial due to its focus on the impact of the cancer diagnosis on the individual as a whole, for example how cancer effects how they think, feel, their ways of coping and their relationships. As Small (2001) notes, social work is ideally placed to help people who have been diagnosed with a life threatening illness given social work is used to dealing with loss in all of its dimensions. Social work is also concerned with exploring the experience of the individual within the wider context of family, community and society, and helping individuals manage change in their lives. The use of a narrative therapeutic approach will be explored, as a tool to assist and accompany people through the liminal space.

Study context

This study discussed below focused on the psychosocial needs of young Irish women who had been diagnosed with early stage breast cancer. Young women were defined as women who were premenopausal and /or under the age of fifty. This was in order to ensure alignment with existing medical oncology research which used these parameters in their definition of a young woman. Healthcare provision in Ireland has been shaped by the policies of successive governments which have resulted in a very particular mix of public and private care. The PhD study was carried out in a mixed public and private hospital in Dublin. In terms of oncology healthcare provision, Ireland has eight specialist cancer centres which are located and networked within each of the four Health Service Executive (HSE) administration areas. BreastCheck is the national breast screening programme which aims to detect and treat breast cancer in women who have no symptoms of the disease. The service is offered free of charge, and is offered to women aged 50-69.

Study Aim and Research Questions

The aim of the research was to explore the experiences of young women, who had been diagnosed with early stage breast cancer, as they transitioned from treatment to survivorship. In order to try to capture their lived experiences, the methodology adopted for the research was constructivist grounded theory (Charmaz, 2003, 2005, 2006).

The core research question of the PhD research was “What are the psychosocial issues of young women finishing treatment for early stage breast cancer?” Psychosocial in this context referred to the social, psychological, emotional, spiritual, and functional aspects of each woman’s journey as they finished their treatment for early stage breast cancer. Following from the primary research question, there were a number of subsidiary questions which were as follows:

- Do these young women have psychosocial issues that are unique to their life stage?
- Are there particular psychosocial issues associated with the end of treatment?

- Are there implications for social work practice when working with young women entering the survivorship phase?
- If so, how can social workers best meet the needs of these young women?

Sample and ethical considerations

The inclusion criteria comprised women under the age of 50 with a diagnosis of early stage breast cancer who were approaching the end of their chemotherapy treatment. Ethical approval for the research was granted by the hospital, and as part of this approval all potential participants were approached initially by a member of the medical or nursing team and given a brief overview of the research. If the person was willing to discuss it further, then they were approached by the researcher and given detailed information. Consent to participate was gained in written format, and verbally at the beginning of both interviews. Recruitment of the twenty-five participants was carried out over a seven month period.

A total of twenty-five women participated in a first interview, and twenty-two women participated in a second round interview. The profile of the participants with their pseudonyms is presented in **Appendix 1.**

Choice of method

A constructivist, grounded theory research method, using unstructured in-depth interviews (Bowling, 2005:379) was chosen meet the study aims. This allowed participant’s voice to be heard and emerge from the narrative. The advantages of unstructured interviews are that more complex issues can be probed, answers can be clarified and a more relaxed research atmosphere may obtain more in-depth as well as sensitive information. Authors such as Lee (1995) and Rubin and Rubin (2005) contend that the in-depth interview is an exceptionally sensitive and well-suited means of developing an intimate understanding of experiences best communicated through rich narratives and detailed examples, and Charmaz (2006: 25) notes that it is a useful method for interpretive enquiry.

Data collection and analysis

Two interviews were carried out with the participants, one towards the end of treatment and another six months later. The decision to use two interviews over a six month interval was in order to try to capture changes that occurred between the time of diagnosis and treatment and the end of treatment. Whilst there has been research focusing on the diagnosis and treatment phases for cancer patients, there is a more limited research on the end of treatment and the time immediately following that. The tape recorded interviews ranged in duration from fifty minutes to an hour and twenty minutes, with the average interview being approximately seventy minutes long.

