Exploring the experiences of survivors of breast cancer. Can illness representations be used to understand pain experienced in survivorship?

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The candidate confirms that the work submitted is his own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

Background: Advanced treatment options have resulted in more women surviving breast cancer. However, breast cancer treatment is often associated with negative side-effects, which can impact on survivors' quality of life. Chronic pain is a recognised long-term consequence associated with breast cancer and its treatment, and is reported by 25-60% of breast cancer survivors. Chronic pain experienced by breast cancer survivors is often underdiagnosed and undertreated. Research attempting to understand the underlying mechanisms of chronic pain in breast cancer survivors is inconclusive. Illness representations have been used to predict a number of illness outcomes experienced by a range of different health conditions including breast cancer; however, there are no current studies that have used illness representations to understand chronic pain experienced by breast cancer survivors. The aim of the current study was to explore the association between illness representations, health-related quality of life (HRQoL) and chronic pain in women who have survived breast cancer.

Methods: A cross-sectional online survey design was used. Data from 182 women who participated in the survey were analysed. Participants provided demographic and illness-related information. Illness representations were assessed using the Illness Perception Questionnaire - Revised (IPQ-R); pain was assessed by the Brief Pain Inventory – Short Form (BPI-SF); HRQoL was assessed by the EuroQol – visual analogue scale (EQ-VAS); and, depression and anxiety were measured using the Patient Health Questionnaire – 8 items (PHQ-8) and the Generalised Anxiety Disorder scale – 7 items (GAD-7), respectively. Ordinal logistic regression models were used to quantify the relationship between illness representations, HRQoL and pain, adjusted for demographics, illness-related and psychological (e.g. anxiety and depression) factors.

Results: Chronic pain was reported by 66% of respondents. Using the BPI-SF, participants were categorised into one of four pain categories: no pain (34.1%); mild pain (35.7%); moderate pain (25.3%) and severe pain (4.9%). Of the illness representation dimensions, timeline (acute/chronic), consequences, timeline (cyclical), treatment control and causal factors (stress and state of health), were significantly associated with pain severity. Having a strong illness identity (IPQ-R subscale which assesses the number of symptoms an individual attributes to their illness) was found to be a significant predictor of pain severity (OR 1.21, (95% CI 1.07-1.37), p=0.003). The results also found that

HRQoL was significantly associated and predictive of pain severity (OR 0.97, (95% CI 0.95-0.99), p<0.001). An additional finding was that not being in paid work was strongly associated with being in a higher pain category (OR 5.92, (95% CI 1.84-19.05), p=0.003).

Discussion: The findings of this study show that dimensions of illness representations are associated with chronic pain experienced by breast cancer survivors. However, results from the logistic regression analysis showed that in a fully adjusted model, only the IPQ-R identity domain remained an independent predictor of chronic pain, along with reduced HRQoL and not being in paid work. Furthermore, the high prevalence of chronic pain reported in this study highlights an important unmet clinical need, whereby breast cancer survivors are not receiving adequate pain management, resulting in reduced HRQoL associated with a high prevalence of moderate to severe pain. These findings have made a contribution to existing research which has attempted to understand chronic pain experienced by this population. These findings should be used to inform future research and clinical practice, which could result in better prevention, assessment and management of pain experienced by breast cancer patients and/or survivors.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

Abbreviation	Meaning
ACT	Acceptance and commitment therapy
ALND	Axillary lymph node dissection
ANOVA	Analysis of variance
BPI	Brief pain inventory
BPI-SF	Brief pain inventory – short form
Brief IPQ	Brief illness perceptions questionnaire
CBT	Cognitive behavioural therapy
CFS	Chronic fatigue syndrome
CI	Confidence intervals
CKD	Chronic kidney disease
CSM	Common sense model
EQ-5D	EuroQol-5 dimension
EQ-VAS	EuroQol – visual analogue scale
FA	Factor analysis
GAD-7	Generalised anxiety disorder scale 7 items
HRQoL	Health-related quality of life
IPQ	Illness perceptions questionnaire
IPQ-R	Illness perceptions questionnaire – revised
M	Mean
MPQ	McGill pain questionnaire
MPQ-SF	McGill pain questionnaire short form
NHS	National Health Service
NRS	Numerical rating scale
OR	Odds ratio
PCA	Principal component analysis
PHQ-8	Patient health questionnaire 8-items
PHQ-9	Patient health questionnaire 9-items
QoL	Quality of life
SD	Standard deviation
SF-36	36-item short form health survey
SLNB	Sentinel lymph node dissection
SoMREC	School of medicine research ethics committee
SQRT	Square root
TOPS	Treatment outcomes of pain survey

