


'A new normal with chemobrain': Experiences of the impact of chemotherapy-related cognitive deficits in long-term breast cancer survivors

Health Psychology Open
January-June 2019: 1–10
© The Author(s) 2019
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/2055102919832234
journals.sagepub.com/home/hpo


Fiona ME Henderson, Ainslea J Cross and Amy R Baraniak

Abstract

Chemobrain is one of the most commonly reported side-effects of cancer treatment. However, there is limited research into its psychosocial concomitants. This study aimed to explore the long-term lived experience of chemobrain. Interpretative phenomenological analysis allowed an in-depth investigation of 12 breast cancer survivors suffering from perceived cognitive deficits at least 1-year post-treatment. Themes were organised around the illness representations framework. Commonly reported cognitive deficits related to memory, language and processing speed, which affected participants' sense of identity and their interactions with others. Individual experiences were mediated by health beliefs regarding controllability, validation and impairment trajectory.

Keywords

breast cancer, cancer, chemobrain, cognitive impairment, illness perception, interpretative phenomenological analysis, quality of life, qualitative methods

Breast cancer is the most prevalent of all cancers among women, with approximately 2 million new cases reported in 2018 (World Cancer Research Fund (WCRF), 2018). Mortality rates have been declining since 1989 (American Cancer Society, 2016), resulting in 10-year survival rates of approximately 78 per cent (Quaresma et al., 2014). However, adjuvant therapies such as chemotherapy can have long-lasting side-effects (Mandelblatt et al., 2016), which impact survivors' recovery and well-being (Selamat et al., 2014). With the increasing prevalence of breast cancer survivors (BCS), understanding the long-term sequelae of such therapies in order to minimise harm, develop appropriate interventions and improve quality of life (QoL) is an important concern.

Cancer-associated cognitive decline is gaining recognition as an important issue for people living beyond cancer (Ahles and Hurria, 2018). Often referred to as 'chemobrain' or 'chemofog' (Moore, 2014), it has been defined as subtle but persistent cognitive dysfunction frequently experienced during or post-chemotherapy with particular difficulties relating to maintaining attention, memory and perceived mental slowness (Janelsins et al., 2014). Although its

aetiology remains unclear, there is increasing evidence of structural and functional alterations in survivors, in terms of reductions in brain volume (Koppelmans et al., 2012) and altered neural activity (Menning et al., 2017).

Chemobrain affects up to 75 per cent of patients during treatment with 35 per cent reporting symptoms post-treatment (Janelsins et al., 2014). While deficits are generally described as mild or moderate, even a minor deterioration in cognitive function can have a profound impact on daily functioning and QoL (Hutchinson et al., 2012). Survivors experiencing chemobrain typically report feeling 'less sharp' post-treatment, with greater mental effort required for everyday tasks (Kanaskie and Loeb, 2015). These struggles become particularly pertinent when returning to work (Rimke et al., 2018). To date, there is limited research into the psychosocial impact of chemobrain (Bolton and Isaacs,

University of Derby, UK

Corresponding author:

Fiona ME Henderson, University of Derby Online Learning, University of Derby, Derby DE1 3LD, UK.
Email: fionahenderson100@gmail.com



2018) and the lack of prior information, validation or understanding from healthcare professionals, friends and family, has led to reports of disempowerment and subsequently receiving minimal levels of emotional and professional support (Mitchell and Turton, 2011).

While patients often notice cognitive impairments during treatment (Kanaskie and Loeb, 2015), several studies have reported that these deficits only become problematic when individuals attempt to return to routine activities (Selamat et al., 2014). The majority of research on chemobrain focusses on patients from diagnosis to 18 months post-treatment (Selamat et al., 2014). In this time-frame, the more detrimental side-effects of cancer treatment are still very present, with patients facing additional challenges such as fatigue, hormonal changes and fears of recurrence. However, evidence suggests that these impairments may persist for many years in a subset of survivors (Ahles et al., 2012).

Emotional well-being and how individuals cope with such challenges are shaped by health beliefs, with illness representations being key concomitants of medical and psychosocial outcomes (Kaptein et al., 2015). The self-regulatory model of illness (SRM; Leventhal et al., 1992) posits that common-sense illness beliefs provide a schema for individuals to find meaning or cope with existing health challenges and potential health threats. These are appraised through a cluster of perceptions regarding the identity, cause, duration, consequences and controllability of the condition (Leventhal et al., 1992). A recent meta-analysis found that higher perceived consequences and identity, perceptions of timeline as chronic and lower perceived controllability and illness coherence resulted in higher distress levels (Richardson et al., 2017). Furthermore, a study by de Ridder et al. (2007) found that patients and healthcare professionals were often reluctant to discuss illness perceptions when these were at odds with perceived medical beliefs; however, consultations that did focus on illness perceptions more directly addressed patient concerns and also tended to trigger action planning conversations. This research aims to explore the experience of living with chemobrain, within an illness representation framework, to gain insights into how BCS experience and adjust to chemobrain over the long term, in order to inform professionals how to provide better support and promote positive outcomes.