The process of analysis began with each interview being transcribed verbatim. A three stage process began with line by line coding of the data without prior categories and by open coding, and then moved onto focused coding. Having carried out the line by line and open coding and then focused coding, it was possible for theoretical coding to happen. An example of this process is described in **Appendix 2**. Analysis of the data obtained from the interviews, theory construction from the data and from existing research resulted in four themes emerging as central to understanding the participant's experiences of their journey through breast cancer:

1. A year out of your life
2. Making changes and creating meaning
3. Living with fear
4. Who am I now and who will I be in the future?

Study limitations

One of the limitations of this research was the fact that the women were recruited from one hospital site only and were relatively homogenous in terms of ethnicity, socio-economic status and educational status.

Findings and discussion

A Year Out of Your Life

The strongest theme that emerged from the analysis of the data alluded to a sense of loss, a lost time in the woman's life, as this respondent put it, they could rationalise about the need for this time for treatment but the costs were hard to predict:

"She said it would be a year of my life – chemotherapy, surgery and then chemotherapy (so) I had always assumed it was just going to be a year of my life, where I'd have to tackle it and I could manage it, and I went about it on that basis. You know. But I hadn't quite realised how significant it was, what I had, really". (Jacqueline)

Whilst there is a need to give a positive message to women that early stage breast cancer was very treatable, this idea of a year lost often created anxieties or false expectations. One of the women described feeling as though her life was on pause, and she was waiting to 'press the play button' once treatment was over. Others found it a struggle between wanting to resume life as it had been, and realising that they would no longer be the same people. The study by Ivers et al (2009, p.23) found that cancer patients often felt let down by the health service's expectation that they could get back to normal without much assistance, and also by their families expectations of 'normality' once treatment was over.

It was only when Jacqueline started to reflect upon the impact that breast cancer would have on her life during this year that the full emotional, social and economic consequences became apparent:

"...just have to keep going during the process, and you haven't time to think about how it is affecting so many other aspects of my life?.......But then afterwards, in that period of reflection, you think, I can't borrow money, I can't get life insurance. I really can't move jobs now because nobody – I wouldn't get the disability cover I have now in the firm. So it has a whole load of ramifications which are unseen at first. And you only think about them subsequently".

This notion of transition has been described by Stanton et al (2005) as the liminal space where people transition from 'cancer patient' to 'person' as the 're-entry' phase, and point out that the challenges faced during this re-entry phase were often unanticipated, and many individuals feel unprepared to deal with them. Drageset et al (2016, p. 209) comment that returning to normal life was a highly motivating factor for recovery and an efficient way of coping with the situation. Professionals working with the women in this study appear to be of the same mindset using the description 'a year out of your life' for the process of diagnosis and treatment. Although this notion of 'year out of your life' may have helped to alleviated some anxiety in the initial stages, it would appear that unintentional harm may have been caused, as revealed in follow up interviews. As a consequence, most respondents highlighted a need to get to know the ‘new self’, post-treatment. The notion of only ‘a year out of your life’ implied that life would go back to where it had been prior to diagnosis and treatment, with no room to acknowledge and explore inevitable changes that had occurred. A hope that once treatment was finished that life would go back to the way it had always appeared to have been unattainable for the women and their social and family networks. As one commented:

“*So I would have changed a lot. I feel that strongly now…..but everybody else around me still perceives that I’m the very, very same*”. (Wendy)

Making changes and creating meaning

Some women tried not to stress so much about little things, to devote more time to themselves, or make life changes in terms of new educational or employment opportunities. This moment often marked with a sense of optimism, where changes were often framed in terms of having much clearer priorities for future life, as expressed in terms such as ‘living each day’ or ‘appreciating what I have’. In sum, these changes and matching expectations were variable, sometimes referring to immediate, medium and long term aspirations. The concept of post traumatic growth might be a helpful explanatory idea in this context (Sumalla et al, 2009), particularly in the event of unexpected or unintentional result of an adverse event and the consequent life changes. It appears that accommodation rather than assimilation processes are important in this respect. In the assimilation processes the trauma related information becomes incorporated within pre-existing schemas built around the world/others/self, the converse is the case with accommodation processes. By changing these schemas then accommodation of the new information regarding the traumatic event can occur (Sumalla et al: 2009). Dragseset et al (2016, p.208) found in their study that the women's cancer experience enhanced self –development by increasing their self-confidence and finding inner peace. For the majority of women in this study, this was also the case, though it is critical not to assume that all women will experience positive outcomes or outlooks on their lives. For a small number of the women interviewed, their diagnosis and treatment for breast cancer was a traumatic experience that did not yield increasing inner peace or positive life changes.