Chapter 1: Literature Review

This first chapter begins with a scoping literature review. Relevant research articles were identified through a complete search of a number of databases: Medline, PsychInfo and Embase in January 2020, March 2021 and April 2021. A comprehensive list of key search words and terms was generated and comprised of the following: breast cancer (and cancer, physical health, illness, survivorship); pain (and measurement, management, multidimensional, risk factors); common sense model and its associated terms (CSM, self-regulation model, illness perceptions, illness representations, illness cognitions, beliefs, illness perceptions questionnaire); and illness outcomes (and coping, quality of life (QoL), psychological well-being, health). Relevant articles were appraised and then referenced throughout the literature review.

This literature review begins by introducing cancer epidemiology and then specifically focuses on breast cancer epidemiology including: types and incidence rates, risk factors, mortality rates and treatment options, and then survival rates. There will then be a discussion about the ongoing difficulties experienced in breast cancer survivorship. This section will then discuss the prevalence and impact of chronic pain as a negative long-term health problem from a more general perspective, before focusing on pain in relation to cancer and then specifically breast cancer. There will be consideration for risk factors, measuring pain and pain management. A multidimensional approach will be used as a way of understanding chronic pain as a phenomenon. In an attempt to understand the variance in chronic pain experienced in breast cancer survivorship, there will be a focus on the role of illness beliefs, and in particular using the common sense model (CSM) and illness representations as a way of trying to make sense of this variation. There will then be a review of previous research that has utilised the CSM as a framework to understand coping and illness outcomes in a variety of health conditions, including cancer and breast cancer. Finally, the chapter will conclude with a context and rationale for this current study.

1.1 Cancer epidemiology

Cancer is considered one of the most prevalent diseases worldwide, with more than 14 million new cases diagnosed annually (Richardson, Schüz, Sanderson, Scott, & Schüz, 2017). In the United Kingdom (UK), annual diagnostic rates are approximately

367,000 new cases per year, and mortality rates are more than 166,000 per year (Cancer Research UK, 2021a). Over the past decade, mortality rates for all cancers combined have decreased by 9% (Cancer Research UK, 2021a). In the UK (2010-11), approximately 50% of people survive their cancer for ten years or more (Cancer Research UK, 2021a). Population level epidemiology data suggest that there are now an estimated 2 million cancer survivors living in the UK (Ashley, Marti, Jones, Velikova, & Wright, 2015). The most common types of cancer include breast, prostate, lung and bowel cancers, which account for more than 53% of new cases in the UK (Broggio, 2019). Breast cancer alone accounted for 15% of all new cancer cases in 2017, and therefore is one of the most common cancers in the UK (Cancer Research UK, 2021b). In 2012, it was estimated that there were 6.3 million women living with breast cancer worldwide (MacMillan Cancer Support, 2017).

1.2 Breast cancer epidemiology

1.2.1 Types and incidence rates

Breast cancer can be divided into: non-invasive (carcinoma in situ) and invasive (NHS UK, 2020). Non-invasive breast cancer is when it is found in the ducts of the breast but has not spread to the surrounding breast tissue, whereas invasive breast cancer is when the cancer cells have spread to the surrounding breast tissue (NHS UK, 2020). There are other less common types of breast cancer and it is also possible for breast cancer to become metastatic and spread to other parts of the body, which accounts for approximately 5% of breast cancer cases at the time of diagnosis (Breast Cancer Now, 2021). Invasive is the most common type of breast cancer, with approximately 55,200 new cases in the UK each year (2015-2017), in comparison to 8,100 annual cases of non-invasive breast cancer (2015-2017) (Cancer Research UK, 2021b).

