

Keywords: persistent pain, chronic pain, cancer survivor, cancer, living with and beyond cancer

ABSTRACT:

Objective

This qualitative evidence synthesis aimed to identify, review and synthesise qualitative research describing the experience of persistent pain in adult cancer survivors.

Methods

A systematic literature search was conducted between December 2007 and June 2019. Data synthesis followed Thomas and Harden's (2008) method of thematic synthesis.

Results

Four studies were identified, together incorporating findings from 52 female breast cancer survivors. Six themes were generated: 1) Interwoven relationship between experience of cancer and persistent pain 2) Lack of preparedness and support for persistent pain 3) Physical impact of persistent pain 4) Employing coping strategies 5) Emotional experience of persistent pain and 6) Conceptualisation of persistent pain.

Conclusions

Persistent pain is intrinsically interwoven with women's experiences of cancer. Persistent pain was unexpected and women did not feel supported. Women need more information about persistent pain after cancer treatment and support with self-management of pain. Ways to best support cancer survivors with persistent pain need exploration and a review of current available services is required. More research is needed to understand the experiences of men and other cancer groups

MAIN TEXT

INTRODUCTION

Survival rates for cancer are improving and more people are living for longer following their cancer treatment (Maddams, Utley and Møller, 2012; Siegel and Miller, 2019). However, people can experience many problems and symptoms in the months and years following treatment (Armes et al., 2009; Bennion and Molassiotis, 2013; Maher et al., 2018). A common problem and concern for cancer survivors is pain (Capelan et al., 2017; Schmidt, Wiskemann and Steindorf, 2018). A recent systematic review of 117 studies (n – 63,533) found 39% of people treated for cancer, experience pain after curative treatment (Van Den Beuken-Van Everdingen et al., 2016). Similarly, Schmidt et al (2018) found 34% of breast cancer survivors experienced pain. A study into the prevalence of unmet needs in 625 women living beyond a diagnosis of early breast cancer found 19% had unmet needs relating to pain (Capelan et al., 2017). These findings demonstrate that pain is a significant problem for cancer survivors, yet they do not describe cancer survivors' experiences of pain. Understanding the experiences and needs of cancer survivors is key to improving how well people live after cancer (Maher et al., 2018). The current study therefore aimed to identify, review and synthesise qualitative research describing the experience of persistent pain in adult cancer survivors.

A particular challenge in this field is the lack of consensus in the literature or national clinical guidelines regarding definition of the term 'cancer survivor' (Rees, 2018). The European Organisation for Research and Treatment of Cancer (EORTC) Survivorship Task Force define it as any person diagnosed with cancer, who has completed his or her primary treatment (with exception of maintenance therapy) and who has no active disease (Moser and Meunier, 2014). This study adopts this definition. Persistent pain is defined as pain that persists for three months or more (IDC11).

METHODS

Protocol registration

A protocol for this study was registered with the International prospective register of systematic reviews (PROSPERO) in December 2017 (PROSPERO 2017 CRD42017082562).

Review question

What is the experience of persistent pain in adult cancer survivors?

Search strategy

A comprehensive search strategy was developed to locate all available studies. Key search terms were used to search relevant databases: CINAHL Plus, Medline, PsycINFO, Embase and Cochrane (Table 1). The search terms were informed by a cancer survivor, the published pain literature and discussion with the study team. Reference lists of identified papers were reviewed. Figure 1 outlines the search strategy. A search limit of 2007-2019 was set.

Inclusion and exclusion criteria

Inclusion:

- Primary research adopting a qualitative methodology (either stand alone or as a discrete element of mixed method research)
- Explores cancer survivors' experience of persistent pain
- Includes populations of adults over 18 years old when diagnosed and treated for cancer
- Published in English between 2007 and 2019
- Full peer review articles (not abstracts or conference proceedings only)

Exclusion:

- Quantitative research
- Commentary articles and clinical updates
- Studies including sample populations of those exclusively on active treatment or end of life care
- Studies of survivors of childhood cancer

The question is most appropriately addressed by qualitative research as qualitative research seeks to understand lived experience, behaviours and social contexts to explain phenomena of interest (Braun and Clarke, 2013). Survivors of childhood cancer or those at the end of life were excluded. This was because survivors of childhood cancer may have experiences that are unique to that population such as challenges with social integration (Lea *et al.*, 2019) and transitioning from paediatric to adult cancer services (Casillas *et al.*, 2010) or disruption in schooling (Park *et al.*, 2018). Equally, those at the end of life have unique needs (Hackett, Godfrey, Bennett, 2016). A limit of studies published between 2007 and 2019 was applied to ensure the most up to date research was identified. Treatment for cancer has been progressing and changing over time, particularly in breast cancer. Therefore a start date of 2007 was set as publications beyond that date were likely to be representative of current patient experience.