Methods

A qualitative design using semi-structured interviews and interpretative phenomenological analysis (IPA) (Smith et al., 2009) were used to explore the lived experience of chemobrain in BCS.

Procedure and participants

Ethical approval was sought and obtained from the University of Derby (ref. 15/16/51647315) with local

approvals from organisations assisting in the recruitment process. These included a private oncology clinic, the National Cancer Centre Singapore, the Breast Cancer Foundation (Singapore) and through local support groups in the United Kingdom. Purposive sampling was employed, with these organisations distributing recruitment flyers. Inclusion criteria required that participants had been diagnosed with non-metastatic breast cancer, had completed chemotherapy at least 1 year prior to the interview and reported experiencing cognitive impairment post-treatment. Interviews were conducted in English.

In total, 19 participants expressed an interest in taking part; 6 individuals failed to respond and 1 failed to meet the inclusion criteria, leaving a final sample size of 12 participants. Identity was protected using pseudonyms; however, participants were informed that quotes from the interviews might be used in the final report. Participants' ages ranged from 29 to 68 years with a mean age of 51 years and time since chemotherapy ranged from 1 to 14 years with a mean time of 5.4 years post-chemotherapy (YPC) (Supplemental Appendix 1).

Participants were asked to complete a short questionnaire addressing demographic information and treatment details, sign a consent form and were informed of their right to withdraw. This was followed by face-to-face semi-structured interviews, lasting approximately 45 minutes, which were used to explore participants' experiences of living with chemobrain. Interview questions were developed based on key themes emerging from a review of the literature. Opening questions addressed general treatment-related issues in order to establish rapport and gradually focused on more specific aspects, for example, the impact of chemobrain on identity (*Have these changes made you feel differently about how you see yourself?*) and coping (*What have you found helps you to overcome or cope with symptoms?*). An inductive approach was taken to the interview process, which allowed the discussion to follow the participant's particular concerns when recounting experiences.

Qualitative analysis

The current study adopted a qualitative design, using a phenomenological framework. IPA (Smith, 1995) has been widely used within the health psychology literature (Smith and Osborn, 2015). It was deemed to be well-suited to the sensitive nature of this research as it focuses on the lived experience and is also based primarily on a hermeneutic of empathy (Dickson et al., 2007). Furthermore, while it acknowledges the co-constructive roles of both participant and researcher, the idiographic focus puts the participant at the centre of the analysis (Smith and Osborn, 2015). An inductive approach was used for the interviews and analysis; the theoretical framework for the analysis was drawn from Leventhal's SRM (Leventhal et al., 1992; Moss-Morris et al., 2002) as the major themes arising from the

existing literature mapped closed onto the domains of the SRM. The SRM presents a useful framework for exploring the appraisal of health beliefs. For the purposes of this study, we use the term ‘symptom beliefs’ to refer to participants’ characterisation of chemobrain as symptoms, rather than referring to a specific illness.

The data were analysed based on procedures by Smith (1995). Transcripts were read repeatedly for familiarisation, with exploratory coding and initial emergent themes noted in the margins. These emergent themes were then scrutinised for interrelationships and clustered over several iterations within the broader themes of the illness representation framework and then finally organised into three superordinate themes. Extracts were then selected which best conveyed the essence of the themes.

Results

Some women focussed on finding meaning in their experiences of chemobrain, while others reflected retrospectively on their experiences and the trajectory of ‘getting back to normal’. Three superordinate themes (the new normal, beliefs and expectations, coping with chemobrain) emerged from the data which broadly encompass the domains of the SRM (Leventhal et al., 1992; Moss-Morris et al., 2002). These are represented together with subordinate themes in Table 2 of Supplemental Appendix 2.

Participants tended to describe general experiences of chemobrain, rather than specific events, potentially reflecting the impaired memory issues that many of the women reported. They often described drawing a ‘total blank’ when asked to recall specific episodes, leaving them to estimate the actual prevalence of these episodes and the passage of time.

The new normal

The first theme, ‘the new normal’, encompasses the SRM domains of identity (relating to the manifestation of chemobrain) and consequences (relating to the impact to self, changes in social interaction, disclosure and consequences within the workplace). It was the most dominant theme in the interviews and shapes the remaining themes as it highlights the women’s attempts to adapt to cognitive changes. The participants’ experiences of chemobrain and their sense of self was inextricably linked with their interaction with others, their beliefs about chemobrain as a phenomenon and their ability to cope.

Identity

Experience of cognitive changes. The subordinate theme of ‘identity’ explores the participants’ experiences of the manifestation of chemobrain and adjusting to a new normal. There were many similarities in the participants’ experience

of cognitive dysfunction, particularly the perceived inability to perform tasks that prior to treatment had been appraised as straightforward, mostly relating to memory, word finding, processing and multitasking.