1.2.2 Risk factors, mortality rates and treatment options

Whilst breast cancer can occur in any gender, 99% of new cases of breast cancer are in women (Breast Cancer Now, 2021). Other key risk factors include age, family history, pre-existing breast conditions, alcohol consumption and obesity (Kamińska, Ciszewski, Łopacka-Szatan, Miotła, & Starosławska, 2015; NHS UK, 2020). In the UK, approximately 80% of breast cancer cases are diagnosed in women over the age of 50 and 25% in women over the age of 75 (Breast Cancer Now, 2021). Breast cancer is also

considered more common in white females than in Asian or Black females, and incidence rates are higher in women from more affluent areas (Cancer Research UK, 2021b). This has been linked to women from more affluent areas having early screen-detected breast cancer (Mayor, 2011). In the UK, breast cancer is the fourth most common cause of cancer death, accounting for 7% of all cancer deaths (2018), with almost half (48%) being in those aged 75 and over (2016-2018) (Cancer Research UK, 2021b). However, in the UK, over the past 10 years improvements in breast cancer treatments have been associated with a 19% decrease in mortality rates (Cancer Research UK, 2021b; Moss et al., 2015). Breast cancer treatment can consist of surgical procedures in the breast (e.g. lumpectomy and mastectomy) and in the axilla (e.g. sentinel lymph node biopsy (SLNB) and axillary lymph node dissection (ALND)), in addition to adjuvant therapy such as radiotherapy, chemotherapy and hormone therapy (Andersen & Kehlet, 2011; Gärtner et al., 2009). If detected at an early stage, breast cancer can be treated with a combination of surgery (81% of patients), radiotherapy (63% of patients), chemotherapy (34% of patients) and in some instances, hormone or targeted treatments (Cancer Research UK, 2021b; NHS UK, 2020). Metastatic breast cancer is not curable and the aim of treatment is to relieve symptoms (NHS UK, 2020).

1.2.3 Survival

Despite high prevalence rates associated with breast cancer, due to early screening and detection, increased awareness and advanced treatment options (Dubey, Gupta, & Jain, 2015), breast cancer survival has increased. In the UK, there are an estimated 600,000 survivors of breast cancer, which is expected to rise to 1.2 million in 2030 (Breast Cancer Now, 2021). Research suggests that in the UK, 85% of women diagnosed with breast cancer survive for five years or more and 76% survive for ten years or more (2013-2017) (Cancer Research UK, 2021b). Age is considered a predictor of increased survival, with 9 in 10 women aged between 40-69 diagnosed with breast cancer surviving for five years or more, in comparison with 7 in 10 women aged 80 and over (2009-2013) (Cancer Research UK, 2021b). Early detection has also been considered a significant predictor for increased survival rates, with 100% of patients diagnosed at stage 1 surviving for at least one year, in comparison to 66% diagnosed at stage 4 (Broggio, 2019). Similarly, five-year net survival decreases from stage 1 (100%), to stage 2 (90%), to stage 3 (72%), to stage 4 (26%) (Cancer Research UK, 2021b). Although high mortality rates are still

associated with breast cancer, it appears that survival rates are increasing. However, research has found that women who survive breast cancer are often faced with numerous long-term consequences such as decreased psychosocial functioning and reduced health-related QoL (HRQoL) (Duijts, Faber, Oldenburg, van Beurden, & Aaronson, 2011). Therefore, it is important to explore any factors that could impact on HRQoL in survivorship.