During her second interview Alexia reflected on the experience of cancer and what it meant for her. She commented that:

"You get an awful lot more philosophical from all of this, you're very aware of the life, more aware of life and death, more determined to get out there and do something with it and you just become an awful lot more philosophical and you talk…. I'd be quieter".

Alexia's reflection fits with what Nelson (1996) describes as 'expanding the present'. Her study of women diagnosed with breast cancer used this notion to explain how patients made sense of uncertainty; where living with the present and the moment were substituted for thoughts about the future: "…the women were choosing their life paths rather than being worried about what might happen to them in the future" (1996, p. 70).

Living with fear

Although breast cancer treatment has made significant advances in recent years and women treated for early stage breast cancer generally have an excellent prognosis, a cure cannot be assured. Fear of disease recurrence is one of the most prevalent long-term psychological consequences of surviving cancer (Van den Beuken-Everdingen et al, 2008). This fear was present in all of the interviews carried out with the women; notions of mortality were real and immediate. In this liminal space that personal, social and emotional change takes place, as Nelson (1996, p.63) noted in her study, "…uncertainty among the women living with breast cancer was a dynamic process that evolved from diagnosis to living with the disease". The fear of recurrence could surface in a woman's consciousness at any time when she connected to her past through symbolic representation. Such a process was evident in Helen's account of her recovery and fear of recurrence:

"It's not just 'Listen, you got sick and now you're better. Congratulations, off you go. See you, bye'. You're always waiting for the next sort of, I suppose, test. And the result of the test. You know? Because when you had your first mammogram you assumed that would be okay. And it wasn't. So, after all the treatment, you assume the next one – but there's a little doubt there. You expected the last one to be normal, why should I expect this one to be? What happens if it comes back on the other side?".

Fear was also expressed about the loss of the 'safety net' of the hospital, many women felt vulnerable when expected to take responsibility for the monitoring of their health having been dependent on professionals to carry out this role. Notions of fear were also differentiated by the type of process that led to the diagnosis. For example Jacqueline and Emer discovered their cancer by chance as part of a routine medical screening test organised by their employers. The fact that neither woman had suspected that there was anything wrong made them fearful that they may not be able to identify if they have a recurrence of their breast cancer. As Jacqueline put it:

"And I found – just the chance, just the luck, good luck or bad luck, or whatever you call it. It's just – there's no rhyme or reason to it, is there? I find that hard".

Emer seemed to sum up what the majority of women on expressing fears about being discharged from the hospital system:

"I'm afraid to move on because you're out of the hospital and out of the comfort zone. But on the other hand, I don't think I can really get on with my life until the treatment has stopped and you can go".

One of the tasks that all of the women faced as part of survivorship, was learning to live with the fear of recurrence. It is not surprising, given the complexity of identities and experiences of having cancer that there appeared to be a range of different coping mechanism used to deal with fear and uncertainty. For some, such as Una, there was a sense of making the most out of every moment in life in order to make the journey through diagnosis and treatment manageable and worthwhile:

"You can't control it, and you do have to live. Because there's no point in going through all this to not want to live the most you can. You know? Otherwise why are you doing it?".

Wendy described how difficult it was to live with the fear. Her approach was to avoid thinking about the past and future uncertainties, but nonetheless could not avoid moments of intense fear:

"*It's just every now and then, things like that, you get caught off-guard, when you weren't expecting. And then all of a sudden – and you're struggling for a few minutes to cope with it until you can settle your mind and put it back out of the way. Just live for the now, and stop worrying".*

Who am I now?