Participants described feeling slower in their ability to process information, but were typically still able to accomplish day-to-day tasks, although these often required much greater mental effort. Claire (3.5 YPC) described ‘feeling five steps behind’ when trying to keep up with a conversation. All participants had identified themselves as previously being able to juggle demanding schedules, and therefore, these deficits impacted what they perceived as basic activities of daily living:

That’s how I describe my thoughts sometimes, like will-o-the-wisp. They come into your head, like they just float in and I can’t even grab them, to get a hold of that thought properly and then write them down so I don’t forget. (Alice, 6.5 YPC)

Many participants described difficulties with working memory. Without prompts, names and appointments were routinely forgotten. However, the perceived severity of the deficit varied considerably between individuals, with some areas of cognition more adversely affected than others. Victoria reports more substantial cognitive deficits including significant memory loss:

I read some of my meeting notes and it’s clearly my hand writing and I have no memory of taking those notes ... no memory that that meeting ever happened ... but it’s my handwriting! I was clearly there! And that is very shocking to me. (Victoria, 2.5 YPC)

Women also described challenges with higher-order cognitive functions, such as difficulties with (1) critical or strategic thinking, (2) creative thinking, (3) assimilating information and (4) making connections. Alison valued her ability to develop creative solutions, prior to treatment:

In the past making connections between things that didn’t appear to have connections, was something I specialized in because we used to comment on it. And that’s a big thing in my kind of work and I don’t think I can do that now. I feel like ... I feel ... I don’t do it. I have to really think things through. And it used to be just instant .. that relates to that .. and I could see a connection. (Alison, 2 YPC)

All participants discussed factors which they appraised as likely to exacerbate the symptoms associated with chemobrain; lack of sleep and stress were most common. Depression, infections and increased awareness of deficits in unfamiliar or perceived pressurised situations were also appraised as worsening the effects of chemobrain:

The more I want to do it the more nervous I get the more mistakes I make. (Katherine, 1 YPC)

I was not sleeping at all well. I was quite depressed – I know that when I don't sleep ... well that screws everything else up. (Cantor, 11 YPC)

Consequences. The consequences of chemobrain were also often described in terms of adjusting to a 'new normal', which was characterised by changes in personal identity, social interactions and as adjustment to working life.

Impact on self and relationships. Sentiments reflecting profound loss and a powerful undermining of identity ran through most participant accounts, but these dissipated over time. Women predominately perceived themselves as previously capable individuals who now felt less competent, less intelligent and often with a diminished sense of control and agency. Perceived cognitive failures reduced confidence and increased doubts about their ability to return to work:

I think there is a piece that's lost ... it's like a bereavement in a sense. Part of me is lost or dormant. (Rita, 6.5 YPC)

Changes in social interaction. Many of the women also mentioned feeling easily overwhelmed post-treatment and the struggle to adjust to a 'new normal' was associated with a detrimental impact on their relationships and QoL. Claire described difficulties in dealing with relationship stress:

When he comes home highly-strung I can feel it immediately and then things just deteriorate because I just can't ... his stress I can't deal with his stress because it ends up making me stressed out. (Claire, 3.5 YPC)

In contrast, Katherine and Lili reflect on the impact their altered identity had on family members. They blamed themselves for what they saw as an inability to maintain their old capabilities. Katherine suggested that she perceives her 'new self' to be less loveable and that she had, in some way, let her husband down:

He used to really adore me ... but now he thinks that I'm very ... I'm a bit slow. (Katherine, 1 YPC)

Disclosure. Social interactions with unfamiliar individuals were also affected by participants' desire to hide their cognitive deficits, as cognitive failures were often appraised as a source of shame and embarrassment:

No. No. I'd never ever divulge that I don't remember. No. I will with friends, but not ... not just random people. Because then you have to explain why you don't remember. (Claire, 3.5 YPC)

Consequences within the workplace. Participants' biggest concerns about disclosure and the impact of cognitive deficits were in the domain of work. All but one of the women

had careers. Four of the women reported having supportive work environments which eased their return to work, allowing them to disclose their deficits and to ask colleagues for help and support. Cantor's account demonstrates her openness regarding potential deficits:

It's a team effort and we do things together. It's not an up and out environment I work in where you would feel you couldn't say that because it would show weakness. (Cantor, 11 YPC)

Here, there is no sense of additional pressure or the possibility of being judged or failing to meet required standards. However, Leng's response was more guarded:

He took me in, knowing that I'm a survivor, knowing that I'm a breast cancer survivor for six years. And what if he knew about this study? ... would he take me? It's a big question and I kept it to myself and I never tell people I had chemobrain. (Leng, 14 YPC)