1.3 Breast Cancer Survivorship

As highlighted, breast cancer mortality rates have decreased. However, breast cancer treatment can be associated with persistent side-effects and toxicity, which can have a negative impact on HRQoL (Montazeri et al., 2008). The long-term impact of breast cancer and its treatment have been associated with both positive and negative effects on recovery and HRQoL (Chopra & Kamal, 2012). For example, in a systematic review it was found that long-term survivors of breast cancer can often experience good HRQoL, particularly those who did not need chemotherapy; who had sufficient emotional support; and who had no comorbid conditions (Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005). Despite these findings, research suggests that those who experience breast cancer and its treatment are often faced with long-term difficulties, such as physical problems (e.g. fatigue, disturbed sleep, and pain) and psychological distress (e.g. depression, anxiety, body image problems, and fear of cancer recurrence) (Chopra & Kamal, 2012). These difficulties can have an adverse impact on an individual's HRQoL and survivorship (Knobf, 2007).

Difficulties such as fatigue, sleep disturbance and depression are common symptoms following breast cancer diagnosis and treatment and can persist for many years, impacting survivors' overall QoL (Bower, 2008; Cvetković & Nenadović, 2016). Approximately 25% of breast cancer patients will be faced with clinically significant psychological problems (e.g. depression and anxiety) (Glanz & Lerman, 1992). Fatigue has often been considered one of the most common and distressing symptoms that a breast cancer survivor experiences (Deimling, Bowman, & Wagner, 2007). In a study of 1- to 6-year breast cancer survivors, 75% of individuals reported experiencing fatigue and the severity did not decrease over time (Berglund, Bolund, Fornander, Rutqvist, & Sjödén, 1991). In a follow-up study, recovery from the psychological and physical effects of breast cancer often worsens after one-year post-treatment and declines in the following

two years (Ganz et al., 1996). Furthermore, one of the biggest concerns for breast cancer survivors is fear of recurrence, and in one study it was found that 70% of individuals show clinical levels of fear of cancer recurrence (Thewes et al., 2012).

Research has found that different anti-cancer treatments are associated with a variety of difficulties in survivorship. For example, breast cancer surgery and adjuvant treatment, such as chemotherapy or radiotherapy, have been associated with fatigue, lymphedema, pain and psychosocial problems (Chopra & Kamal, 2012). Research has also found that the type of breast cancer surgery can have an impact on mood, body image and feelings of attractiveness, with more positive outcomes being associated with a lumpectomy versus a mastectomy (Rowland et al., 2000). Likewise, women who undergo a mastectomy also report more physical problems, such as pain (Rowland et al., 2000). Therefore, due to increasing survival rates, it is important to understand long-term implications of breast cancer treatment and the potential adverse impact on a patient's overall HRQoL.

1.4 Prevalence and impact of pain

One of the most common and distressing long-term health problems that individuals are often faced with following disease or injury is pain (Mills, Nicolson, & Smith, 2019). Pain is often categorised into acute and chronic (McMahon, Koltzenburg, Tracey, & Turk, 2013). Acute pain is described as brief and intense, and is often associated with a specific injury or following a medical intervention (e.g. surgery) (Lavand'homme, 2011). As the body heals, acute pain will often subside; however, for some individuals this pain will become chronic and persisting (Macrae, 2001). Chronic pain can cause major disruption in many aspects of an individual's life, including physical status, mood and sleep (Davison & Jhangri, 2005). Pain is considered chronic when it persists for more than three months following injury, surgery and/or treatment (Ferreira, Prado, Panobianco, Gozzo, & Almeida, 2014; Treede et al., 2015). In a recent meta-analysis and systematic review, it was found that chronic pain affects between one-third and one-half of the UK population, which corresponds to 28 million adults (Fayaz, Croft, Langford, Donaldson, & Jones, 2016), and is considered to be the leading cause of disability and disease burden worldwide (Vos et al., 2017).