One of the over-riding issues for the women was the struggle to reflect upon a past, relatively healthy life when compared to the changed and constantly changing identities that were characterised by pathology and loss. Many described that once they were diagnosed with cancer they went from being healthy young women to 'cancer victims' in the eyes of the people around them. Hair loss generally occurs twelve to fourteen days after the first cycle of chemotherapy, so within the first month of treatment the women had to deal with changes in their physical appearance and also other people's reactions to those changes. The analysis of the data suggested two aspects of this sense of shifting identity. In the first round of interviews the threat seemed to be largely external, in the sense that the women spoke about how the physical changes affected them and others. Many spoke movingly about looking in the mirror and not recognising themselves, or when they lost their hair, other people did not recognise them. In the second round of interviews they tended to focus on how their internal views about themselves and others had been affected. They had to reappraise who this new person was following the completion of treatment. Even though their hair had grown back the question about 'who am I' constantly returned: *"I'm not the same 'me' as I was six months ago".* (Emer)

It is important at this point to further consider this notion of shifting identities, often described by the women in terms of stages. In the early stage of diagnosis and treatment there tended to be a perception that they had to deal with other people's reactions, there was the realisation that they were changed by the experience of the 'other' (family, friends, professionals), followed by a realisation that the reassurance that it would only be 'a year out of your life' may not be true. This finding mirrors those in Nelson's (1996) study, where she also describes this sense of ontological insecurity when an individual experiences a major, life changing event. The individual's past methods of coping are no longer meaningful nor valid and it becomes apparent that new strategies are needed to recover a sense of safety and security. This shift in coping styles was apparent in the current study to deal with the knowledge that there could be a recurrence of the disease at any time. Although most had a very strong urge to return to ‘normal’, poignantly they became aware that that was no longer possible.

Within the second interviews the participants discussed the impact of their hair re-growing differently which was a continuation of the changes to the physical-self theme that ran through the first interviews. What was different from the first interviews was that the majority of the women described how the fact that their hair grew back differently (different colour, different texture) seemed like concrete evidence that they were no longer the same person. The physical changes that predominated the first interviews, gave way to reflections on the changes within themselves – to use Jennifer’s term, ‘the essence’ of each woman.

Tennen and Affleck (1998) argue that some aspects of identity are derived from their personal trajectory, which offers goals and rewards in the future. Goals can vary from being short-term or immediate to long term aspirational goals. In all aspects of life, goals and rewards provide structure and motivation and are the core component of the assumptive world (Brennan, 2001). As already noted, posttraumatic growth is a term that is widely used within the literature on cancer survivorship. One of the issues with the concept of posttraumatic growth is that there seems to be an expectation that this growth is always of a positive nature, although Carpenter et al (1999) use the term ‘self-transformation’ in order to take account of the fact that the changes may be both positive and negative. Cancer survivorship is generally portrayed in positive terms. Kromm et al (2007:303) who studied the portrayal of cancer survivorship in print news found in their research that “all survivors who addressed the issue of post-cancer life presented the disease in overwhelmingly positive terms”. Providing a positive message is certainly an important task but it may run the risk of giving an idealised portrayal of a cancer survivor. Much like a woman with breast cancer being portrayed as young, vibrant and feminine, there is a risk that the survivor is expected to have a new, and better, outlook on life. A positive message about cancer survivorship may help to reduce stigma associated with a cancer diagnosis, but there is a danger that the positivity may alienate some survivors. There may well be plenty of survivors who do not believe that being diagnosed with cancer is a positive thing. As Kromm et al (2007:302) commented "a narrow portrayal of survivors may have unintended consequences – perhaps serving to exclude or stigmatise individuals who do not fit the description of an energised, dynamic survivor warrior".

Implications for social work practice

The second part of the paper now focuses on how medical social workers can meet the needs of women who have survived breast cancer. Within the medical setting, social workers often demonstrate a range of skills, knowledge and values in enhancing the psychological, social and emotional well-being of the individual and their family. This may involve, for example, counselling, support, and practical assistance to the patients, and their families or carers, who may be experiencing difficulties during their hospital stay. Psychosocial assessments involve considerations of how the person's problem solving, coping, emotional and developmental capacities in the context of their social and environmental circumstances. One of the key elements of the social work role is the recognition of the importance of emotional and subjective aspects of the human experience; this may involve the determination of meanings that may not be immediately evident in the presenting problem. As Taplin (2016, p. 157) notes that the challenge for social workers and health and social care organisations is to recognise the changing world of cancer care and the importance of meeting the needs of those who are living with, as well as dying from, cancer through ongoing psychosocial intervention and support.