Finding employment opportunities for those who had either been unemployed or freelance prior to diagnosis also posed a significant challenge, in terms of unexplained gaps in their CVs, or the need to find part-time as opposed to full-time work. The extracts below demonstrate the practical and emotional impact of the cancer diagnosis on Rita's and Alison's careers:

I am unable to work. Even if I do reach a point where I feel able to work, the gap in my employment will, by then, make it much more difficult for me to be even shortlisted for a post. This has considerable financial implications for me which further restricts what I can do. (Rita, 6.5 YPC)

Alison explains that she feels incredibly fortunate to be back in the workplace. She describes herself as 'driven by work'; however, her loss of confidence results in a much greater need for feedback and reassurance:

... I appreciate that when you start something new that there is always a bit of anxiety, but it really feels heightened ... I really feel ridiculously anxious about whether I understood their comments and whether I've incorporated them in a way that makes sense. And because they haven't commented yet on my final report .. I'm ... just nervous. (Alison, 2 YPC)

When discussing the day-to-day impact of cognitive deficits and adjustment to a 'new normal', the most common emotional reactions were frustration and increasing exasperation. However, participants often minimised the extent of cognitive issues when viewed in relation to the wider experience of breast cancer and its impact on QoL, as described by Victoria in the quote below:

Due to the experiences of cancer and the re-evaluation of what matters to me in life ... I'm better at coping with nuisances. (Victoria, 2.5 YPC)

Beliefs and expectations

This theme encompasses the SRM domains of timeline (the impairment trajectory), cause (an uncertain aetiology) and illness coherence (awareness and validity).

Timeline

The impairment trajectory. The timeline of chemobrain was appraised in terms of beliefs about recovery and improvement in chemobrain symptoms. Most women reported being aware of cognitive deficits during treatment but only appraised them as problematic when persistence exceeded their expected timeline of recovery:

You know all that started happening, was during that time as well, but really you know I could say that that was my recovery period. But post a year you can't really say that's your recovery period any more. (Claire, 3.5 YPC)

Participants differed in their expectations of the recovery timeline. Most women had initially assumed that cognitive deficits were likely to be transient. Survivors at 1 to 2 years post-treatment were hopeful of recovery, but as time progressed, women, particularly those between 2 and 6 years post-treatment, reappraised their expectations and were less optimistic of full recovery:

I have a hard time picturing them getting better. If anything I'm hoping they will just stay at their current level versus progress (Rachel, 2 YPC)

But I have noticed more recovery in the last 6 months than in the previous 6 years. (Rita, 6.5 YPC)

But I can't think when that really came back. It was years, rather than months. (Cantor, 11 YPC)

The majority of accounts suggest that recovery takes considerably longer than initial expectations. All participants reported varying degrees of improvement in memory, concentration and multitasking. However, while the majority of women up to 6 years post-treatment reported only slight improvement, some participants who were above 10 years post-treatment acknowledged some residual deficits, but felt their cognitive functioning was within the expected norms of women their age:

You're fuzzy for that period of time and you expect to come out of it and you do to a certain extent but there is always a little bit that doesn't connect ... (Claire, 3.5 YPC)

Cause

An uncertain aetiology. All participants attributed the cognitive deficits that they experienced to chemotherapy, but to varying levels. However, acknowledgement that there is uncertainty surrounding the underlying aetiology of

chemobrain led to significant speculation about the extent to which other factors, such as fear, rumination, cognitive overload, mental inactivity and age, may also contribute to the condition:

It's very difficult to know how much of that's to do with the shock of what happened and how much it's to do with the drugs that they were giving me and how much was what the chemo did to me. (Cantor, 11 YPC)

This suggests that causal attributions for chemobrain-related symptoms are complex and may be ascribed to other aspects of the cancer experience. Such causal attributions were also problematic as none of the women received adequate information from healthcare professionals. Many felt that it was poorly understood or as Lucy describes 'yet to be taken seriously' (Lucy, 3 YPC). Consequently, several women questioned whether these deficits were a genuine side-effect of treatment, or the result of stress, heightened monitoring, a symptom of metastasis or the onset of dementia.

Illness coherence

Awareness and validity. Most participants reported that they began chemotherapy being unaware of chemobrain as a potential side-effect of treatment. While they developed some understanding of the condition through fellow survivors or Internet searches, the majority dealt with their symptoms without actively seeking reassurance from the medical community. This initial lack of awareness often resulted in shock and panic, but over time, as they began to acknowledge these deficits, there was an increasing need for validation. Many women mentioned discovering chemobrain almost by accident:

I overheard it in the chemo suite type place, you know. And somebody would say 'oh, it's your chemobrain again, Jane' or whatever and I thought gosh, that's incredibly rude to say that. And then I realized that it was not always being used as an insult. (Lucy, 3 YPC)