Screening

The search resulted in 683 potential studies. Figure 2 outlines the study selection process. Titles and abstracts were reviewed against the inclusion and exclusion criteria and were excluded or referred for full text review. Two authors independently reviewed full texts of remaining studies. Initially 64 papers were excluded because the study design or patient population did not meet the inclusion criteria for this synthesis, the studies were presented as abstracts only or not published in English. Authors met and discussed decisions and brought the remaining studies (n = 16) to the wider team for further discussion. This resulted in clarification of the inclusion and exclusion criteria:

- If the population has completed anti-cancer therapy but were on hormone treatment, they could be included
- If the population had metastatic disease, they would be excluded

- If populations included a mix of those who had completed treatment and those on treatment but results could not be separated between groups, then the study would be excluded
- If studies initially appeared to meet inclusion criteria, but on closer reading did not fully explore experiences of persistent pain as there was only a passing comment about pain, then authors would be contacted to request more data (if available) about the experience of persistent pain.

Twelve authors were contacted for more information about their study. From these, five replied to say they had no further information about the experience of persistent pain or did not have the data readily accessible, and the remaining authors did not reply.

Quality assessment (selection and evaluation criteria)

Quality assessment of studies was undertaken using an adapted version of the Critical Appraisal Skill Programme (CASP) Checklist for Qualitative Research (Critical Appraisal Skills Programme, 2017) to ensure methodological rigour and ethical standards were met. Two authors independently assessed and then reached agreement over the quality of the included studies (table 2).

Data extraction

A standardised form, based on Noyes et al (2015) and Tanay, Armes and Ream (2017) was used to extract data. To ensure accuracy, data were extracted from each study by two authors. Thomas and Harden (2008) suggest that all text labelled as 'results' or 'findings' should be extracted. The team discussed findings that included direct participant quotes and authors' interpretations of the interview data. The team decided that during the analysis and synthesis phase, when direct participant quotes were provided, then they should be analysed as much as possible. When a quote was not available, author interpretations were to be used. It was agreed that without using both

participant quotes and author interpretations, then some of the richness of the papers would be lost.

Strategy for data synthesis

Data synthesis followed Thomas and Harden's (2008) method of thematic synthesis of qualitative research. During stage one, two authors independently coded each line of text according to its meaning and context. During stage two, "descriptive themes" were created to summarise meanings of initial groups of codes. The final stage involved 'going beyond' the context of original studies to generate 'analytical themes'. The team discussed the analytical themes and they were further refined until sufficient to reflect all initial descriptive themes.

RESULTS

Four studies were identified. Three studies were from Scandinavia and one from France. These studies generated findings from 52 female breast cancer survivors. Sample sizes ranged from 8 to 21 and women ranged from 26 to 83 years with a median age of 54.5 years. All women were treated with surgery and some with adjuvant radiotherapy, chemotherapy and/or hormone therapy. All were sub studies to larger studies, all used interviews for their data collection method and interviews lasted between 30 minutes and four hours. See table 3 for characteristics of studies.

From the final stage of Thomas and Harden's (2008) method of thematic synthesis, six analytical themes were generated: 1) An interwoven relationship between experience of cancer and persistent pain 2) Lack of preparedness and support for persistent pain 3) The physical impact of persistent pain 4) Employing coping strategies 5) The emotional experience of persistent pain and 6) Conceptualisation of persistent pain. Table 4 outlines the presence of themes in each paper.

An interwoven relationship between the experience of cancer and persistent pain

Some women found it difficult to distinguish their experience of persistent pain from their experience of a breast cancer diagnosis and the threat to their existence posed by cancer, and these

were intricately woven together. The presence of pain was viewed by many as an indicator of their current cancer status and represented their transitional state between health and illness but also served as a reminder of the threat that they had experienced to their mortality.

For some, the pain had negative connotations relating to their cancer diagnosis and when women experienced pain, they immediately started to question what the pain represented and wondered what it meant in terms of their cancer - was something wrong? Increased physical symptoms could 'automatically reawaken worries about the progress of the cancer' (Bjorkman, Arner and Hyden (2008)p.1023). Consequently, some exhibited signs of somatization as they feared for the worse and the pain made them feel vulnerable:

'You really listen to your body in quite a different way now. Every little thing you feel in your body could be signs of something abnormal' (10) (Hellerstedt-Börjesson et al., 2016).

Yet for others, the presence of pain was reassuring and a positive indicator of their cancer status, as they interpreted the pain as a sign that the cancer treatment was working or had worked:

'(the pain) was proof that everything was reactivated, it was being renewed' (Sharon) (Peretti-Watel et al, 2012)

The presence of pain complicated their feelings and perceptions about finishing their cancer treatment because, whilst they had completed treatment for their cancer, they still experienced pain and the pain sensations 'coexisted with a continuum of other altered sensations and sensation disorders' (Bjorkman, Arner and Hyden (2008)p.1022). Thus, they were balanced between a state health and of illness:

'Now I've finished my treatment but am stuck in a period where I sit and think 'am I healthy or am I not?' It's like something in between' (10) (Hellerstedt-Börjesson et al., 2016)

'When you think about what you've been through, it's like the pain doesn't only exist in my arm, but in my whole body' (3) (Hellerstedt-Börjesson et al., 2016)

The pain also served as a reminder of the threat that they had experienced to their mortality. This manifested in both an impatience with others and recognition that they had survived their treatment:

'It felt like everyone was driving too slowly and I didn't have the time to sit there and wait ... I felt like 'you have all the time in the world, but my time's running out' (11) (Hellerstedt-Börjesson et al., 2016).

