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Abstract

This article explores the relationship between cancer survivors' use of self-management practices and their search for normality. Using Frank's illness narratives (A. W. Frank, 1995) and other theoretical literature on normality in chronic illness (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Barovsky, 1978; Bury, 1982; C Foster & D Fenlon, 2011; G. Williams, 1984), it draws on findings from a qualitative study to explore different ways cancer survivors use self-management practices to re-establish normality in their lives post-cancer. The findings suggest that 'normality' represents different things to cancer survivors. We suggest that normality in survivorship is not a static concept, but is fluid and at certain times cancer survivors may display some or all of these different versions of normality. The findings show that self-management practices can help cancer survivors experiment with different health and lifestyle processes, to help support their 'normal' daily lifestyle activities, quality of life and wellbeing.

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Introduction

This article will build on the existing theoretical literature on self-management, cancer and normality in chronic illness (Barlow et al., 2002; Barovsky, 1978; Bury, 1982; Charmaz K, 1995; Corbin J.M & A, 1988; C Foster & D Fenlon, 2011; G. Williams, 1984) to show how self-management practices can be utilised by cancer survivors to guide them towards their newly realigned normalities in survivorship. Using the theoretical literature as a schema to structure this article and paying particular attention to Frank's (1995) illness narratives, it will use findings from a qualitative study to explore the different ways cancer survivors use self-management practices to re-establish normality in their lives post-cancer. It will clearly articulate how the links between self-management, cancer and normality in chronic illness were established, by comparing and contrasting the theoretical literature with the qualitative findings using considered, transparent methods. It will also demonstrate the benefits of applying theory to research as a means of translating theory into practice, for the benefit of patients and health professionals. The research findings describe a gap in the literature, as they focus on how the illness experience elucidates different purposes for using self-management practices in survivorship, thus validating their use. This will be helpful to clinicians interested in understanding more about why cancer survivors use self-management practices to improve their health and wellbeing.

'Normality and chronic illness'

The concept of normality in relation to health and illness is one which describes the extent people adjust to and accept their ability to live with a chronic illness (Bury, 1982; S. Williams, 2000). Cancer can often produce a transitionary process or sense of 'liminality' in people's lives as they start adjusting to changes to their mind and body (Trusson, 2013). These changes can undermine the unity between the body and the self, bringing about

identity changes and alterations to cancer patients' lives to accommodate for these bodily losses and to try to regain this unity (Charmaz K, 1995). This 'identity reconstitution' can occur repeatedly for people living with chronic illness as they experience new losses and are faced with having to adapt their lives accordingly, through revising their identity goals (Charmaz K, 1995; Corbin J.M & A, 1988).

Frank's (1995) concept of illness narratives can be used to help understand the experience of suffering, by conveying the 'voice of the illness experience' through people's stories (A. W. Frank, 1995; Thomas-Maclean, 2004). This can be therapeutic and empowering for the person experiencing illness or disease and can increase understanding for those listening (Kilty, 2000; Thomas-Maclean, 2004). Illness narratives provide opportunities for the storyteller to unravel the truth of their illness experience and adjust to the person they have become, so that they can begin to imagine who they might yet become (Kilty, 2000) . The sharing of stories and experiences can help people recognise they are not alone, but have similarities with others with chronic illness (Hoybye, Johansen, & Tjornhoj-Thomsen, 2004; Kilty, 2000; Thomas-Maclean, 2004)..

Frank (1995) suggests that three main types of illness narrative are experienced by people with chronic illness: restitution, chaos and quest. The restitution narrative minimises the experience of chronic illness and limits individual responsibility to taking medicine and trying to get well (A. W. Frank, 1995). In the restitution narrative, illness is viewed as a life interruption that must be overcome to return to a time when life was normal (A. W. Frank, 1995; Thomas-Maclean, 2004) . This may be of limited value for people trying to 'make sense' of their illness and may reflect the medical focus on cure, requiring only compliance from the patient in 'moving past' their illness and into survivorship (Kaiser, 2008; Sandaunet,

2007). This resonates with the traditional patient 'sick role', whereby co-operating fully with the doctor is viewed as the best way to aid recovery and return to normal, in return for the doctor's specialist knowledge and skills (Parsons, 1951).

In contrast, those identifying with the chaos narrative may feel like passive victims, undergoing a loss of control, with a feeling their lives have no sense of order, meaning or purpose (Ezzy, 2010; Thomas-Maclean, 2004). In both the restitution and chaos narratives, illness is conveyed as meaningless, empty and devoid of purpose, without any control or future hope (Ezzy, 2010). Conversely, those who resonate with the quest narrative meet suffering head on, accept their illness as part of their new life and seek to use it positively, often embracing new ideas and experiences (Thomas-Maclean, 2004). This involves looking to a different future than previously anticipated and persevering with the challenges of their illness, whilst recognising the uncertainties in their lives (Ezzy, 2010). The quest narrative suggests that cancer patients may construct a new normality post-treatment, based around their lived experiences and emotions (Trusson, 2013). It recognises that in chronic illness it is not always possible to return to a previous sense of normal through compliance with medical advice and expertise, as Parson's (1951) work suggests. Instead the quest narrative acknowledges that individuals living with chronic illness need to take steps to adjust to their lives post-cancer, to assemble a revised normality for themselves (Thomas-Maclean, 2004).

Although cancer and its treatment often result in individuals experiencing acute illness, they can also lead to chronic symptoms and side-effects (C Foster & D Fenlon, 2011). However within many societies there is often an implicit and ongoing expectation that cancer patients should cope with cancer by returning to normal life as quickly as possible post-cancer as a symbol of their valued self (C Foster & D Fenlon, 2011; Sanderson, Morris, Calnan,

Richards, & Hewlett, 2011). This tacit, moral acceptance that 'normal is good' places social pressure and responsibility on individuals to maintain an appearance of normality whatever the cost (Sanderson et al., 2011). If, at times, cancer survivors struggle to return to their previous lifestyles, due to debilitating side-effects, their sense of self may become threatened, causing a crisis of identity if they struggle to overcome their liminal state (Charmaz, 1983; C Foster & D Fenlon, 2011; Sanderson et al., 2011). This may manifest in social isolation, restrictions to daily life, financial problems and altered relationships with family and friends (Charmaz, 1983; C Foster & D Fenlon, 2011). Therefore, on entering survivorship, cancer survivors often need to work to reshape and refine their identities, which may need realigning to reflect their newly found circumstances (Bury, 1982).

Bury (1982) views chronic illness as a disruptive event, shaking the structures of everyday life as pain, suffering and death, become recognised, real concerns, rather than the plight of others. The idea of chronic illness as a stable entity is replaced by a fluctuation in symptoms and unclear outcomes, adding to the uncertainty of illness (Bury, 1982; Weiner, 1975). People with chronic illness may, therefore, look to supplement their medical knowledge about their illness from their own personal biographies, to search for a sense of meaning and a cause for its onset (Bury, 1982; G. Williams, 1984).