In addition to these generic approaches, a broad range of specialist interventions are available to social workers in helping to meet the needs of women who have survived breast cancer, of particular note is the narrative approach. This assumes that human experience is shared, storied and maintains recognisable narrative patterns (Gubrium &Holstein, 2009). Where individuals have been diagnosed with a life threatening illness, the flexibility of narrative creation allows the ill person and those who care for them to cope with the biographical disruption that might have been produced by the discovery of the disease and make send of their lives (Vindrola-Padros & Brage, 2017, p. 16). Illness calls for stories that not only in the literal sense of providing updates, but also in the existential sense of repairing the damage that the illness has done (Kirkpatrick, 2008, p.62). The narrative approach makes the assumption that narratives are not linear representations of identities, lives and problems, but that they 'constitute' these experiences (Bruner, 1986, 1987, 1991; White, 1995).

White and Epstein (1990) note that, in order to make sense of their lives, individuals must try to arrange their experience of events in a linear sequences over time in order to provide a coherent account of themselves. This involves a beginning (or a history), a middle (or a present) and an ending (or a future), so that the interpretation of current events is as much future-shaped as it is past determined (1990, p.10). How an individual incorporates the unfamiliar depends on how they interpret or make sense of new ideas or circumstances. Key to the use of such interventions by social workers is the 'not knowing stance'. Not knowing refers to a practice position that implies that professionals do not have access to privileged information, can never fully understand another person, and that they are always open to be informed by the relationship with the client in terms of what has been said and left unsaid

(Anderson, 1997, p.134). Adopting a 'not-knowing' stance challenges the subject-object or knower-known dualism often critiqued in hermeneutic and social constructionist theories (Gergen, 1982; Shapiro and Sica, 1988). The not-knowing concept allows for dialogue and the creation of meaning whilst also acknowledging that practitioners should not ignore their accumulated knowledge, in the search for meaning.

For women who have experienced cancer, it is important that each can tell their unique story of her experiences and how of often profound changes to identity and relationships with others are explored. As Tighe et al (2011, p.227) women's experience of diagnosis and treatment is a complex feature of breast cancer survival. The narrative approach, it is argued, can facilitate women to negotiate these difficult, traumatic readjustments, and to help inform possible renegotiations of identity. The central purpose for researchers and professionals using this approach is to improve the care of those who suffer through informing clinicians about the socio-political and emotional context in which people live their lives (Kleinman, 1988). As Shuman (2012) notes narratives can act as a window into socio-culturally sanctioned norms.

Interventions in the current study took place across two phases where women are coming towards the end of their treatment and those who have entered the survivorship phase, as discussed earlier. The women interviewed for this research were at a particular stage of the life cycle, all were young and pre-menopausal. Many of the women interviewed commented on how they did not experience a life threatening illness at this stage of their life. The interaction between time, identity and narrative is one that needs to be explored when discussing narrative therapy. Crossley (2000:10) comments that "everything experienced by human beings is made meaningful, understood and interpreted in relation to the primary dimension of 'activity': this incorporates both 'time' and 'sequence'". In order to make sense of these experiences humans need to understand, or try to make sense of, the sequence of events. Crossley (2000) notes that it is by looking at, and exploring the link between, the diagnosis and treatment of early stage breast cancer and its impact on self and others, that the woman can begin to make meaning. It is the connections or relationships between events that constitute their meaning.