'There is always someone worse off than yourself. There are those who do not have the chance to live' (Stella) (Peretti-Watel et al, 2012)

Lack of preparedness and support for persistent pain

It was evident that many of the women were unprepared for the experience of persistent pain after their cancer treatment had ended. They expressed an expectation that they would experience acute pain during treatment, and many of the women felt supported during this time, yet did not recall being given information about persistent pain. When persistent pain manifested, they felt health care professionals avoided addressing it or dismissed their concerns and thus they felt abandoned and alone in the responsibility to manage their pain.

The absence of preparedness for persistent pain was evident as 'some participants clearly lacked information about pain' (Peretti-Watel et al, 2012, pg 6) as *'No one told you what kind of pain you could develop' (No 7) (Hovind, Bredal and Dihle, 2013).* Yet it was acknowledged that, at the time of intensive treatment, persistent pain may have been mentioned but women did not view it as important at the time because they were *'not concerned about pain. My focus wasn't there' (No 8) (Hovind, Bredal and Dihle, 2013).*

When pain persisted, women felt it was not recognised or acknowledged by some health care professionals as when women asked them about it *'they were... 'Forthcoming, calming... but in terms of pain, I have to talk about it myself' (no 3) (Hovind, Bredal and Dihle, 2013).* However, in some

instances, when women did tell physicians about their pain, they felt either dismissed as *'they (the doctors) told me it was normal (to feel pain)'* (Eva) (Peretti-Watel et al, 2012) or were sent to a psychiatrist. Peretti-Watel et al (2012) consider that 'such 'psychiatrization' of pain made women feel impotent and guilty because it implied that their pain was not 'real' (pg 6). This emphasised that women felt abandoned by health care professionals and alone in managing their pain as they were not given support to self-manage it or its impact:

'I wished that my pain at home was followed up much more (No 7) (Hovind, Bredal and Dihle, 2013)

The problems start after that (the end of treatment): whom do you turn to when you have pain in your hip like I do? (4) (Hellerstedt-Börjesson et al., 2016)

The lack of preparedness may have also contributed to a perceived gap in expectation of recovery from women themselves and also their family members:

'They (the doctors) said in a year you'll be back to your regular everyday life, and I'm not. It's a disappointment (13) (Hellerstedt-Börjesson et al., 2016)

'I also see that my family demands more of me now, which I'm not always able to live up to' (13) (Hellerstedt-Börjesson et al., 2016)

The combination of these elements may have given rise to the feeling of being alone in an existential way - as one women expressed, she *'felt disappointed in life, like I was abandoned and totally alone. Not abandoned by my fellowman but abandoned by life...'* (Hellerstedt-Börjesson et al., 2016).

The physical impact of persistent pain

The physical impact of the pain on women came across in three studies and was described in terms of both physical limitations and the fact that the pain was ever present as a bodily sensation.

Women felt it *'doesn't go away'* (Emmy) (Peretti-Watel et al, 2012, p4) and is now a *'permanent'* (Sharon) (Peretti-Watel et al, 2012, p4) element of their life. One woman said that her pain *'doesn't only exist in my arm, but in my whole body'* (3) (Hellerstedt-Börjesson et al., 2016).

Living with persistent pain was hard on the women as it hindered them at work, in physical activities and in their social and personal lives. The physical aspects of the pain caused difficulties in performing day to day activities:

[what kind of domestic activities did you stop doing because of the pain?] 'cleaning, ironing, washing the windows of course, and I cannot drive on long trips'(Nancy) (Peretti-Watel et al, 2012)

'I can't ride a scooter, I can't raise my arms... I can't lift a pack of milk, it's too painful' (Emmy) (Peretti-Watel et al, 2012)

'When I want to peel something, I drop it' (8) (Hellerstedt-Börjesson et al., 2016)

For one participant, a hairdresser, pain prevented her from drying as many clients' hair as before, therefore, it caused both a physical limitation and negatively affected her ability to work:

'Before my cancer I used to blow dry 20 clients hair every day, but now after 4 or 5 I must stop because my arm hurts too much' (Cindy) (Peretti-Watel et al, 2012).

Employing coping strategies

Women adopted a variety of methods of coping with their persistent pain. These included adapting and altering daily activities to work around their pain and the use of social comparison as a coping method. Social comparison was used by the women themselves and also health care professionals. For some, there was an acceptance of pain as a normal phenomenon of a cancer journey and recovery, and consequently women 'expressed a desire to live as normal a life as possible' (p.1048) despite the pain (Hovind, Bredal and Dihle, 2013).