The lack of a clear illness identity and the paucity of professional guidance made it difficult for the women to make sense of their deficits, and this lack of coherence was exacerbated when situated within the wider cancer experience. This resulted in a relentless struggle both internally and at times with others. Two extracts from Claire encapsulate this struggle and also express the need for reassurance:

As soon as I started getting fuzzy I started googling chemobrain and all that kind of stuff ... and at that time it was still kind of very wishy washy about whether it existed or not. I don't know if that's ... I don't really google it any more ... because I know that I have it and I don't care what anyone says. (Claire, 3.5 YPC)

Even such a clear attribution fails to alleviate the doubt and the following extract highlights this dissonance:

I do accept it. But, you know .. but at the same time I go a little bit crazy because I do like ... this isn't normal, that I feel like this ... and then I started thinking that it had spread to my brain and maybe that was what was affecting ... you know ... all these things. So I did end up getting an MRI a couple of weeks ago. (Claire, 3.5 YPC)

While this demonstrates that being able to label the condition does not necessarily nullify Claire's doubts, the majority of women reported that being able to attribute their deficits to chemobrain had positive repercussions, in terms of acknowledgement and reassurance. Without validation, the lack of clarity surrounding the identity of chemobrain limited opportunities for both help seeking and reassurance.

Coping with chemobrain

This theme encompasses the SRM domain of perceived control (compensatory strategies, support and understanding). Participants mainly reported proactive attitudes towards dealing with their difficulties which involved finding support and also identifying effective compensatory strategies that helped them to manage, prevent or improve situations arising from their cognitive impairments.

Perceived control

Compensatory strategies: beliefs of curability. All participants reported the value of planning, preparation and writing things down. However, participants who viewed deficits as transitory and curable placed greater emphasis on trying to exercise their brains first, with 'being mindful' and 'trying my best' being common themes throughout their accounts:

So I'm conscious of it and I try to, when I really have to think in a strategic way I actually don't even open my outlook ... I just slow down and that really works because I really focus. (Victoria, 2.5 YPC)

I have to tell myself 'just try to do this one moment at a time'. (Lucy, 3 YPC)

When the additional effort resulted in positive outcomes, this approach increased perceived control. However, when perceived effort was less successful, this appeared to exacerbate the sense of failure:

It really adds on the pressure when I'm already trying very hard to do well but then when I fail to do so, having someone tell me that you're not ready, it's just that ... you know ... it's ... er ... I guess ... it lowers my self-esteem. (Katherine, 1 YPC)

All participants relied to some extent on strategies focussed primarily on external memory aids, and this was particularly salient for those who viewed deficits as permanent or incurable:

So my phone really is my lifeline. It ... my daily schedule and everything is in there with reminders, like beeping reminders to tell me when I have to go and all that kind of stuff. (Claire, 3.5 YPC)

Support and understanding. Participants' ability to manage their deficits was also influenced by their social environment and feedback from others. The greatest sources of support came from family and close friends and, in a few cases, work colleagues. However, reluctance to disclose cognitive issues limited the sources of help available. One common theme related to the value of reciprocity. Finding a safe environment to openly discuss these issues provided an invaluable source of information sharing which helped women to develop effective ways to manage their symptoms:

Yeah when I met fellow survivors at BCF (Breast Cancer Foundation) ... yeah ... I thought, they also experienced what I have experienced. So it's OK. It's not too bad and we laughed about it. (Leng, 14 YPC)

However, for Rachel, her friends' attempts to normalise her issues, such as 'Oh don't worry about it ... happens to me all the time' or 'Yeah, I need to write lists all the time' (Rachel, 2 YPC), acted as an additional source of distress:

because when people do things like that it basically invalidates your feelings, of ... whether you feel inadequate, or frustrated or those types of things, it basically says your feelings are worthless, because that's normal. And well ... yes, it is. But it's my new normal, it's not my old normal. (Rachel, 2 YPC)

She argues that recognising the changes would be a far more supportive strategy as this would acknowledge her former self, perhaps mitigate blame and empathise with her loss.

Discussion

This study explored the experiences of BCS adjusting to living with cognitive deficits at least 1-year post-chemotherapy. The findings highlight the role of symptom beliefs in shaping experiences using the revised six dimensions of illness representations (Moss-Morris et al., 2002). These themes build on constructs raised in previous research on chemobrain, for example, identity disruption, social interaction and coping (Kanaskie and Loeb, 2015; Von Ah et al., 2013). In terms of *identity*, the symptoms of chemobrain are experienced as problems with memory, information assimilation and processing, multitasking, critical and

creative thinking, and making connections. Factors that exacerbate the experience of chemobrain included a lack of sleep, elevated stress, depression and experiencing perceived pressured situations. Such symptoms were perceived as particularly problematic if the *timeline* of the symptoms exceeded their beliefs about the recovery and improvement of chemobrain symptoms. Chemobrain presents a challenge in adjustment to the 'new normal' (*consequences*), undermining the sense of self, particularly relating to work and social relationship domains. While participants acknowledged chemotherapy as the *cause* of their symptoms, there were varying levels of this belief as some acknowledged that there could be other cancer-related factors at play. Furthermore, there were varying levels of *illness coherence* as it was acknowledged that chemobrain has an unclear aetiology. With limited guidance or acknowledgement of chemobrain from healthcare professionals, participants reported difficulty in finding evidence-based information which resulted in feelings of frustration at the lack of professional acknowledgement of their symptoms. Perceived *control* of chemobrain symptoms was achieved through the use of experience-based compensatory strategies such as remaining present, mindfulness, making lists, slowing down the pace of life and social support.