The metaphors of map and journey are quite often used when discussing the process of narrative therapy. White (2007) discusses the use of Bruner's (1986) metaphors of journey and map in narrative therapy. When people first engage in therapeutic conversations they may feel that they are departing from the familiar and embarking on journeys to new destinations without maps. As the reconstruction gathers pace however, White believes that it quickly becomes clear to the clients that they are drawing from a stock of maps relevant to journeys already taken, and that they know a lot about mapmaking (2007:76). There is a sense that the women who have been diagnosed with breast cancer may feel as though they are on a journey without a map, and it is from this 'mapless' state, and commonly because of this 'mapless' state, that the women seek therapeutic intervention. As part of the therapeutic work with clients, the social worker embarks on this journey with the client accompanying her as she negotiates her way. Tighe et al (2011, p.227) comment that the use of the term 'cancer journey' was a useful heuristic device as it furthered the shared language between patients, professionals and care-supporters. To achieve positive outcomes in this field medical social workers need to be confident in using a skilled questioning process. Interviews may start with some general questions to explore how the the woman is feeling and understanding her external narrative. It is then possible to begin to encourage the woman to talk about, and to, their internal narrative, and the impact of the changes on her and her relationships. The changes can be explored in depth, helping her to recruit an audience, which refers to enabling the woman to identify those who have been supportive to her since her diagnosis. Many of the women in the current research discussed how, despite the fact that family and friends felt they were being supportive, there was a relative lack of understanding about the changes the women had been through. In addition, unrealistic expectations about being positive at all all times, left them feeling emotionally isolated. For some women, the social worker may act as her audience, providing a safe space where she can freely discuss feelings, thoughts and fear without having the edit them.

The data from the current study suggest that the process of renegotiating identity within the survivorship phase is one that may last weeks, months or even years. The threat of recurrence of the cancer was one that almost all of the women commented on and had to find ways to manage. Uncertainty regarding fertility was ongoing for many of the women, which makes the search to find 'who she is now' even more difficult. As part of the renegotiation of her identity the social worker may focus on the 'disnarrated', that is all of the events that do not happen though they could have (Vindrola-Padros & Brage, 2017, Prince, 1992). Questions might include 'What does the future look like for you now?, Is that a different future to the one you thought you would have? The social worker may meet the woman a number of times during her survivorship journey. In doing so they may help them discuss the impact of the uncertainty on her and help her to explore the different futures that may exist, in the context of the therapeutic relationship.

Conclusion

Breast cancer is the most commonly diagnosed cancer in women, but has increasingly favourable survival rates; cancer can be viewed as a chronic rather than an acute disease in this respect. For those who have progressed through diagnosis and treatment, there can be a period of confusion and uncertainty. It has been suggested in this paper that this liminal space, ‘betwixt and between’ is an experience that many of the women experienced in the study. The study findings highlighted uncertainty inherent in a cancer diagnosis and the experience of living with fear and meaning making and identity reconstruction. The experience of life immediately after cancer treatment was often poorly understood. Survivorship was very much seen as being uncharted water by the women in this research. They did not know what to expect and many were confused by the emotional reactions they were experiencing. The elation and joy that others expected them to feel at the end of treatment did not occur for many of the women and they were confused and upset by this. The findings from this research found that one of the tasks of survivorship for the women interviewed was to make meaning of their experiences, and also the need to contemplate not only who she is now at the end of treatment, but who she will be in the future.

Medical social workers who are adept at working in situations involving grief and loss and also in taking a systemic approach in their practice are ideally placed to give voice to these concerns, and hopes and fears about the future. Personal stories have the potential to challenge dominant cultural narratives, and social workers are in a position to bear witness to this. It is argued that narrative approaches should be part of effective cancer support services. As Taplin (2016, p.166) puts it: “good practice in this field must be based on listening to the stories of individual people who have survived cancer and who have (literally) ‘lived to tell the tale’”

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Appendix 1: Participant Profile Summary