It has been suggested that people establish this sense of meaning through a narrative reconstruction of their changing relationships with the world and the creation of illness within it, to help them understand their illness according to their past social experiences (G. Williams, 1984). As such, moral, religious, familial and social factors become central in elucidating the illness experience and making the biographical disruption they have experienced intelligible (G. Williams, 1984). People's ability to self-manage and make

adjustments to the emotional, physical, social and psychological changes that have occurred, may influence how easily their lives regain a sense of normality and order (Bury, 1982; Hall, Rubin, Dougall, & Hungin, 2005; G. Williams, 1984).

The biographical disruption experienced may be more tolerable and less surprising to people already accustomed to ill health, or to older people, who have experienced previous biographical disruption from illness (Singding & Wiernikowski, 2008). For these people, the onset of a new illness may be incorporated into their lifestyle as an ongoing, cumulative and inevitable part of their health history (Singding & Wiernikowski, 2008). Similarly, for people who have already experienced significant personal, financial or emotional challenges (such as the loss of a loved one, social deprivation or unemployment), cancer may not be the biggest disruptive event in their lives, in comparison to the challenges they have already overcome (Singding & Wiernikowski, 2008).

Regardless of the scale of the biographical disruption experienced, cancer survivors may seek reassurance, often from health professionals, as to whether the symptoms they are experiencing are normal within their specific model of disease, affecting their subsequent confidence and self-efficacy (Desnoo & Faithfull, 2006). Definitions of normality can overlap and clash, with someone's cultural or subjective normality being perceived as abnormal when viewed from a health perspective (Tiefer, 2004). This can result in people altering their boundaries of normality as they reassess the new norms and expectations determined by their disease. The desire to achieve normality, albeit a changing one, may reflect a need to construct order and control amidst the uncertainty of cancer (Tishelman & Sachs, 1998). Once this is achieved cancer survivors may redefine normality based around the mechanisms they have incorporated to help them to adapt (Desnoo & Faithfull, 2006).

This may be through changes in appearance, adjustments to daily and social life, or by reassessing how they are perceived (Denford, Harcourt, Rubin, & Pusic, 2011; Hall et al., 2005). The interplay between the processes of reassessing normality, fighting to maintain normality and maintaining the appearance of normality may be integral in helping people with chronic illness reach their new health-related normalities (Hall et al., 2005). Being normal means different things to different people and being healthy is intertwined with this, influencing the way normality is perceived (Denford et al., 2011; Hall et al., 2005).

Self-management and chronic illness

In relation to chronic illness, individual self-management can be described as the 'ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition' (Barlow et al., 2002) **.** By focusing on the self-management of a condition over time, people living with chronic illness can delay progression of their disease impairments and improve their quality of life (Bandura, 1998). Cancer survivors' lifestyles contain significant elements of self-management, as they monitor and adjust health and lifestyle activities such as taking medication, sticking to diet plans, exercise regulation and other specific disease-related behaviours (Gallant, 2003). Through self-management of these lifestyle behaviours and activities, attempts can be made to lessen the negative effects of their condition on their physical and psychological health and wellbeing, by keeping their illness in check (Clark N.M et al., 1991; Gallant, 2003).

The management of health and lifestyle behaviours can be facilitated through a collaborative approach to self-management, which is concerned with delineating how both health professionals and healthcare organisations can support patients to self-manage (C Foster & D Fenlon, 2011). It encourages health services to aid and promote strategies and interventions

that will motivate people with cancer to improve or maintain their health and wellbeing (Fenlon & Foster, 2009), thus improving their side-effects from cancer and quality of life (C Foster & D Fenlon, 2011). It is also important from a health service planning and policy perspective due to the escalating economic costs associated with an increasing number of cancer survivors living with long-term repercussions from cancer (Grimmett et al., 2013).

Cancer, normality and self-management

The changing profile of cancer means it is moving from an acute to a chronic-illness model (C Foster & D Fenlon, 2011; Maramaldi, Dungan, & Poorvu, 2008). Perceptions of normal life pre-cancer may alter once cancer treatment begins due to its mental and physical impact. However, unlike the majority of chronic illnesses, such as heart disease, diabetes or multiple sclerosis, most cancer patients have to adapt to and survive a gruelling treatment regime, necessitating further reassessments and reconstructions of normal life (Curt et al., 2000, Hofman et al., 2007). Yet, this is not always the case, with some cancer patients having relatively straightforward treatment plans and treatment side-effects, whilst those with other chronic illnesses may experience complicated treatment programmes with unsatisfactory outcomes.

In addition, a fear of recurrence sets cancer apart from other chronic illnesses and may make some people reluctant to identify as cancer survivors, believing this term to be too incongruent to the uncertainty they feel (Lee-Jones, Humphris, Dixon, & Hatcher, 1997; Shilpa, Mehta, Lubeck, Pasta, & Litwin, 2003) (Kaiser, 2008). Rather than feeling they have 'beaten' cancer, they may instead view it as an ongoing, insidious process in which they are neither healthy or ill and over which they operate little control (Fosket, 2000; Kaiser, 2008; Little, Paul, Jordens, & Sayers, 2002). The very nature of cancer as a diversified illness

experience, which is dependent on factors such as cancer type, treatment plan, severity of symptoms, age at onset and other co-morbidities, make it difficult to generalise in relation to other chronic illnesses, where the scope and nature of the disease may be more tightly defined.

Cancer literature suggests that fatigue affects the majority of patients undergoing chemotherapy and radiotherapy and is usually significant enough to impact on daily life by necessitating alterations to patients' normal routines and their ability to carry out activities of daily living, as well as decreasing their social activities (Curt et al., 2000; Hofman, Ryan, Figueroa-Moseley, Pascal, & Morrow, 2007). Other debilitating side-effects from treatment include nausea and vomiting, night sweats, physical weakness, weight changes, sleep disturbances, depression, constipation, diarrhoea and a dry mouth (Lianqi et al., 2009; Sitzia, Hughes, & Sobrido, 1995). Self-management practices can be used to ameliorate these problems and may help cancer survivors to re-align their normal lives, by guiding them through this uncertain process.

This article will explore the different roles that self-management can play in helping cancer survivors to realign themselves with their own normalities, something that is of increasing relevance as more people are faced with making long-term adjustments to their lifestyle behaviours post-cancer. This is reflected in the increasing profile of survivorship research, with research organisations (American Cancer Society, 2016; National Cancer Institute, 2016) focusing on programmes to improve the quality of life of cancer survivors, by identifying their unmet health needs and targeting interventions, such as diet, exercise and

psychological therapies, to help improve the transition from cancer patient to cancer survivor and hence, regain normality.