There were inconsistencies regarding the severity of these deficits and their impact on QoL. In line with previous research (Richardson et al., 2017), the women who perceived consequences to be more severe and who viewed their deficits as likely to be permanent had higher levels of distress and struggled more with role and social functioning than those who were able to downplay their difficulties. While many women reported episodes involving moderate-to-severe cognitive issues, almost all participants also described overall deficits as 'not too bad'. Similarly, while many participants downplayed the impact on QoL, they also reported struggling to come to terms with altered identities and adapting to a 'new normal', which was characterised by a profound sense of loss both in terms of capability and self-esteem, and also in personal control and agency. This highlights the value of IPA, with its focus on the 'double hermeneutic' and the researcher's attempt to interpret the participants' efforts to make sense of their experiences (Smith et al., 2009). These inconsistencies may simply reflect recall issues. However, these apparent contradictions may also suggest that psychosocial impact is likely to be influenced by whether deficits are viewed in isolation or compared to the immeasurable and persistent existential threat of the cancer diagnosis.

Following an inductive approach using the existing literature, we found that the data closely aligned to the domains of the SRM, with the dominant theme of adjustment to the new normal, permeating the less salient themes. The key tenet of the SRM is that an individual's cognitive and emotional appraisal of a health threat or condition prompts a coping response designed to alleviate both the

threat and the associated distress (Hagger et al., 2017). Using the SRM as the theoretical framework for this research, therefore, provides an important platform for the development of future interventions for chemobrain. Hagger et al. (2017) recently offered a revised model, which advocates targeting not only specific illness domains associated with positive outcomes (e.g. improved role and social functions, lower levels of psychological distress and increase well-being) but also the coping response elicited by such representations. They argue that targeting specific dimensions can lead to both adaptive and maladaptive outcomes, depending on the specific circumstances. This proposed model fits well with the findings from this study. Adopting problem-focussed coping strategies to tackle the symptoms of chemobrain may elicit adaptive outcomes in those who believed that the condition was controllable, but maladaptive outcomes in those who regarded it as uncontrollable or in particularly stressful situations. In these circumstances, adaptive emotion-focussed strategies might prove more effective and highlights the utility of exploring the SRM domains with women as part of the move towards personalised cancer care.

The lack of illness coherence and lack of professional validation regarding chemobrain hindered adjustment for many women. Participants articulated a sense that impairments should be hidden from public view, causing much of the anxiety to be internalised and limiting opportunities to seek support. The issue of disclosure was particularly pertinent to the workplace. For many women, the return to work represents a milestone in recovery, providing income, identity and renewed social contact (Wolwers et al., 2018), but for some participants, cognitive deficits and lower levels of self-efficacy made the prospect challenging. While supportive work environments allowed survivors to ask for help, those who were either self-employed or looking for new employment opportunities struggled to mask impairments for fear of being penalised in some way. Approximately 30 per cent of cancer patients fail to return to work after 18 months and a significant number of those with impaired ability either change or leave their jobs (De Boer et al., 2009). Therefore, providing rehabilitation programmes and raising awareness within the workplace may prove a beneficial way to improve outcomes.

Compensatory strategies were linked to control and curability symptom beliefs (Leventhal et al., 1992). Participants who believed that chemobrain was transitory regarded deficits as a challenge that needed to be overcome and placed emphasis on strategies that involved exercising the brain and mindfulness. In contrast, participants who felt the impairments were permanent reported a greater reliance on external prompts and technology. These differences in perceived permanence were often related to time post-treatment.

Previous qualitative studies have typically regarded long-term survivors as a single cohort (Selamat et al., 2014);

however, in this study, participants' experiences appeared to be stage specific. When deficits were viewed as part of the 'recovery period', they were generally deemed to be unproblematic; however, the impairments had a much greater psychological impact when persistence exceeded expectations. Participants in this study were initially alarmed, but at 2 to 6 years post-treatment, this gave way to frustration and resignation, with diminished hopes of a return to 'normal'. However, the three participants who were 10 years post-treatment reported some residual deficits but significant improvement overall. Some studies have shown deficits persisting 10 years post-treatment (Yamada et al., 2010), while others have found significant improvement at 3 years (Zheng et al., 2014). To date, there has been little research into the trajectory of perceived improvement (Von Ah et al., 2013). Therefore, further longitudinal research into symptom beliefs and the psychosocial impact of chemobrain along the impairment trajectory may provide a useful avenue for improving care.