Epidemiological research has focused on identifying risk factors that increase an individual's susceptibility to developing chronic pain. There have been a number of socio-economic and environmental factors that have been linked to an increased likelihood of experiencing chronic pain, such as increasing age, greater deprivation, being unemployed, smoking and lower education level attainment (Mills et al., 2019). However, one of the biggest risk factors for developing chronic pain is the presence of co-morbid physical and/or mental health conditions (Dominick, Blyth, & Nicholas, 2012). Chronic pain has been linked to multiple physical health conditions such as cardiovascular diseases (Barnett et al., 2012), cancer (Bouhassira, Luporsi, & Krakowski, 2017) and neurological conditions (Cragg et al., 2018). It has also been linked to mental health conditions such as depression and anxiety (Mills et al., 2019; van der Windt, Kuijpers, Jellema, van der Heijden, & Bouter, 2007); however, the causal relationship between chronic pain and associated risk factors remains inconclusive. For example, de Heer et al. (2018) found that 20-50% of patients with chronic pain have co-morbid depression, while Mills et al. (2019) reported that the experience of chronic pain increases the likelihood of experiencing depression. Pain catastrophising has been shown to be a robust predictor of perceived pain (Craner, Sperry, Koball, Morrison, & Gilliam, 2017; Roth, Geisser, & Williams, 2012). Studies have found that greater levels of pain catastrophising are associated with various outcomes such as greater perceived pain intensity, disability and distress (Burns et al., 2015; Craner et al., 2017; Scott, Kroenke, Wu, & Yu, 2016).

Another healthcare-related factor associated with the development of chronic pain is surgical and medical interventions. Although rates of post-operative pain vary, evidence suggests that up to 80% of patients experience some form of acute post-operative pain and for 10% of patients this becomes chronic (Fletcher et al., 2015; Mills et al., 2019). Patients who experience acute post-operative pain that is difficult to control are more likely to transition to chronic pain, which is often unresponsive to opioids (P. A. Glare et al., 2014). Whilst this gives some insight into potential risk factors, the transition from acute to chronic pain is complex and multifactorial, and remains a topic of interest for research (Fregoso, Wang, Tseng, & Wang, 2019). The development of chronic post-operative pain is thought to be particularly common for patients who experience amputation, cardiac surgery, thoracotomies and breast surgery (Macrae, 2008).

1.5 Pain and Cancer

As highlighted, chronic pain is a major cause of disease burden and disability, but is often undertreated and misunderstood (Green, Hart-Johnson, & Loeffler, 2011). Improvements in diagnosis and cancer treatments have resulted in more people surviving cancer; however, approximately 75% of cancer survivors experience negative health-related consequences, which can vary depending on the type of cancer and treatment received (Corbett, Groarke, Walsh, & McGuire, 2016). Pain has been described as one of the most frequent and distressing symptoms following cancer that can have a significant negative impact on QoL (Paice & Ferrell, 2011), sleep (Sharma et al., 2012) and mood (Wildgaard et al., 2011). For patients undergoing cancer treatments, pain related to these treatments or the tumour is considered a short-term problem during active treatment; however, pain can become chronic for cancer survivors if it persists after treatment has ended (Glare et al., 2014). These long-term effects of cancer and its treatment can impact on survivors' physical, psychological and cognitive functioning (Sun, Borneman, Piper, Koczywas, & Ferrell, 2008).

Cancer-related pain is considered a major clinical issue, with research reporting that 30-40% of cancer survivors experience chronic pain that they identify as being a consequence of their cancer or cancer treatment (Green et al., 2011). Factors such as being treated with more invasive surgeries and receiving adjuvant treatment have been found to predict chronic pain in long-term survivors (Ganz et al., 2002; Katz et al., 2005). In addition to chronic treatment-related pain, cancer survivors are at increased risk of developing co-morbid painful conditions such as arthritis and osteoporosis, and this risk is greater for older adults (Sun et al., 2008). Cancer-related pain is both underreported and undertreated, particularly for older adults and ethnic minority patients (Bernabei et al., 1998). The impact of persisting and poorly treated pain can have a significant impact on a patient's HRQoL (Breivik et al., 2009); however, despite being a major clinical issue, there is little consensus about what specific factors may increase a patient's susceptibility to developing chronic pain following cancer. Furthermore, there are many different types of cancer-related pain including: neuropathic, bone, soft tissue, phantom and referred pain (Cancer Research UK, n.d.). Therefore, identifying the type and cause of pain that a patient is experiencing is vital in enabling the appropriate treatment to be identified (Mulvey, Bennett, Liwowsky, & Freynhagen, 2014a; Mulvey et al., 2014b).