Women adapted and altered their daily lives to help them cope with their pain in a physical and social sense. They planned and incorporated regular breaks into their activities and changed how they carried out domestic duties in response to it:

'I have to make plans, to be careful when moving' (no6) (Hovind, Bredal and Dihle, 2013)

'If I sit down in the evening, my body starts to twitch, then I have to get up and around again. Just like in the morning, I have to sit for a while' (8) (Hellerstedt-Börjesson et al., 2016)

'I learned to change some of my movements. I learned movements that relieve. Instead of wringing the kitchen glove like that, now I wring it like this, against the side of the sink' (Linda) (Peretti-Watel et al, 2012)

They adapted their activities throughout the day, ensuring they were sufficiently rested, to enable them to have maximum energy for when they felt they needed it most, for example, to care for their children:

'The space I had when they were in school and at leisure time, when I was able to be at home and rest, gave me energy to take off when they arrived back home again (13) (Hellerstedt-Börjesson et al., 2016)

In addition to changing how they carried out certain activities, women in the Peretti-Watel et al (2012) study used downward social comparison as a coping mechanism. Some women were able to take comfort from comparing their pain to others' experiences and if they felt others had more challenging conditions to cope with:

'I prefer to be like this than in a wheelchair. There are some who are more unfortunate than me. Not thinking only about myself comforts me' (Mary) (Peretti-Watel et al, 2012)

'My boyfriend's situation is worse than mine, he had mouth cancer. They ripped out all his teeth and now he has a special apparatus because he cannot eat, he cannot chew, he must suffer a lot (Eva) (Peretti-Watel et al, 2012)

However, whilst social comparison could be used positively and empower women to feel that they could face the challenge of persistent pain, for some, social comparison could be used as a means to dismiss concerns and worries. This appeared to be used by women but also by health care professionals:

'When I saw myself in this state I thought: there are some people who are worse off. So then I told myself: I have no right to complain... there is always someone worse off than yourself. (Stella)
(Peretti-Watel et al, 2012)

'Yes there are difficult moments. But you see, I had two small pupils who had leukemia.... seeing all these little children, with such large perfusions... you know, when I start to complain about my pain, I think about her... and I feel I have no right to complain (Linda) (Peretti-Watel et al, 2012)

'There is a doctor who told me 'you know, if you feel pain madam, take a short tour of accident and emergency and you'll see, you will immediately get better' He said' go and see a few kids at A&E, you'll stop complaining all the time' I was so shocked that I never returned to that hospital' (Nancy)
(Peretti-Watel et al, 2012).

The emotional experience of chronic pain

A wide range of emotions were expressed when describing the experience of living with persistent pain and the emotional aspect of experiencing it during cancer survivorship was evident in all the papers. Women were stoical about how they discussed their pain, talked with seeming acceptance as they tried not to let it have too great an impact and attempted to carry on with what they wanted to do:

'We must learn to live with it' (Emmy) (Peretti-Watel et al, 2012)

'I try to ignore the pain and continue with what I'm doing' (No 7) (Hovind, Bredal and Dihle, 2013)

Yet some women also felt frustration with their pain, experienced fatalism that it would carry on and expressed resignation that this was how life was going to be for them now:

'I can't use the body as I wish to' (8) (Hellerstedt-Börjesson et al., 2016)

'I suppose that this is how I have to live' (No 1) (Hovind, Bredal and Dihle, 2013)

'If it was going to disappear, I think it would already be gone' (Bree) (Peretti-Watel et al, 2012)

Living with persistent pain also raised fears for the future and the ‘symptoms constantly reminded them of their own or close relatives’/friends’ vulnerability’ (Hellerstedt-Börjesson et al., 2016) (p. 469) and uncertainty of what lay ahead:

‘Sometimes when I wake up I think ‘will the pain be like this everyday, always, always... that’s hard to manage sometimes’ (15) (Hellerstedt-Börjesson et al., 2016)

Conceptualisation of persistent pain

It was evident in the studies that women struggled to conceptualise and articulate the physical sensation and impact of their pain, and often used metaphors to help to describe it:

‘I felt like I’d been run over by a steamroller’ (14). (Hellerstedt-Börjesson et al., 2016)

‘I felt like I was in a dryer, and I was thrown back and forth, like I was torn and ripped into pieces’ (3). (Hellerstedt-Börjesson et al., 2016)

‘It kind of radiates somehow, it’s like there are flashes that come into my ^{breast} – they come very suddenly, like a wind’ (W5) (Bjorkman et al., 2008)

Over time, it appeared women were more likely to label the sensations they experienced as pain. This was observed most clearly in the longitudinal study by Bjorkman et al (2008) study which explained that ‘sensory disturbances were evaluated (by participants) in different ways at different points in time. During later interviews, women retrospectively expressed that sensory disturbances ... had been rather painful... in retrospect, the word pain could appear in their descriptions, when it had not ... in earlier interview (s)’ (p1023) and ‘it was striking how they initially steered clear of or directly avoided calling their sensations pain, even though the sensations could cause them some discomfort’(p1021). In keeping with this, Hovind, Bredal and Dihle (2013) commented that words other than pain were used such as:

‘It is prickly, it hurts and is tender’ (no.3) (Hovind, Bredal and Dihle, 2013)

To summarise, women's experiences of pain and of cancer were interwoven and persistent pain following treatment was unexpected. When it did occur, they did not feel supported to manage it. Persistent pain had a physical and emotional impact on the women, and they utilised various ways of coping. Women had often used metaphors to help describe and conceptualise their pain.