Implication for clinical practice

The lack of clarity regarding the aetiology of chemobrain, together with an inability to accurately assess reported impairments, may explain the lack of medical acknowledgement (Player et al., 2014). However, consistent with earlier research (Boykoff et al., 2009), this study found the lack of prior information or acknowledgement of perceived cognitive symptoms increased psychological distress and worries of disease progression or dementia. These findings highlight the need for healthcare professionals to recognise chemobrain as a legitimate issue for survivors. Proactively addressing these issues and empowering survivors through the development of effective interventions and management strategies may help to mitigate the impact of cognitive impairment and increase QoL. Von Ah et al. (2013) advocate raising awareness among friends and family, as a basis for future interventions. However, others may benefit more from raising awareness in cancer support groups, as this appears to provide an important outlet of open discussion and meaningful support, by normalising experience and providing a valuable opportunity for knowledge sharing.

Conclusion

Overall, this study adds to the body of research on the lived experience of chemobrain in BCS. Findings suggest that post-treatment cognitive impairments have a negative impact on survivors' identity, relationships and their ability to return to a pre-diagnosis sense of wellness. Findings highlight the need to educate healthcare professionals on how best to empower survivors, through validation and effective interventions. Further research into the long-term impairment trajectory may also enhance opportunities for developing stage-specific interventions that help to improve care and promote positive outcomes for BCS.

Declaration of conflicting interests

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

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

References

- Ahles TA and Hurria A (2018) New challenges in psycho-oncology research IV: Cognition and cancer: Conceptual and methodological issues and future directions. *Psychooncology* 27(1): 3–9.
- Ahles TA, Root JC and Ryan EL (2012) Cancer- and cancer treatment-associated cognitive change: An update on the state of the science. *Journal of Clinical Oncology* 30(30): 3675–3686.
- American Cancer Society (2016) What are the key statistics about breast cancer? Available at: <http://www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-key-statistics>
- Bolton G and Isaacs A (2018) Women's experiences of cancer-related cognitive impairment, its impact on daily life and care received for it following treatment for breast cancer. *Psychology, Health & Medicine* 23(10): 1261–1274.
- Boykoff N, Moieni M and Subramanian SK (2009) Confronting chemobrain: An in-depth look at survivors' reports of impact on work, social networks, and health care response. *Journal of Cancer Survivorship* 3(4): 223–232.
- De Boer AG, Taskila T, Ojajarvi A, et al. (2009) Cancer survivors and unemployment: A meta-analysis and meta-regression. *JAMA* 301(7): 753–762.
- De Ridder DTD, Theunissen NC and van Dulmen SM (2007) Does training general practitioners to elicit patient's illness representations and action plans influence their communication as a whole? *Patient Education and Counseling* 66: 327–336.
- Dickson A, Knussen C and Flowers P (2007) Stigma and the delegitimation experience: An interpretative phenomenological analysis of people living with chronic fatigue. *Psychology & Health* 22(7): 851–867.
- Hagger MS, Koch S, Chatzisarantis NLD, et al. (2017) The common sense model of self-regulation; Meta-analysis and test of a process model. *Psychological Bulletin* 143(11): 1117–1154.
- Hutchinson AD, Hosking JR, Kichenadasse G, et al. (2012) Objective and subjective cognitive impairment following chemotherapy for cancer: A systematic review. *Cancer Treatment Reviews* 38(7): 926–934.
- Janelsins MC, Kesler SR, Ahles TA, et al. (2014) Prevalence, mechanisms, and management of cancer-related cognitive impairment. *International Review of Psychiatry* 26(1): 102–113.
- Kanaskie ML and Loeb SJ (2015) The experience of cognitive change in women with breast cancer following chemotherapy. *Journal of Cancer Survivorship* 9: 375–387.
- Kaptein AA, Schoones JW, Fischer MJ, et al. (2015) Illness perceptions in women with breast cancer – A systematic literature review. *Current Breast Cancer Report* 7(3): 117–126.
- Koppelmans V, De Ruiter MB, Van der Lijn F, et al. (2012) Global and focal brain volume in long-term breast cancer