As discussed, normality can mean different things to different people (Denford et al., 2011; Hall et al., 2005) and this article is interested in exploring the process by which study participants used self-management to search for and construct their own definitions of normality. Drawing on data from a qualitative study, it will build on existing theory, including Frank's (1995) illness narratives, to explore the ways cancer survivors may re-establish normality in their lives, through the use of self-management practices. It will use the salient characteristics of the restitution, quest and chaos narratives described (A. W. Frank, 1995) to establish how closely study participants align with these illness narratives and to what extent their use of self-management practices in survivorship is shaped by their personal experience of illness. The theoretical literature on normality in chronic illness that has been presented, serves as an organisational framework on which to hang the data from the qualitative study, providing a comparative context within which to analyse the qualitative findings (Sandelowski, 1993). We sought to apply in a consistent and visible way (Bradbury-Jones, Taylor, & Herber, 2014) established theories on the different narratives of chronic illness, to our data on the self-management practices of cancer survivors, to make a contribution to the emerging literature on self-management (table 1). Thus, the aim of this article is to expand on the theoretical concepts of health related normality described, by exploring whether cancer survivors who display different, and often overlapping, elements of Frank's (1995) three illness narratives undertake different types of self-management practices to help them to achieve normality.

Study Design

The qualitative study was part of a sequential mixed methods study, made up of a survey and then interviews, and which examined patterns of self-management practices in cancer survivors from pre-diagnosis, through treatment and into survivorship and its relationship with quality of life (Shneerson, Taskila, Greenfield, & Gale, 2015; C Shneerson et al., 2015; Shneerson C.S & Gale N.K, 2015). The interview topic guide was informed directly from the survey findings and covered themes relating to them. For example, the survey identified a positive association between self-management uptake and quality of life. This initiated questions in the topic guide relating to the impact of cancer on quality of life, such as '*How has cancer changed your outlook on life'* and *'Can you tell me about any day-to-day problems resulting from the after effects of cancer?'* The topic guide also asked questions about how cancer had affected participants' views of their health, such as *'How much control do you feel you have over your own health and illness?'* and *'What influences the decisions you make about your health and lifestyle choices?'* These questions allowed an understanding of how and why self-management practices are incorporated into the lives of cancer survivors.

One of the overarching findings of the survey study was that self-management practice uptake was highest in survivorship, compared to pre-diagnosis and during treatment, suggesting an increased perceived need for self-management strategies in survivorship. The subsequent interviews built on this finding, by exploring, inductively, why and how cancer survivors used certain self-management practices post-cancer. Wanting to stay fit and strong, rebuild health, ameliorate any side-effects from treatment and promote holistic benefits to the mind and body, were common reasons for cancer survivors undertaking self-management practices in survivorship.

The theme of normality was the theme which emerged most prominently from the interview dataset, being constantly spoken about throughout participants' narratives. Participants spoke of normality in relation to their lives pre, during and post-cancer. They also spoke frequently of how certain self-management practices were used to help them get back to normal life post-cancer, reinforcing the findings from other qualitative analyses (Hall et al. 2005). It became apparent to us that participants' approaches to self-management were largely influenced by the extent to which they viewed the severity of their illness and its subsequent impact on their lives. Therefore it seemed appropriate to focus on this concept in relation to self-management, as the search for a health-related normality seemed to be a major driver in participants' use of self-management practices.

Having drawn issues and concepts relating to the idea of normality in chronic illness from the literature, we wanted to interrogate our dataset further using these concepts of normality, by exploring its relationship with self-management uptake in cancer survivorship. As a result, we decided to draw on the theoretical literature and utilise Frank's illness narratives as a structure on which to hang our inductive, qualitative findings. We worked with our interview dataset, re-examining it to identify which participants displayed elements of the restitution, quest or chaos illness narratives and to what extent. We were then interested in trying to establish to what extent and why their illness narratives influenced their self-management uptake and how this impacted on their attainment of normality in survivorship.

Setting

The study took place in a large teaching hospital in the West Midlands, United Kingdom. Ethical approval was sought and obtained from the local research ethics committee in

February 2012 (Study protocol number RG_11-175, REC reference 12/WM/0030). Individual written consent was taken from participants before they undertook the interview study.

Access, Recruitment and Sampling

Four hundred and forty-five participants took part in the survey study (C Shneerson et al., 2015; C Shneerson et al., 2015). Access to the study population was gained through contacting relevant oncology consultants at the participating hospital. To be eligible for inclusion in the study, participants had to have been free from metastatic disease/local recurrence at the start of the study and must have finished their active cancer treatment more than one year previously (C Shneerson et al., 2015; C Shneerson et al., 2015).

We selected our qualitative sample from our survey population, using a purposive sampling strategy. Forty participants were sampled for individual face-to face interviews. This number fits with previous work around sample size and data saturation in qualitative interviews, being large enough to be confident that most or all of the perceptions that might be important would be uncovered, without becoming so large that the data would become repetitive or superfluous (Mason, 2010).

We used purposive sampling to obtain diversity, on the basis of cancer type, socio-demographic variation and participants' different patterns of self-management over time. First, we included participants from the ten most common cancer types, to account for variation in experiences of diagnosis, treatment and prognosis as well as other embodied and social variations in the experience of cancer. Second, the demographic data collected from the survey enabled us to sample cancer survivors by ethnicity, gender and age. This survey

data was representative of the wider West Midlands population (C Shneerson et al., 2015; C Shneerson et al., 2015). We were then able to look for any differences between these characteristics when analysing the interview data, enabling us to explore the research questions from a range of different perspectives and viewpoints (Shneerson C.S & Gale N.K, 2015).

Finally, we sampled our participants based on the findings of the survey study which provided us with details of the patterns of self-management use over time among cancer survivors. Across six self-management categories (diet, exercise, CAM, psychological therapies, spirituality/religion, support groups), different patterns of uptake were found over time. For support groups, psychological therapies and diet, uptake increased incrementally from pre-diagnosis to survivorship. For exercise and spirituality/religion, uptake was lowest during treatment and highest in survivorship. Finally, uptake of CAM was the same pre-diagnosis and treatment, but rose in survivorship (C Shneerson et al., 2015). Based on these patterns of uptake, we selected participants for the interview study whose own self-management uptake pattern had followed one of these trends.

Data Collection

We took a narrative approach to data collection, by using open-ended questions, which allowed interview participants to talk freely about their cancer experience and their use of self-management practices and allowed us to construct a commentary and interpretation from the narratives. We developed a topic guide for the interview study, which covered themes relating to issues of normality, including health perspectives, social networks, attitudes to self-management, work ability, quality of life and the future. By taking a narrative approach to data collection, depth, detail and meaning were added to the findings (Geertz, 1973), to

help explain participants' experiences in relation to normality and their use of different self-management practices.