DISCUSSION

This qualitative evidence synthesis sought to identify and review literature surrounding experiences of persistent pain in adult cancer survivors. A comprehensive search resulted in only four papers. Thus, whilst it is established that almost 40% of cancer survivors experience pain after cancer treatment (Van Den Beuken-Van Everdingen et al., 2016), very little is known about the experiences and needs of those living with persistent pain.

All participants were female and breast cancer survivors despite the inclusion criteria stipulating that all cancer survivors were included. No research was located that included men or those with non breast cancer malignancies. It could be that breast cancer survivors have more pain than survivors of other cancers, and thus, research has focused on them. However, in the UK breast cancer receives the most funding for research (National Cancer Research Institute (NCRI), 2018) therefore it could be that pain is reported more in the breast cancer population because there is less research into other cancer sites, rather than survivors from other sites not experiencing persistent pain.

The persistent pain that women experienced had a physical impact on their daily lives. This reflects the literature into the experiences of non-malignant persistent pain. Toye et al (2017) conducted a *mega*-ethnography study, a synthesis of qualitative evidence syntheses using the methods of meta-ethnography, to explore the experiences of living with persistent non-malignant pain. They cite the 'all-pervading nature of pain which invades all aspects of my day and night' (p.5). This suggests it is the symptom of persistent pain and the ever present bodily sensation of pain, rather than the aetiology, which causes the physical impact on daily life. However, the strongest theme in Toye et al's (2017) study, represented in all qualitative evidence syntheses included in their *mega*-

ethnography study, was people's quest for a 'holy grail' of a medical diagnosis for their pain (p.5). However, this did not feature in the current study, possibly because women in this study had a known cause for their pain. Paradoxically, the most evident theme in this qualitative evidence synthesis, which featured in all the identified papers, was an interwoven relationship between the experience of cancer and persistent pain. Thus pain was not considered in isolation but was related to the cancer experience. The experience of pain and cancer were intrinsically linked together and pain was viewed as an indicator of cancer status. The pain caused the women to question if their cancer was returning. This is reflected in the wider literature in which researchers have suggested that new symptoms can be interpreted by cancer survivors as a sign of cancer recurrence (Raphael et al, 2019) and the presence of physical symptoms, like pain, can lead to increased risk of fear of recurrence (Simard et al., 2013). Van Den Beuken-Van Everdingen et al (2008) found pain to be a strong predictor of fear of recurrence and Cupit-Link, Syrjala and Hashmi (2018) discuss this in the context of Damocles' syndrome, whereby the fortune of survivorship is tempered by persisting fears of recurrence and long term health sequelae after treatment. Bovbjerg et al (2019) found cancer survivors with persistent breast pain had significantly higher levels of emotional distress, pain catastrophizing and worry that breast pain indicates cancer compared to survivors without persistent breast pain.

Findings in the current study demonstrate how women compare themselves to others when coping with their persistent pain. This process, known as social comparison, refers to how individuals evaluate their own abilities, opinions, attitudes and feelings in relation to other groups (Guyer and Johnston, 2017). Our data described how women used downward comparisons and self-enhancement, whereby they compared themselves to others who they perceived to be in worse situations than themselves. Thus, for some women in this qualitative evidence synthesis, social comparison appeared to help as they were able to evaluate their own pain experience in the context of other peoples' problems. This mirrors findings of Wood, Taylor and Lichtman (1985) who found the majority of breast cancer patients in their sample (n = 78) instinctively highlighted how their

situation, although unfortunate, was preferable to others with more advanced disease. However, it could also be argued that, by comparing themselves to others, women were being overly self-dismissive and discounting their own experiences.

It was evident in the studies that patients felt they had not been given sufficient information regarding the risks of persistent pain. Women expressed they had felt prepared for the risk of acute pain but not persistent pain. Women did acknowledge however, that at diagnosis and treatment, persistent pain may have been mentioned but that it did not seem important at the time. This is similar to suggestions that other late effects, such as chemotherapy induced peripheral neuropathy, are considered to be of minimal importance in the context of a cancer diagnosis (Tanay, Armes and Ream, 2017) but become more significant once experienced. However, in this synthesis, it appears women's information needs were met at the beginning of treatment, but less so at the end. This is reflected in a recent scoping review that highlights a paucity in literature relating to information needs following completion of treatment (Fletcher et al., 2017). This may have also contributed to feelings of abandonment that some women expressed. Feeling abandoned by the health care system is an experience that has been reported by many cancer survivors at the end of treatment (Parry et al., 2011; Bennion and Molassiotis, 2013). Equally, a lack of empathy by health care professionals towards women with persistent pain was shown in the synthesis. Feeney et al (2018) recognise that a lack of empathy towards patients can lead to mistrust and anger which can ultimately damage therapeutic relationships.

These findings highlight that women need more information about the risks of persistent pain after cancer treatment, and services to support them with self-management of pain. Health care professionals supporting cancer survivors with persistent pain need to be aware of the impact the experience of cancer may have on the intensity and emotional distress surrounding the experience of persistent pain.