1.6 Pain and Breast Cancer

1.6.1 Epidemiology

Breast cancer and its treatment are associated with numerous long-term negative consequences, including chronic pain (Sun et al., 2008). Breast cancer patients may develop acute pain shortly after initial treatment; however, this can persist for many years once treatment has finished (Hamood, Hamood, Merhasin, & Keinan-Boker, 2018). Within this population, pain usually affects the anterior and/or lateral region of the thorax, axilla and upper limb (Macdonald, Bruce, Scott, Smith, & Chambers, 2005). Chronic pain following breast cancer and its treatment is a major clinical problem, with 1 in 3 women who had experienced breast cancer perceiving themselves as living with chronic pain (Bao et al., 2018). The reported prevalence of chronic pain following breast cancer ranges from 25-60% (Andersen & Kehlet, 2011). The presence of chronic pain has been linked to reduced HRQoL, including impaired physical functioning and increased psychosocial distress (Akechi, Okuyama, Imoto, Yamawaki, & Uchitomi, 2001; Caffo et al., 2003; Tasmuth, Estlanderb, & Kalso, 1996).

Research has shown that up to 47% of survivors of breast cancer experience pain 1 to 3 years post-treatment, which was significantly linked to higher levels of psychological distress (Gärtner et al., 2009). Similarly, it was found that 74% of breast cancer survivors who were on average 7 years post-diagnosis experienced chronic pain (Hamood et al., 2018). A systematic review found that 51% of breast cancer survivors experienced pain 8 to 10 years post-diagnosis (Mols et al., 2005). Therefore, research would suggest that chronic pain can persist years after treatment has ended. Although pain appears to be a common symptom experienced by breast cancer survivors, there are inconsistencies regarding the severity of pain experienced. For example, Jensen et al. (2010) argued that moderate to severe pain may be less common, as they found that only 6% of participants reported moderate to severe pain in the previous week. However, it was found that more than 30% of breast cancer survivors reported above average pain 10 years post-treatment (Forsythe et al., 2013). Similarly in a study by Bredal, Smeby, Ottesen, Warncke, and Schlichting (2014), in a sample of breast cancer survivors (N=832) who reported pain (41%), 51% had mild, 41% moderate and 8% severe.

1.6.2 Risk Factors for chronic pain following breast cancer

While the pathogenesis of chronic pain has not been fully understood (Divella et al., 2020), a growing body of research has attempted to understand the risk factors that predict the development of chronic pain in breast cancer survivors (Jensen et al., 2010). High prevalence rates for chronic pain have been linked to the type of anti-cancer surgery and/or treatment a patient receives (Peuckmann et al., 2009). Evidence suggests that damage caused to the nerves innervating the breast and surrounding tissue during breast cancer surgery is a significant risk factor for the onset of chronic pain in survivorship phase (Caffo et al., 2003). However, the evidence regarding specific treatments and/or surgery and the onset of chronic pain in breast cancer survivors is mixed. For example, pain has been considered a more frequent symptom when a patient has undergone ALND, mastectomy or lumpectomy (Ferreira, de Oliveira Guirro, Dibai-Filho, de Araújo Ferreira, & de Almeida, 2015; Ferreira et al., 2014). In one study, 50% of women who underwent a mastectomy and 39% who underwent a lumpectomy with ALND reported chronic pain (Jung, Ahrendt, Oaklander, & Dworkin, 2003; Sun et al., 2008). In a large nationwide study in Denmark exploring pain following breast cancer treatment, it was found that chronic pain was prevalent for 25% of patients who received a mastectomy without any adjuvant therapy, in comparison to 60% of patients who underwent a lumpectomy, ALND and radiation (Gärtner et al., 2009). Furthermore, the prevalence and severity of chronic pain was found to be lower after less invasive procedures, in comparison to major surgery (Andersen & Kehlet, 2011; Divella et al., 2020). Arguably, the inconsistent results could be due to the heterogenous nature of breast cancer treatment (L. Wang et al., 2016) and it is important to consider other factors.