Data analysis

All 40 interviews were recorded using a digital voice recorder before being transcribed. Starting from the interview data, we also took a narrative approach to analysing the interview transcripts (Mattingly & Garro, 2000), by examining each one individually, to see which of the three illness narratives: restitution, quest or chaos (A. W. Frank, 1995), it resembled the most, if any. Table 1 provides an illustration of how the interview transcripts were matched to the most salient features of Frank's illness narratives. Two of the transcripts were coded by all three authors to ensure consistency of approach. Differences were resolved through discussion. Then sections of interview transcripts were coded by one researcher (CH) as restitution, quest or chaos according to how well they matched these narrative types. Some transcripts resembled different illness narratives at different times and in these cases the transcripts were coded to reflect this. Once the different, and often convergent, narrative types had been identified, we used them to establish a working analytical framework and, using the constant comparative method (Bryman, 2008), were able to establish any similarities and differences that existed between participants' use of self-management practices and the illness narrative(s) they matched most closely.

Data from the transcripts were inserted into a Framework matrix to enable ordering and synthesis of the data, whilst retaining the meaning and feeling of the interviewees' words (Gale N.K, Heath G, Cameron E, Rashid S, & Redwood S, 2013). The matrix format enabled within and cross case analysis of the data from all forty participants. Codes and categories were developed to describe and interpret the interviews and comparisons made between

participants according to which of Frank's illness narrative(s) each best fitted into. This allowed us to easily compare and contrast the data across and within cases, so that we could pull out relevant themes relating to normality and self-management. It also made the dataset more manageable (Ritchie & Lewis, 2003), while illuminating relationships that existed between the different categories.

Through studying the transcript data, alongside Frank's (1995) illness narratives and other existing literature on normality (Barovsky, 1978; Bury, 1982; Charmaz K, 1995; Corbin J.M & A, 1988; Hall et al., 2005; Singding & Wiernikowski, 2008), we were able to further develop our themes based around normality and the use of self-management practices in cancer survivorship, by placing them within the context of these illness narratives. The findings will now be explored in more depth.

Findings

Restitution, Quest and Chaos Illness Narratives

When analysing the dataset we took time to identify how well each of the participants' narratives reflected the restitution, quest and chaos narratives (A. W. Frank, 1995). Though some participants' stories distinctly resembled one of the three illness narratives, for others there was substantial overlap between the three narratives, with different feelings and emotions being expressed at different points throughout their cancer pathway. This finding is unsurprising, as it seems unlikely that the three illness narratives described would neatly capture all of the participants' lived experiences, due to their nuanced, diverse, complex and personalised nature. However, the findings reported on go some way to describing some of the more common narratives identified by survivors of cancer and are worthy of attention

when considering how self-management practices may help to support them through their cancer care pathways.

Restitution: Twelve participants most closely matched the restitution narrative, speaking of how they had beaten cancer and of how their outlook and daily life remained unchanged, still enjoying hobbies and holidays as before. They spoke of having to fight and 'get better' from cancer, of having a belief in their survival and knowing they would be cured. Cancer was spoken of as being firmly in the past, unable to destroy their lives.

'I don't like that word remission. I think, 'No I'm not. I'm a survivor. I've, that's all happened now.'

(Female, 63yrs, White, head and neck cancer)

For some participants, the importance of being normal led to them projecting an outwardly facing appearance of normality to others when in social situations, especially to peers and at times health professionals, partly due to a fear of being labelled as a cancer patient, partly due to not wishing to be a burden or cause distress and partly to try to forget about their illness for a while.

'When I went out with friends it was brilliant. You didn't want to be…The person who'd got cancer…So you'd probably make more of an effort to be a bit more social, a bit more funny, a bit more cute...Than normally you would do, because you're just thinking, 'Gosh, you know, I don't want people to feel,' not pitying, but, 'to......Treat you differently.'

(Female, 36yrs, White, breast cancer)

Some participants were 'black and white' in their attitude to cancer, removing themselves from their situation and focusing scientifically on getting better, rather than being engulfed by their illness. This was done by separating the physical self from the emotional or spiritual self, treating them as two separate entities. Some spoke of the pointlessness of cancer, inhibiting them from getting on with their normal lives. Self-management practices were often used to keep the mind and body strong during treatment, to provide relaxation and manage any side effects. Walking, swimming, gardening and yoga were often viewed as methods for maintaining control over their health and their bodies. For these participants, the idea of returning to a 'normal life' post-treatment was vital.

'I do think it's possible to control through diet and thought process, and looking after your body as a functioning mechanism, that you can influence some things, hopefully for the good.'

(Female, 61yrs, White, melanoma)

Self-management was frequently seen as a mechanism for improving any physical and mental impairments, helping participants return to who they were pre-diagnosis and regain an appearance of normality. This could be through the mental benefits of carrying out religious practices such as prayer, through the holistic benefits commonly attributed to CAM, through promoting health and fitness though diet and exercise regimes and through psychological input or gaining advice and sharing experiences at support groups (Hoybye et al., 2004).

'The best thing that happened to me after, after I'd finished all my ops and [chemotherapy and radiotherapy], I started hot yoga...That was the best thing, because, actually, the

[lymphedema] has...It's gone really...I couldn't move this arm very well...So I've been able to move...You've gotta find something that works.'

<div align="center">

(Female, 40yrs, South Asian, breast cancer).

</div>

Quest: Fourteen participants resonated most strongly with the quest narrative. These participants were more accepting of learning to live with cancer, feeling it had happened for a reason. They spoke of cancer making them appreciate their own mortality and what mattered in life. Participants spoke of how cancer had made them think more deeply and spiritually about life, increasing their sense of peace and calm as they learnt to place more value on people over material things. These participants had no desire to return to their old 'normality' with some expressing the view that cancer had served as a 'wake-up call' and had prompted them to view things from a larger life perspective rather than get caught up in its minutiae.

'Cancer can be a bit of a wakeup call...You can appreciate more...The fragility of life and...Your mortality and things you took for granted before...Like a lot of people I got a bit lazy and...Maybe didn't make the most of my opportunities but now I've got that sort of awareness which I hope I don't lose.'

<div align="center">

(Male, 51yrs, White, head and neck cancer)

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These participants spoke of how their cancer experience had made them positively value their relationships with family, friends or work colleagues, bringing them closer to their loved ones by opening up communication channels. Others spoke of how cancer had alerted them to who their friends really were, as some people 'didn't want to know' whilst others 'rallied round',

resulting in some participants terminating friendships or relationships they no longer valued. One woman spoke of her shock at the level of support her husband had shown her throughout her cancer treatment. She felt that cancer had changed both of their outlooks and strengthened their relationship.