Limitations

Whilst the literature search and selection process for this qualitative evidence synthesis were thorough and robust, only four studies were identified in which all participants were female and breast cancer survivors. No studies were identified which reported the experience of men. Studies with survivors of childhood cancer were excluded and only one longitudinal paper was identified in this search. Within this paper there were suggestions that how survivors conceptualised pain over time changed and it may have been possible to explore this further if more longitudinal studies had been included. Only studies published within the search dates and in English were included. These factors may have influenced the findings of the synthesis. Future studies may want to address these limitations.

The synthesis adopted a descriptive methodology and, by their very nature, descriptive qualitative evidence syntheses allow for limited interpretation of meaning. However, the approach taken, thematic synthesis, was suitable for studies that explore perspectives and experiences.

Conclusions and recommendations for further research

This synthesis has highlighted that persistent pain results in physical difficulties and emotional consequences for cancer survivors. The nature of persistent pain for cancer survivors is intrinsically interwoven with their experiences of cancer and cancer care. Women felt that persistent pain following treatment was unexpected and when it happened, it was not addressed by health care professionals. Women felt they were left to manage their persistent pain on their own and used various ways to help them do this. This synthesis has highlighted the paucity of research into the experiences and needs of cancer survivors living with persistent pain, especially men and those with non breast cancer malignancies. Further studies are needed in this area, in particular with respect to male perspectives and those with different cancer types, to explore how healthcare services can help and support cancer survivors with the self management of their persistent pain.

References

Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., ... Richardson, A. (2009).

Patients' supportive care needs beyond the end of cancer treatment: A prospective, longitudinal survey. *Journal of Clinical Oncology*, 27(36), 6172–6179. <https://doi.org/10.1200/JCO.2009.22.5151>

Bennion, A. E., & Molassiotis, A. (2013). Qualitative research into the symptom experiences of adult cancer patients after treatments: A systematic review and meta-synthesis. *Supportive Care in Cancer*, 21(1), 9–25. <https://doi.org/10.1007/s00520-012-1573-x>

van den Beuken-van Everdingen Marieke, H. J., Peters Madelon, L., de Rijke Janneke, M., Schouten Harry, C., van Kleef, M., & Patijn, J. (2008). Concerns of former breast cancer patients about disease recurrence: A validation and prevalence study. *Psycho-Oncology*, 17(11), 1137–1145.

Björkman, B., Arnér, S., & Hydén, L.-C. (2008). Phantom breast and other syndromes after mastectomy: Eight breast cancer patients describe their experiences over time: A 2-year follow-up. *The Journal of Pain*, 9(11), 1018–1025. <https://doi.org/10.1016/j.jpain.2008.06.003>

Bovbjerg, D. H., Keefe, F. J., Soo, M. S., Manculich, J., Van Denburg, A., Zuley, M. L., ... Shelby, R. A. (2019). Persistent breast pain in post-surgery breast cancer survivors and women with no history of breast surgery or cancer: Associations with pain catastrophizing, perceived breast cancer risk, breast cancer worry, and emotional distress. *Acta Oncologica*, 58(5), 763–768. <https://doi.org/10.1080/0284186X.2019.1574023>

Braun, V., & Clarke, V. (2013) *Successful qualitative research: A practical guide for beginners*. (August), pp. 382. Retrieved from <http://eprints.uwe.ac.uk/21156/3/SQRChap1ResearchRepository.pdf>

Capelan, M., Battisti, N. M. L., McLoughlin, A., Maidens, V., Snuggs, N., Slyk, P., ... Ring, A. (2017). The prevalence of unmet needs in 625 women living beyond a diagnosis of early breast cancer. *British Journal of Cancer*, 117(8), 1113–1120. <https://doi.org/10.1038/bjc.2017.283>

Casillas, J., Kahn, K. L., Doose, M., Landier, W., & Bhatia, S. (2010) *Transitioning childhood cancer survivors to adult- centered healthcare: Insights from parents, adolescent, and young adult survivors*. 990 (December 2009), pp. 982–990.

Cupit-Link, M., Syrjala, K. L., & Hashmi, S. K. (2018). Damocles' syndrome revisited: Update on the fear of cancer recurrence in the complex world of today's treatments and survivorship. *Hematology/Oncology and Stem Cell Therapy*, 11(3), 129–134. <https://doi.org/10.1016/j.hemonc.2018.01.005>

hemonc.2018.01.005

Feeney, L. R., Tormey, S. M., & Harmon, D. C. (2018). Breast cancer and chronic pain: a mixed methods review. *Irish Journal of Medical Science*, 187(4), 877–885.

Fletcher, C., Flight, I., Chapman, J., Fennell, K., & Wilson, C. (2017). The information needs of adult cancer survivors across the cancer continuum: A scoping review. *Patient Education and Counseling*, 100(3), 383–410. <https://doi.org/10.1016/j.pec.2016.10.008>

Guyer, J., & Johnston, T. V. (2017). *Encyclopedia of personality and individual differences*. (July). Retrieved from <http://link.springer.com/10.1007/978-3-319-28099-8doi:10.1007/978-3-319-28099-8>

Hackett, J., Godfrey, M., & Bennett, M. I. (2016). Patient and caregiver perspectives on managing pain in advanced cancer: A qualitative longitudinal study. *Palliative Medicine*, 30(8), 711–719.