In a meta-analysis by L. Wang et al. (2016), it was found that younger age, ALND and radiotherapy contributed to the development of chronic pain following breast cancer. Further studies have also reported that younger age is associated with an increased risk of developing chronic pain following breast cancer (Gärtner et al., 2009; Poleshuck et al., 2006). To understand this association, it has been argued that pain may have a greater interference in a younger person's life, which may contribute to mood disturbance and distress, and therefore explain why younger age is associated with higher levels of pain in this population (Novy & Aigner, 2014). Other factors that have been associated with an increased risk of developing chronic pain following breast cancer include previous

comorbidities (e.g. arthritis, fibromyalgia) and experiencing chronic pain prior to breast cancer (Bao et al., 2018; Bredal et al., 2014), and more severe post-operative pain (Habib, Kertai, Cooter, Greenup, & Hwang, 2019; Katz et al., 2005; L. Wang et al., 2016). Post-surgical complications (e.g. infection, hematoma, seroma) have correlated with more severe acute post-operative pain, which then contributes to the development of chronic pain (Andersen & Kehlet, 2011; Divella et al., 2020). Hovind, Bredal, and Dihle (2013) interviewed breast cancer survivors experiencing chronic pain and found that whilst participants had expected to experience acute post-operative pain, they did not expect it to persist and could not recall receiving information about managing their pain. This highlights a clinical need for more information and support about pain management for this population.

Psychological factors such as anxiety, depression and stress have been found to correlate with pain, but the association is weak and therefore it is unclear whether this is a specific risk factor for developing chronic pain (Bredal et al., 2014; L. Wang et al., 2016). Overall, although research has highlighted several risk factors that may increase susceptibility of developing chronic pain following breast cancer, the evidence is inconclusive. It could be concluded that there are several interacting factors that could explain prevalence rates; however, more research is needed. Nevertheless, it is evident that chronic pain experienced by this population is a major clinical problem that needs addressing.

1.7 Measurement of Pain

One criticism surrounding research exploring cancer pain is in relation to inconsistent use of assessment tools across studies (K. Wang et al., 2018). Although multiple assessment tools have been developed to measure and characterise pain, the evaluation of pain can be challenging due to its multidimensional nature (Ferreira et al., 2014). Several pain and symptom assessment tools exist and have been used to evaluate chronic pain experienced by breast cancer survivors, including: the MD Anderson Symptom Inventory (Cleeland et al., 2000), the Edmonton Symptom Assessment System (Chang, Hwang, & Feuerman, 2000), the numerical rating scale (NRS) (Katz et al., 2005), and the Treatment Outcomes of Pain Survey (TOPS) (Tang & Tanco, 2021), among others. The Brief Pain Inventory (BPI), which also has a short form version (BPI-SF), was originally developed to assess pain experienced by cancer populations and has been

adopted widely across many clinical populations (Bredal et al., 2014; Jensen et al., 2010). The BPI has been validated for use in a variety of pain states, and measures pain severity, location, impact on daily function, analgesic medications, and the amount of pain relief achieved from medications (Tang & Tanco, 2021). Another popular validated tool is the McGill Pain Questionnaire (MPQ), which also has a short form version (MPQ-SF) (Caffo et al., 2003; Ferreira et al., 2015). It consists of 3 parts measuring dimensions of pain experience: sensory-discriminative, affective-motivational, and cognitive-evaluative (Tang & Tanco, 2021).

Therefore, whilst there are multiple accessible assessment tools for measuring pain, there is a lack of agreement on a standard assessment tool for cancer pain, resulting in inconsistencies among studies (Burton, Chai, & Smith, 2014). In order to enable adequate pain management, it is important that cancer pain is assessed using a valid, reliable and multidimensional tool (Burton et al., 2014; Ferreira et al., 2015).