'He was marvellous to me, and I never thought he would be...I honestly thought he would…Not care at all...Cos he's not very...If you're crying...He's not really that supportive in that respect. But he was...So that relationship improved in a way I never expected...He was...Fantastic. Knowing the way he was and what I would have expected of him. '

(Female, 68yrs, White, non-hodgkin's lymphoma)

Participants described feeling lucky to have survived cancer, refusing to let it hold them back, despite feeling that it might return. Many described feeling more motivated, as cancer had released new feelings, adding value to their life experiences, as they focused on the moment. They employed a range of self-management practices such as exercise, diet and attendance at support groups, as a means of taking more control of their health and lifestyles, to try to maintain their quality of life. Participants spoke of being more aware of how they treated their bodies, using self-management practices to nurture and protect them from ill health. Some participants had specifically altered their diets by eating more natural, organic and non-processed foods.

'I think it's just changed my way of thinking...Avoiding processed food...I made a conscious effort to look into the ingredients of certain types of food, and if there's so many additives... I would avoid them...That's probably the most wholesome way.'

(Female, 41yrs, South Asian, colorectal cancer)

Many participants believed that by taking care of the mind and body, the production of a positive outlook would be expedited and vice versa. Self-management was seen as an important tool in this, leading to participants feeling more in control of their health and wellbeing. A sense of control, calm and relaxation was brought about by engaging in self-management practices, such as meditation, yoga, dietary changes and walking. One woman spoke of how post-cancer she experienced the therapeutic benefits of being outdoors and gardening, improving her sense of peace and wellbeing.

'I just loved to be outdoors...I'd spend lots and lots of time in the garden...Since I've been ill...You suddenly realise, you watch every little bud that's – that suddenly starts sprouting up...And thinking oh this is what life's about...And just feel that peace and that air...I suppose it changed my outlook.'

(Female, 51yrs, White, breast cancer)

Chaos: Six participants reflected the chaos narrative when talking about the impact of their cancer, speaking of their lives being devoid of purpose, being in disarray, seeing no way forward and of having 'next to nil' quality of life. They were often scared to look to the future and think about what might be in store. This led to some participants feeling depressed, anxious and even suicidal, struggling to cope with daily life.

'I do get very anxious...I can't explain it. It's like...I was almost saying, 'What's wrong with you? Keep yourself together.' I can't – which, I don't think I had that before.'

(Female, 56yrs, Black, colorectal cancer)

Participants described the negative effects of cancer on their work, finances, family, social lives and emotional and physical health. Guilt was often experienced at being unable to perform their old roles, whether as a spouse, parent, grandparent, friend or employee. Yet, despite these feelings of guilt and anxiety, some participants felt pressure to put on a 'brave face', to present a 'normal' exterior to friends and family (Goffman, 1959; Hall et al., 2005). However, participants' physical and mental impairments meant they could not always present their 'normal' exterior to others. This incompatibility between the projected and the private self could lead to repercussions in terms of disrupting participants' social interactions, leading to feelings of embarrassment and discreditation (Goffman, 1959).

'Social life has changed. I mean after work you'd go for a drink or you've got football or something to discuss, like men things and laughing and joking at work and you miss that kind of thing...You're just there with your wife and then next she probably gets a bit bored and then we get a bit bored.'

(Male, 55yrs, White, non-hodgkin's lymphoma)

For these participants, self-management practices played a smaller role in their life than participants who fitted the restitution or quest narratives. This was often due to decreased energy, motivation and confidence, or because they were physically incapacitated post-cancer. However, most participants who closely fitted the chaos narrative had utilised a self-management practice which offered them psychological or emotional support, such as counselling or accessing support groups, to try to help them cope.

'I'm going for some wellbeing counselling...I never had any - any counselling like this before...Since I've been back to the doctor and asked for these antidepressant tablets like you know, the small things were getting - you know all these pressures.'

(Male, 55yrs, non-hodgkin's lymphoma)

Other people used self-management practices to try to regain a sense of calm in their otherwise chaotic lifestyles, using practices such as hypnosis, reiki, support groups and walking, to temporarily escape from their tumultuous daily lives and alleviate their anxiety.

'I find [walking]...Therapeutic 'cause I can get anxious – I don't want to say the word angry ... Walking can be therapeutic in the way of just trying to... I don't know, I just find it helps.'

(Male, 55yrs, White, melanoma)

Overlapping Narratives: Frank's three narratives are not fixed and set apart, rather they often overlap and coexist in the life story of the same narrator, carrying more or less emphasis in different peoples' stories (A. Frank, 2007; Garrett, 2004). The fluidity of peoples' lived experiences are reflected in their storytelling as its dimensions change and reshape in different contexts (Thomas-Maclean, 2004). Previous research using Frank's illness narrative types to understand the experiences of people living with cancer and other chronic illnesses have shown that a combination of the narrative types are often present as people recall different elements of their stories (Thomas-Maclean, 2004; Whitehead, 2006).

This overlap was apparent in the interview transcripts as although many participants' accounts aligned more closely with either the restitution, quest or chaos narratives, to some extent they all displayed combinations of the narrative types, as participants reflected on the different experiences and emotions they had encountered. Eight participants' in particular strongly exemplified this, displaying a diverse combination of the restitution, quest and chaos narratives, depending on which part of their cancer journey they were recalling. Participants who were generally positive in their attitude towards cancer, had moments when the chaos narrative emerged and they spoke of feeling despair and uncertainty. This can be exemplified by one man, who had previously had lung cancer, and who often resounded with the restitution narrative, by talking about how cancer was not going to destroy him.

'I've always had a positive attitude but now I've got a more...Positive attitude. This isn't going to destroy my life.'

(Male, 68yrs, White, lung cancer)

This determination to rid his body of cancer was reflected in his attitude towards recovery, as he spoke of how, with his wife's help, he had changed his diet and exercise habits, to remain as fit and healthy as possible.

'From the very first day I was discharged from hospital I started walking...Round the houses, the blocks...We do more walking...Now than I ever did in...Sixty five years previously…My wife still likes to cook meals...Although we have more salads than we ever did.'

(Male, 68yrs, White, lung cancer)

He also spoke of how his cancer experience had led to psychological health benefits, as he felt stronger mentally and more able to cope. This was partly due to his family, who had provided him much of his motivation to carry on and keep living. This reflection on the improvements cancer had brought to his life resembles the quest narrative, which seeks to use the experience of illness in a positive way so that it can be used to enrich, rather than deplete, life.

'Mentally, I probably feel stronger than I did before the operation...I've felt stronger since.'