Name	**Age**	**Marital Status**	**Children**	**Educational Status**	**Employment Status**	**Treatment**
Ann	46	Married	2 daughters	Not known	Worked outside the home prior to her diagnosis. Hoping to return	Chemotherapy, Radiotherapy and Hormonal Treatment
Bairbre	36	Partner	1 son - was hoping to have more	3rd level education	Full-time at home	Chemotherapy and Hormonal Treatment
Ciara	43	Married	4 sons	3rd level	Works outside the home	Chemotherapy and Hormonal Treatment
Deirdre	44	Married (separated between interviews)	2 children - a son and daughter	3rd level	Runs her own business	Chemotherapy, Radiotherapy, Double Mastectomy and Reconstruction
Emer	44	Married	3 children - a daughter and 2 sons	3rd level	Works outside the home	Chemotherapy, Hormonal Treatment, Mastectomy and Reconstruction
Fiona	35	Separated	2 children - a son and daughter	2nd level	Works outside the home	Chemotherapy, Radiotherapy, Hormonal Treatment, Mastectomy and Reconstruction
Grainne	37	Married	1 son and 1 daughter	Unknown	Full-time at home	Chemotherapy, Radiotherapy and Hormonal Treatment

Helen	45	Married	2 sons	3rd level	Works outside the home	Chemotherapy, Radiotherapy and Hormonal Treatment
Isobel	43	Married	2 daughters	3rd level	Full-time at home	Chemotherapy, Radiotherapy and Hormonal Treatment
Jennifer	45	Married	3 children - a son and 2 daughters	3rd level	Was due to start work outside the home when she was diagnosed, so had to postpone	Chemotherapy, Radiotherapy and Hormonal Treatment
Karen	46	Married	None	3rd level	Works outside the home	Chemotherapy, Radiotherapy and Mastectomy
Lisa	45	Married	3 daughters	Unknown	Full-time at home	Chemotherapy, Radiotherapy, Double Mastectomy and Reconstruction
Mary	46	Married	2 sons	Unknown	Full-time at home	Chemotherapy, Double Mastectomy and Reconstruction
Niamh	44	Engaged	None - had hoped to have children	2nd level	Works outside the home	Chemotherapy and Mastectomy
Orla	39	Married	3 children - 2 sons and a daughter	3rd level	Works outside the home	Chemotherapy, Radiotherapy and Hormonal Treatment
Patricia	47	Married	None	Unknown	Works outside the home	Chemotherapy, Radiotherapy and Mastectomy

Jacqueline	44	Partner	2 children - a son and a daughter	3rd level	Works outside the home	Chemotherapy, Radiotherapy and Hormonal Treatment
Roisin	47	Married	3 children - 2 daughters and a son	3rd level	Currently unemployed	Chemotherapy, Radiotherapy and Hormonal Treatment
Sarah	48	Married	1 son	3rd level	Works outside the home	Chemotherapy and Hormonal Treatment
Tara	35	Married	None. Had hoped to start a family	3rd level	Works outside the home	Chemotherapy, Radiotherapy and Hormonal Treatment
Una	35	Married	One son. Had been planning to have another	3rd level	Works outside the home	Chemotherapy, Radiotherapy and Hormonal Treatment
Victoria	41	Married	2 sons	3rd level	Works outside the home	Chemotherapy, Radiotherapy and Hormonal Treatment
Wendy	48	Married	3 children - 1 son and 2 daughters	Unknown	Works outside the home	Chemotherapy and Radiotherapy
Alexia	37	Married	4 daughters. Had been hoping to have another	3rd level	Works outside the home	Chemotherapy, Radiotherapy and Hormonal treatment
Yvonne	39	Married	3 children - 2 sons and a daughter	3rd level	Had been hoping to return to work outside the home	Chemotherapy and Radiotherapy

Appendix 1 - Application of Initial and Focussed Codes to Narrative

Narrative	Initial Codes	Focused Codes
Well, you are feeling your way through. It’s just that you’re still full of life, full of vitality, not saying that someone who has the menopause isn’t, but that you’re not ready for that stage in your life yet. It’s something inevitable for all, and yet if it comes earlier than you expect- you don’t know what to expect, you’re not prepared for it. And you don’t know-you’re in nomansland because you are not as you were before, after having treatment, and you kind of feel a bit lost	Finding her way	Negotiating treatment trajectory
	Still vibrant/youthful	Identity
	Not ready for menopause Uncertainty	Change in expected life course
	Feeling isolated	Different and alone
	Not the same person as she was	Renegotiating identity
	Feeling lost	Uncertainty