Hellerstedt-Börjesson, S., Nordin, K., Fjällskog, M.-L., Holmström, I. K., & Arving, C. (2016a). Women treated for breast cancer experiences of chemotherapy-induced pain: Memories, any present pain, and future reflections. *Cancer Nursing*, 39(6), 464–472.

Hellerstedt-Börjesson, S., Nordin, K., Fjällskog, M.-L., Holmström, I. K., & Arving, C. (2016b). Women treated for breast cancer experiences of chemotherapy-induced pain. *Cancer Nursing*, 39(6), 464–472.

Hovind, I. L., Bredal, I. S., & Dihle, A. (2013). Women's experience of acute and chronic pain following breast cancer surgery. *Journal of Clinical Nursing*, 22(7-8), 1044–1052. <https://doi.org/10.1111/jocn.12167>

Lea, S., Martins, A., Bassett, M., Cable, M., Doig, G., Fern, L., ... Taylor, R. (2019). CN47Young people's experiences when active cancer treatment ends. *Annals of Oncology*, 30, (Supplement 5): v829–v835. <https://doi.org/10.1093/annonc/mdz275.002>

Maddams, J., Utley, M., & Møller, H. (2012). Projections of cancer prevalence in the United Kingdom, 2010–2040. *British Journal of Cancer*, 107(7), 1195–1202. <https://doi.org/10.1038/bjc.2012.366>

Maher, J., Petchey, L., Greenfield, D., Levitt, G., & Fraser, M. (2018). Implementation of nationwide cancer survivorship plans: Experience from the UK. *Journal of Cancer Policy*, 48(January), 1–6. <https://doi.org/10.1016/j.jcipo.2018.01.002>

Moser, E. C., & Meunier, F. (2014). Cancer survivorship: A positive side-effect of more successful cancer treatment. *European Journal of Cancer, Supplement*, 12(1), 1–4. <https://doi.org/10.1016/j.ejcsup.2014.03.001>

National Cancer Research Institute (NCRI) (2018). *Spend by research category and disease site [online]*. Retrieved from <https://www.ncri.org.uk/ncri-cancer-research-database/spend-by-research-category-and-disease-site/>

Noyes, J., Booth, A., Cargo, M., Flemming, K., Harden, A., Harris, J., ...Thomas, J. (2015). Chapter 21: Qualitative evidence. In *Cochrane handbook for systematic reviews of interventions*.

Park, J. L., Brandelli, Y., Russell, K. B., Reynolds, K., Li, Y., Ruether, D., & Giese-Davis, J. (2018). Unmet needs of adult survivors of childhood cancers: Associations with developmental stage at diagnosis,

cognitive impairment, and time from diagnosis. *Journal of Adolescent and Young Adult Oncology*, 7(1), 61–71.

Parry, C., Morningstar, E., Kendall, J., & Coleman, E. A. (2011). Working without a net: Leukemia and lymphoma survivors' perspectives on care delivery at end-of-treatment and beyond. *Journal of Psychosocial Oncology*, 2, 175–198. <https://doi.org/10.1080/07347332.2010.548444>

Peretti-Watel, P., Bendiane, M. K., Spica, L., & Rey, D. (2012). Pain narratives in breast cancer survivors. *Pain Research and Treatment*, 2012, 1–8. <https://doi.org/10.1155/2012/153060>

Raphael, D., Frey, R., & Gott, M. (2019). The nature and timing of distress among post-treatment haematological cancer survivors. *European Journal of Cancer Care*, 28(1), e12951.

Rees, S. (2018). A qualitative exploration of the meaning of the term “survivor” to young women living with a history of breast cancer. *European Journal of Cancer Care*, 27(3), 1–8. <https://doi.org/10.1111/ecc.12847>

Schmidt, M. E., Wiskemann, J., & Steindorf, K. (2018). Quality of life, problems, and needs of disease-free breast cancer survivors 5 years after diagnosis. *Quality of Life Research*, 27(8), 2077–2086. <https://doi.org/10.1007/s11136-018-1866-8>

Siegel, R. L., & Miller, K. D. (2019). Cancer statistics, 2019. *CA: A Cancer Journal for Clinicians*, 69(1), 7–34. <https://doi.org/10.3322/caac.21551>

Simard, S., Thewes, B., Humphris, G., Dixon, M., Hayden, C., Mireskandari, S., & Ozakinci, G. (2013). Fear of cancer recurrence in adult cancer survivors: A systematic review of quantitative studies. *Journal of Cancer Survivorship*, 7(3), 300–322.

Tanay, M. A. L., Armes, J., & Ream, E. (2017). The experience of chemotherapy-induced peripheral neuropathy in adult cancer patients: A qualitative thematic synthesis. *European Journal of Cancer Care*, 26(5), e12443. <https://doi.org/10.1111/ecc.12443>

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45.