(Male, 68yrs, White, lung cancer)

However, there were occasions when feelings of chaos emerged. At these times self-management practices were identified as mechanisms for helping to ameliorate his feelings of despair, something which provided great comfort.

'I find Reiki helps, particularly last thing of a night time when things start to look a bit bleak, I find that helps me to relax and forget about the problems.'

(Male, 68yrs, White, lung cancer)

Other participants displayed combined elements of the restitution, quest and chaos narratives in varying proportions. Despite sometimes talking about fighting and getting rid of cancer, these statements were often tempered by more reflective thoughts and feelings. Participants spoke of how cancer had been enlightening, teaching them to view life differently.

'It has made me aware....That I'm not immortal...We tend to live more for the day...I'm aware that things could go wrong at any time, so when I...Wake up in the morning I think great it's another day.'

(Male, 77yrs, White, melanoma)

These participants saw the positives that had come from their cancer experience, and often used self-management practices such as prayer, yoga, reiki, hypnosis, meditation, gardening and walking to help maintain this self-awareness, through focusing the mind and body and to remind them what they had gained from cancer.

'While I was going through it [cancer] I could see lots of blessings that were coming out of it....There's certain parts of my prayers that were answered...If I didn't have my faith...I don't think I would be where I am, I probably would have lost...Myself a bit.'

(Female, 41yrs, South Asian, colorectal cancer)

However, there were times when these participants experienced moments of chaos, when thinking about the potential severity of cancer. At these times, they struggled to control their anxiety, speaking of the precariousness of their situation. This was particularly difficult for participants who had previously felt life was under their control.

'I think this has proved I'm actually fairly controlling...And that's probably why I didn't cope emotionally, as well, as probably other people.'

(Female, 36yrs, White, breast cancer)

At these times, self-management practices – such as psychological therapies, CAM and exercise - were undertaken to try to regain a sense of normality in their otherwise upturned lives. Sometimes participants' sense of chaos was so great that they used psychological therapies to help them stave off acute feelings of depression, anxiety and suicidal thoughts.

'After the first couple of times of seeing him [psychologist], once I understood myself what was wrong, then I could cope with it, because when things weren't right, I knew…And I could say …That's too much…And I could manage that myself…He helped me to understand that.'

(Male, 64yrs, White, head and neck cancer)

Discussion

The findings from the interview data revealed that participants experience different reactions to living with cancer's effects. For some, cancer proved a massive disruption, whilst others spoke of its effect being very limited in their lives, reflecting their diverse and varying experiences. Similarly, whilst some participants identified with either the quest, restitution or chaos narratives more clearly than others (A. W. Frank, 1995), others oscillated between them more widely, depending on their stage in their cancer journey and their changing emotions. This is to be expected, and it would be remiss to assume that participants' narratives could be reduced into three rigid, preconceived categories. The inductive nature of qualitative research assumes that rather than fitting into predefined categories, data analyses will lead to the production of distinctive and subtle variations in participants' stories and experiences, which in turn will lead to a deeper understanding of the complexities of social life and human behaviour. Cancer survivors' experiences of living with cancer are

individual, multifaceted and complex and may inform the extent to and methods with which they seek normality in survivorship. The findings indicate that self-management practices are used by cancer survivors as mechanisms for undergoing these processes for achieving normality.

The interview narratives have illustrated the different ways cancer survivors struggle to make sense of their illness and reclaim their sense of self, as they attempt to come to terms with living with their disease (Conrad & Barker, 2010), so they can feel valued and integrated in society. Self-management strategies may be one method for helping cancer survivors adapt to their new lives post-cancer, providing them with appropriate resources to realign themselves in society and rework their identity. In survivorship, some aspects of cancer patients' lifestyles will revert to how they were pre-cancer, whilst other aspects will have been significantly altered. The level of self-management that a person chooses to engage with will subsequently influence how their future lives are shaped. Thus survivorship can be seen as an active process whereby cancer patients choose to what extent they will use self-management practices as supportive mechanisms to help control their health and lifestyles, shaping their new versions of normality as they do so.

The extent to which cancer has disrupted cancer survivors' lives and the ways that they react to this disruption (Bury, 1982), may influence the types and level of self-management practices they choose to undertake. This may be shaped in part by the moral, religious, familial and social factors that are integral to their lives at this time (G. Williams, 1984). Certain self-management practices may seem more or less appealing as a result, demonstrating the importance of social support in facilitating decision-making processes in survivorship.

Self-management practices can act as facilitative and supportive structures, from which cancer survivors can gain physical and mental strength, in ways that are appropriate and compatible with their health needs and requirements. The different ways cancer survivors make sense of their condition, may provide different motivations for their use of self-management practices. Elements of the restitution narrative are often upheld by people with chronic illness, who are seeking a cure from their disease (A. W. Frank, 1995). These people may use self-management practices such as exercise and diet, to keep the body strong and protect it from ill health. This may complement advice they have been given from health professionals, reinforcing the conventional, biomedically-focused model of care (Parsons, 1951). The inherent power of the doctor/patient relationship suggests that, for some people, decision-making processes about which health and lifestyle practices to adhere to are significantly influenced by compliance with medical advice. However, other people may experience long-term health problems in survivorship and are unable or unwilling to go back to life as it was prior to cancer. As a result alternative ways of coping with cancer and achieving normality are necessary.

The different uses for self-management practices employed by participants, depending on the strength of the illness narrative being experienced, suggests that rather than dividing self-management practices up into specific categories, such as diet or exercise, they should be categorised by their purpose, in line with the needs and wants of the individual. This purposeful use of self-management practices in cancer survivors can be viewed as an attempt to regulate, maintain and improve health after disease onset, to try to re-establish a sense of normality. Cancer survivors displaying different levels of the restitution, quest and chaos narratives may have a variety of reasons for using different self-management practices at

different times, depending on the narrative they are trying to reconcile with most strongly. This will impact on the type of support they need and the outcomes that they are seeking. Regardless of the reasons for using self-management practices, we suggest that they are used to help cancer survivors regain some level of control and stability, to help them work towards their newly-reconciled and often fluctuating normalities.

Many of the qualitative findings presented here may apply to people with other types of chronic illness. Future research could focus on whether the self-management strategies identified in this study for achieving health related normality could be directed towards other conditions. HIV has similarities with cancer in the respect that people are now living with the illness, often symptom free, for many years due to improvements in research and treatments (Foote-Ardah, 2003). Research could explore whether HIV patients use self-management practices as a means of achieving their health related normalities. This research could also be undertaken with people suffering from other chronic illnesses such as multiple sclerosis and diabetes. However, the levels and types of self-management required and desired by individuals with chronic illness is likely to vary according to levels of need, autonomy and disease progression (Thorne & Paterson, 1998).