- survivors exposed to adjuvant chemotherapy. *Breast Cancer Research and Treatment* 132: 1099–1106.
- Leventhal H, Diefenbach M and Leventhal EA (1992) Illness cognitions: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research* 16: 143–163.
- Mandelblatt JS, Clapp JD, Luta G, et al. (2016) Long-term trajectories of self-reported cognitive function in a cohort of older survivors of breast cancer: CALGB 369901 (alliance). *Cancer* 122(22): 3555–3563.
- Menning S, de Ruiter MB, Veltman DJ, et al. (2017) Changes in brain activation in breast cancer patients depend on cognitive domain and treatment type. *PLoS ONE* 12(3): e0171724.
- Mitchell T and Turton P (2011) ‘Chemobrain’ concentration and memory effects in people receiving chemotherapy – A descriptive phenomenological study. *European Journal of Cancer Care* 20(4): 539–548.
- Moore HC (2014) An overview of chemotherapy-related cognitive dysfunction, or ‘chemobrain’. *Oncology (Williston Park)* 28(9): 797–804.
- Moss-Morris R, Weinman J, Petrie KJ, et al. (2002) The revised illness perfection questionnaire (IPQ-R). *Psychology and Health* 17(1): 1–16.
- Player L, Mackenzie L, Willis K, et al. (2014) Women’s experiences of cognitive changes or ‘chemobrain’ following treatment for breast cancer: A role for occupational therapy? *Australian Occupational Therapy Journal* 61: 230–240.
- Quaresma M, Coleman MP and Rachet B (2014) 40-year trends in an index of survival for all cancers combined and survival adjusted for age and sex for each cancer in England and Wales, 1971–2011: A population-based study. *Lancet* 385(9974): 1206–1218.
- Richardson EM, Schuz N, Sanderson K, et al. (2017) Illness representations, coping, and illness outcomes in people with cancer: A systematic review and meta-analysis. *Psychooncology* 26(6): 724–737.
- Rimke B, Duijts SFA, Smith SN, et al. (2018) Functional impairments and work-related outcomes in breast cancer survivors: A systematic review. *Journal of Occupational Rehabilitation* 28: 429–451.
- Selamat MH, Low SY, Mackenzie L, et al. (2014) Chemobrain experiences by breast cancer survivors: A meta-ethnography study investigating research and care implications. *PLoS ONE* 9(9): e108002.
- Smith JA (1995) Semi-structured interviewing and qualitative analysis. In: Smith JA, Harre R and van Langenhove L (eds) *Rethinking Methods in Psychology*. London: SAGE, pp. 9–26.
- Smith JA and Osborn M (2015) Interpretative phenomenological analysis. In: Smith JA (ed.) *Qualitative Psychology: A Practical Guide to Research Methods* (3rd edn). Thousand Oaks, CA: SAGE, pp. 25–52.
- Smith JA, Flowers P and Larkin M (2009) *Interpretative Phenomenological Analysis: Theory, Method, and Research*. Los Angeles, CA: SAGE.
- Von Ah D, Haberman B, Carpenter JS, et al. (2013) Impact of perceived cognitive impairment in breast cancer survivors. *European Journal of Oncology Nursing* 17: 236–241.
- Wolters MD, Leensen MC, Groeneveld IF, et al. (2018) Predictors of earlier return to work of cancer patients. *Journal of Cancer Survivorship* 12: 169–177.
- World Cancer Research Fund (WCRF) (2018) Breast cancer statistics: Breast cancer is the most common cancer in women worldwide. Available at: <https://www.wcrf.org/dietandcancer/cancer-trends/breast-cancer-statistics> (accessed 20 November 2018).
- Yamada TH, Denburg NL, Beglinger LJ, et al. (2010) Neuropsychological outcomes of older breast cancer survivors: Cognitive features ten or more years after chemotherapy. *Journal of Neuropsychiatry and Clinical Neuroscience* 22(1): 48–54.
- Zheng Y, Luo J, Boa P, et al. (2014) Long-term cognitive function change among breast cancer survivors. *Breast Cancer Research and Treatment* 146(3): 599–609.

Appendix A

Table 1: Participant Overview (ranked by length of time post treatment).

Name (pseudonym)	Age (years)	Nationality	Stage at Diagnosis	Time Since Chemotherapy (years)
Katherine	29	Hong Kong	Stage 1	1
Rachel	41	USA	Stage 3c	2
Alison	48	UK	Stage 1	2
Victoria	43	Germany	Unclear	2.5
Lili	59	Singapore	Stage 1	2.5
Lucy	60	UK	Stage 3	3
Claire	43	Canada	Stage 1	3.5
Rita	68	UK	Stage 2	6.5
Alice	57	UK	Stage 2b	6.5
Rose	60	NZ	Stage 1	10
Cantor	49	UK	Stage 3c	11
Leng	59	Singapore	Stage 2	14

Appendix B

Table 2: Superordinate themes and sub-themes.

The new normal	Beliefs and expectations	Coping with chemobrain
<i>Identity:</i> Experience of cognitive changes	<i>Timeline:</i> The impairment trajectory	<i>Perceived control:</i> Compensatory strategies: beliefs of curability Support and understanding
<i>Consequences:</i> Impact to Self Changes in social interaction Disclosure Consequences within the workplace	<i>Cause:</i> Uncertain aetiology <i>Illness coherence:</i> Awareness and validity	