Toye, F., Seers, K., Hannink, E., & Barker, K. (2017). A mega-ethnography of eleven qualitative evidence syntheses exploring the experience of living eleven qualitative evidence syntheses exploring the experience of living with chronic non-malignant pain. *BMC Medical Research Methodology*, 17(1), 116.

Van Den Beuken-Van Everdingen, M. H. J., Hochstenbach, L. M. J., Joosten, E. A. J., Tjan-Heijnen, V. C. G., & Janssen, D. J. A. (2016). Update on prevalence of pain in patients with cancer: Systematic review and meta-analysis. *Journal of Pain and Symptom Management*, 51(6), 1070– 1090.e9. <https://doi.org/10.1016/j.jpain symman.2015.12.340>

Wood, J. V., Taylor, S. E., & Lichtman, R. R. (1985). Social comparison in adjustment to breast cancer. *Journal of Personality and Social Psychology*, 49(5), 1169–1183. <https://doi.org/10.1037/0022-3514.49.5.1169>

Tables

Table 1: Key search terms used for study identification

Cancer OR	A N D	Pain	A N D	Persistent OR	A N D	Qualitative OR	A N D	Survivor*
Oncol*				Persistent		Mixed method*		Patient*
Hemat*				Long-term		Mixed-method*		End N4 treatment
Haemat*				Long-standing				End N4 chemo*
Malignan*				Long term				End N4 radio*
Carcino*				Long standing				Completed N4 treatment
								Completed N4 chemo*
								Completed N4 radio*

Table 2: Quality assessment

Protocol statement	CASP Questions	Paper, author (date)
--------------------	----------------	----------------------

		(Björkman, Arnér and Hydén, 2008)	(Hellerstedt-Börjesson <i>et al.</i> , 2016)	(Hovind, Bredal and Dihle, 2013)	(Peretti-Watel <i>et al.</i> , 2012)
Adopted an appropriate method and design to meet the aims of the study	Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes
	Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes*
	Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes
Used a suitable data collection strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes
	Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes
	Has the relationship between researcher and participants been adequately considered?	Not known	Yes	Yes	Not known
Included pertinent methods of data analysis	Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes
Drew conclusions and interpretations that reflected the findings of the study	Is there a clear statement of findings?	Yes	Yes	Yes	Yes
	How valuable is the research?	Valuable	Valuable	Valuable	Valuable
Obtained ethical approval	Have ethical issues been taken into consideration?	Yes	Yes	Yes	Yes

*Interview data

Table 3: Characteristics of included studies

Author, year, origin	Aims of study	Research design/theoretical framework	Data collection method, data analysis approach	Sampling	n	Demographic details	Treatment	Time point
Björkman, Arnér and Hydén, 2008, Sweden.	To explore women's personal descriptions of if and how phantom breast phenomenon appears within painful sensations	Qualitative, longitudinal and prospective, Explorative	Semi structured interviews, 4x1 hour, discourse and narrative analysis	Consecutive	8	47-72 years, women, breast cancer	Surgery +/-* radiotherapy +/- endocrine or hormonal therapy	1 month, 6 months, 1 year, and 2 years after mastectomy
Hellerstedt-Börjesson <i>et al.</i> , 2016, Sweden	To explore memories of CHIP and any experience long standing treatment related pain	Qualitative, Phenomenological lifeworld	Interviews, 30-90 minutes, Guided phenomenological reflection	Consecutive	15	30-79 years, women, breast cancer	Surgery +/- chemotherapy +/- radiotherapy +/- hormone therapy	One year after treatment
Hovind, Bredal and Dihle, 2013, Norway	Perception of pain and improvement of pain management	Qualitative, Descriptive	Semi structured interviews, 1 hour, Qualitative content analysis	Purposive	8	44-65 years, women, breast cancer	Surgery +/- chemotherapy +/- radiotherapy	Between 12 and 30 months after surgery

Peretti-Watel <i>et al.</i> , 2012, France	1) Compare WHOQOL-BREF questionnaire and interview data 2) Explore attitude and meaning to pain	Qualitative, Inductive	In-depth semi structured interviews, 1-4 hours, Inductive approach based on grounded theory	Purposive	21	26-83 years, women, breast cancer	Surgery +/- chemotherapy +/- hormone treatment	24 months after diagnosis
--	---	------------------------	---	-----------	----	-----------------------------------	--	---------------------------

- + = with chemotherapy, radiotherapy or hormone treatment - = without chemotherapy, radiotherapy or hormone treatment

Table 4 Presence of themes in each paper

Theme	(Björkman, Arnér and Hydén, 2008)		(Hellerstedt-Börjesson <i>et al.</i> , 2016a)	(Hovind, Bredal and Dihle, 2013)	(Peretti-Watel <i>et al.</i> , 2012)	
	Author interpretation	Participant quote	Participant quote	Participant quote	Participant quote	Author interpretation
Interwoven relationship between experience of cancer and persistent pain	x		x	x	x	
Lack of preparedness and support for persistent pain			x	x		x
Physical impact of pain			x	x	x	
Employing coping strategies			x	x	x	
Emotional experience of persistent pain	x		x	x	x	
Conceptualisation of persistent pain		x	x	x		