The theoretical literature on normality in chronic illness has been used to aid the interpretation of the qualitative data (Sandelowski, 1993), something which is of paramount importance when translating research into policy and practice (Meyer & Ward, 2014). This is apparent here, as the study findings will be useful on a clinical level, for health professionals who are interested in understanding how their patients view the world post-cancer. In understanding more about what cancer survivors are trying to achieve through their use of specific self-management practices, health professionals are more likely to be supportive of

patients who choose to use them, depending on their level and type of need. This may be particularly pertinent for general practitioners, who are likely to come into contact with cancer survivors who are displaying elements of the chaos narrative (such as anxiety and depression) and who might benefit from some tailored guidance, support and advice as to which self-management practices might be best suited to help them through this process.

Conclusion

This article has brought together new ideas about the concept of normality in survivorship, drawing on the theoretical literature, to allow a comprehensive and insightful interpretation of the qualitative data to be made, by relating it to the social processes underpinning the study findings (Meyer & Ward, 2014). The findings suggest that for cancer survivors the term 'normality' represents different things, depending on how their experiences are situated within their contrasting, fluctuating and overlapping illness narratives. The extent by which cancer disrupts a person's life will be influenced by their perception of where illness sits within their own personal biography.

We suggest that normality in survivorship is not a static concept, but is fluid and at certain times cancer survivors may display some or all of these versions of normality to a greater or lesser extent. This will be dependent on a multiplicity of factors, such as their level of social support, stage in their cancer journey, financial and employment circumstances and mental and physical health (Molassiotis & Rogers, 2012; Thorne & Paterson, 1998). We propose that self-management practices should be used purposefully, rather than being pre-defined into set categories such as diet and exercise, to allow cancer survivors to experiment with different health and lifestyle processes. In doing so they can measure to what extent specific self-

management practices can support their daily lifestyle activities, quality of life and wellbeing and reconnect them with normality in survivorship.

References

American Cancer Society. (2016). Survivorship and Quality of Life Research. 2016, from http://www.cancer.org/research/survivaltreatmentresearch/cancer-survivorship-grants

Bandura, A. (1998). Health promotion from the perspective of social cognitive theory. *Psychology and Health, 13*(4), 623-649.

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-Management Approaches for People with Chronic Conditions: A Review. *Patient Educ Couns, 48*, 177-187.

Barovsky, I. (1978). Compliance, Adherence and the Therapeutic Alliance 'Steps in the Development of Self-Care'. *Soc. Sci. and Med, 12*, 369-376.

Bradbury-Jones, C., Taylor, J., & Herber, O. (2014). How Theory is Used and Articulated in Qualitative Research: Development of a New Typology. *Soc Sci Med, 120*, 135-141.

Bryman, A. (2008). *Social Research Methods* (3rd ed.). Oxford: Oxford University Press.

Bury, M. (1982). Chronic Illness as a Biographical Disruption. *Sociol Health Illn, 4*(2), 167-182.

Charmaz, K. (1983). Loss of Self: A Fundamental Form of Suffering in the Chronically Ill. *Sociol Health Illn, 5*(2), 168-195.

Charmaz K. (1995). The Body, Identity and Self: Adapting to Impairment. *The Sociological Quarterly, 36*(4), 657-680.

Clark N.M, Becker M.H, Janz N.K, Lorig K, Rakowski W, & L, A. (1991). Self-management of Chronic Disease by Older Adults. *Journal of Aging and Health, 3*, 3-27.

Conrad, P., & Barker, K. (2010). The Social Construction of Illness: Key Insights and Policy Implications. *Journal of Health and Social Behaviour, 51*(S67).

Corbin J.M, & A, S. (1988). *Unending Work and Care: Managing Chronic Illness at Home*. San Francisco: Jossey-Bass.

Curt, G., Breitbartb, W., Cellac, D., Groopmand, J., Horninge, S., Itrif, L., . . . Vogelzangk, N. (2000). Impact of Cancer-Related Fatigue on the Lives of Patients: New Findings From the Fatigue Coalition. *The oncologist, 5*(5), 353-360.

Denford, S., Harcourt, D., Rubin, L., & Pusic, A. (2011). Understanding Normality: A Qualitative Analysis of Breast Cancer Patients Concepts of Normality After Mastectomy and Reconstructive Surgery. *Psycho-oncology, 20*, 553-558.

Desnoo, L., & Faithfull, S. (2006). A Qualitative Study of Anterior Resection Syndrome: The Experiences of Cancer Survivors Who Have Undergone Resection Surgery. *European journal of cancer care, 15*, 244-251.

Ezzy, D. (2010). Qualitative Interviewing as an Embodied Emotional Performance. . *Qualitative Inquiry, 16*(3), 163-170.

Fenlon, D., & Foster, C. (2009). Self-Management Support: A Review of the Evidence. University of Southampton: Macmillan Research Unit.

Foote-Ardah, C. (2003). The Meaning of Complementary and Alternative Medicine Practices Among People with HIV in the United States: Strategies for Managing Everyday Life. *Sociology of Health and Illness, 25*(5), 481-500.

Fosket, J. R. (Ed.). (2000). *Problematizing biomedicine: women's construction of breast cancer knowledge*. London: Macmillan Press Ltd.

Foster, C., & Fenlon, D. (2011). Recovery and Self-Management Support Following Primary Cancer Treatment. *British journal of cancer, 105*, S21-28.

Foster, C., & Fenlon, D. (2011). Recovery and Self-Management Support Following Primary Cancer Treatment. *British Journal of Cancer, 105*, 21-28.

Frank, A. (2007). Five dramas of illness. *Perspect Biol Med, 50*(3), 379-394.

Frank, A. W. (1995). *The Wounded Storyteller*. Chicago and London.: The University of Chicago Press.

Gale N.K, Heath G, Cameron E, Rashid S, & Redwood S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology, 13*(117).

Gallant, M. (2003). The Influence of Social Support on Chronic Illness Self-Management: A Review and Directions for Research. *Health Education and Behaviour, 30*(2), 170-195.

Garrett, C. (Ed.). (2004). *Meaning and Spirituality in Stories of Chronic Illness*: Brill.

Geertz, C. (1973). *The Interpretation of Cultures: Selected Essays*. New York: Basic Books.

Goffman, E. (1959). *The Presentation of Self in Everyday Life*. New York: Doubleday Anchor Books.

Grimmett, C., Armes, J., Breckons, M., Calman, L., Corner, J., Fenlon, D., . . . Foster, C. (2013). RESTORE: An Exploratory Trial of an Online Intervention to Enhance Self-Efficacy to Manage Problems Associated with Cancer-Related Fatigue Following Primary Cancer Treatment: Study Protocol for a Randomised Controlled Trial. *Trials, 14*(184).

Hall, N., Rubin, G., Dougall, A., & Hungin, A. (2005). The Fight for 'Health-Related Normality': A Qualitative Study of the Experiences of Individuals Living with Established Inflammatory Bowel Disease (IBD). *Journal of Health Psychology, 10*(3), 443-455.

Hofman, M., Ryan, J., Figueroa-Moseley, C., Pascal, J.-P., & Morrow, G. (2007). Cancer-Related Fatigue: The Scale of the Problem. *The oncologist, 12*, 4-10.

Hoybye, M. T., Johansen, C., & Tjornhoj-Thomsen, T. (2004). Online interaction. Effects of storytelling in an internet breast cancer support group. *Psycho-oncology., 14*(3), 211-220.

Kaiser, K. (2008). The meaning of the survivor identity for women with breast cancer. *Social Science and Medicine, 67*, 79-87.

Kilty, S. (2000). Telling the Illness Story. *The Patient's Network, 5*(3).

Lee-Jones, C., Humphris, G., Dixon, R., & Hatcher, M. (1997). Fear of recurrence-A Literature Review and Proposed Cognitive Formulation to Explain Exacerbation of Recurrence Fears. *Psycho-oncology., 6*, 95-105.

Lianqi, L., Fiorentino, L., Natarajan, L. P., B, Mills, P., Sadler, G., Dimsdale, J., . . . Ancoli-Israel, S. (2009). Pre-Treatment Symptom Cluster in Breast Cancer Patients is Associated With Worse Sleep, Fatigue and Depression During Chemotherapy. *Psycho-oncology, 18*, 187-194.

Little, M., Paul, K., Jordens, C., & Sayers, E.-J. (2002). Survivorship and discourses of identity. *Psycho-oncology., 11*, 170-178.

Maramaldi, P., Dungan, S., & Poorvu, N. (2008). Cancer Treatments. *Journal of gerontological social work, 50 Suppl 1*, 45-77.

Mason, M. (2010). Sample Size and Saturation in PhD Studies Using Qualitative Interviews. *Forum: Qualitative Social Research, 11*(3).

Mattingly, C., & Garro, L. (Eds.). (2000). *Narrative as Construct and Construction*. London.: University of California Press Ltd.

Meyer, S., & Ward, P. (2014). 'How to' Use Social Theory Within and Throughout Qualitative Research in Healthcare Contexts. *Sociol. Compass, 8*(5), 525-539.

Molassiotis, A., & Rogers, M. (2012). Symptom Experience and Regaining Normality in the First Year Following a Diagnosis of Head and Neck Cancer: A Qualitative Longitudinal Study. *Palliative and Supportive Care, 10*, 197-204.

National Cancer Institute. (2016). Cancer and Public Health. 2016, from http://www.cancer.gov/research/areas/public-health

Parsons, T. (1951). *The Social System.* Glencoe, IL.: Free Press

Ritchie, J., & Lewis, J. (2003). *Qualitative Research Practice: A Guide for Social Science Students and Researchers.* London: Sage Publications.

Sandaunet, A.-G. (2007). The Challenge of Fitting In: Non-Participation and Withdrawal from an Online Self-Help Group for Breast Cancer Patients. *Sociology of Health and Illness, 30*(1), 131-144.

Sandelowski, M. (1993). Theory Unmasked: the Uses and Guises of Theory in Qualitative Research. *Res. Nurs. Health, 16*, 213-218.

Sanderson, T., Morris, M., Calnan, M., Richards, P., & Hewlett, S. (2011). Shifting Normalities: Interactions of a Normal Life and the Normalisation of symptoms in Rheumatoid Arthritis. *Sociology of Health and Illness, 33*(4), 618-633.

Shilpa, S., Mehta, D. P., Lubeck, D. J., Pasta, D. J., & Litwin, M. S. (2003). Fear of Cancer Recurrence in Patients Undergoing Definitive Treatment for Prostate Cancer: Results From CaPSURE. *The Journal of Urology, 170*(5), 1931-1933.

Shneerson, C., Taskila, T., Greenfield, S., & Gale, N. (2015). A Survey Investigating the Associations Between Self-Management Practices and Quality of Life in Cancer Survivors. *Supportive Care in Cancer, 23*(9), 2655-2662. doi: doi 10.1007/s00520-015-2626-8.

Shneerson, C., Taskila, T., Holder, R., Greenfield, S., Tolosa, I., Damery, S., & Gale, N. (2015). Patterns of self-management practices undertaken by cancer survivors: variations in demographic factors. *European Journal of Cancer Care, 24*(5), 683-694. doi: 10.1111/ecc.12252

Shneerson C.S, & Gale N.K. (2015). Using Mixed Methods to Identify and Answer Clinically Relevant Research Questions. *Qualitative Health Research, 25*(6), 845-856.

Singding, C., & Wiernikowski, J. (2008). Disruption Foreclosed: Older Women's Cancer Narratives. *Health, 12*(3), 389-411.

Sitzia, J., Hughes, J., & Sobrido, L. (1995). A Study of Patients ' Experiences of Side-Effects Associated with Chemotherapy: Pilot Stage Report. *Int. J. Nurs. Stud., 32*(6), 580-600.

Thomas-Maclean, R. (2004). Understanding breast cancer stories via Frank's narrative types. *Social Science and Medicine, 58*(9), 1647-1657.

Thorne, S., & Paterson, B. (1998). Shifting Images of Chronic Illness. *Journal of Nursing Scholarship, 30*(2), 173-178.

Tiefer, L. (2004). *Sex is Not a Natural Act and other Essays* (2nd ed.). Boulder, Colo: Westview Press.

Tishelman, C., & Sachs, L. (1998). The Diagnostic Process and the Boundaries of Normality. *Qualitative health research, 8*(1), 48-60.

Trusson, D. (2013). *Living with a New Normal: Women's Experiences Following Treatment for Early-Stage Breast Cancer or DCIS.* (PhD), University of Nottingham.

Weiner, C. (1975). The Burden of Rheumatoid Arthritis: Tolerating the Uncertainty. *Social Science & Medicine, 9*, 97-104.

Whitehead, L. (2006). Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social Science and Medicine, 62*, 2236-2245.

Williams, G. (1984). The Genesis of Chronic Illness: Narrative Re-Construction. *Sociol Health Illn, 6*(2), 175-200.

Williams, S. (2000). Chronic Illness as a Biographical Disruption or Biographical Disruption as a Chronic Illness? Reflections on a Core Concept. *Sociology of Health and Illness, 22*(1), 40-67.

Conflict of Interest

No conflict of interest declared.

Supplementary Materials

Any underlying research materials related to this paper can be accessed by contacting the corresponding author.