1.8 Pain management

When an individual is faced with acute pain following injury or a medical intervention (e.g. surgery), pharmacological interventions such as opioids are often used for pain management (Sinatra, 2010), including for those with cancer-related pain (Kwon, 2014). However, research has found that these interventions are not always successful at eliminating pain, and are often associated with numerous side effects (Portenoy & Lesage, 1999). Acute pain that is difficult to manage and control will often transition into persistent, chronic pain that is unresponsive to opioids (Glare et al., 2014). This has resulted in research trying to establish more adequate ways of managing chronic pain, including safer opioid-sparing analgesic regimens and non-pharmacological interventions (Glare, Aubrey, & Myles, 2019; Glare et al., 2014).

Research has emerged demonstrating the benefits of using non-pharmacological interventions to manage various symptoms following breast cancer, including pain (Novy & Aigner, 2014). There has been more of a focus on using these interventions to manage chronic pain; however, in one study they found that reducing preoperative stress and increasing rehabilitation was effective in relieving acute pain and preventing chronic pain from developing in survivorship (Bender et al., 2008). Multiple psychosocial interventions have been developed and utilised to support patients to manage their chronic

pain, including cognitive-behavioural therapy (CBT), acceptance and commitment therapy (ACT), psychoeducation, relaxation training, and stress management (Novy & Aigner, 2014). These interventions will incorporate different techniques, such as graded exercise, distraction and a focus on modifying a patient's beliefs and attitudes about their condition etc., to try to reduce their experience of pain and improve QoL (Mills et al., 2019). In a meta-analysis by Tatrow and Montgomery (2006), they reported positive, significant results for the use of CBT interventions to reduce pain experienced in breast cancer populations. Another meta-analysis found that psychosocial interventions had a moderate treatment effect on pain severity (effect size = 0.34) and pain interference (effect size = 0.40) amongst cancer patients (Gorin et al., 2012). As this review included patients with heterogeneous cancer diagnoses, another meta-analysis exploring the effect of psychosocial interventions on pain outcomes specifically with breast cancer patients and survivors was conducted, which found a similar effect size (0.37) (Johannsen, Farver, Beck, & Zachariae, 2013).

Whilst these studies do suggest that psychosocial interventions may be an effective way of managing pain experienced by breast cancer patients and survivors, these results should be considered preliminary (Johannsen et al., 2013). Firstly, some studies include heterogenous cancer diagnoses, which makes it difficult to conclude the effectiveness of these interventions on specific types of cancer. Secondly, some of these studies have reviewed psychosocial interventions as a heterogenous group, which makes it difficult to conclude whether there are specific interventions that are effective for cancer pain management. However, it could be argued that if an intervention has been developed and shown to be effective in managing chronic pain, then it should be effective regardless of the cause. It could be concluded that pharmacological interventions may need to be used in conjunction with some form of psychosocial intervention; however, much more research is needed to identify which interventions are most effective. Approximately one-third of cancer patients are undertreated for pain (Shen et al., 2017), and this could be due to a lack of evidence-based guidance on the management of cancer-related pain, which highlights a clinical need for more guidance (Hamood et al., 2018).

1.9 Multidimensional models of pain

Historically, pain has been researched from a biomedical perspective, whereby pain has been viewed as a consequence of, and proportional to tissue damage (Ahles, 1993). However, this has often been criticised for being too reductionist. Consequently, this has also meant that research has focused on the development of medical interventions to manage pain. Exploring alternative non-pharmacological interventions to manage pain is based on the notion that pain is a multidimensional experience (Tavoli, Montazeri, Roshan, Tavoli, & Melyani, 2008). It was previously believed that biomedical factors had the biggest influence on reports of pain; however, it has since been argued that social and emotional factors can have a significant impact (Astin, Shapiro, Eisenberg, & Forys, 2003).

1.9.1 Pain gate-control theory

The pain gate-control theory was developed by Melzack and Wall (1965), and gave the first conceptual framework for the development of multidimensional models of pain (Ahles, 1993). According to the theory, the spinal cord contains a neurological 'gate' that can either block pain signals or allow them to pass through to the brain (Melzack & Wall, 1965). The theory also suggests that the 'gate' opens and closes in response to messages being sent from the brain (Hadjistavropoulos & Craig, 2004). The gate-control theory has been used to understand chronic pain and is based on the notion that affective, cognitive and behavioural factors can impact on pain perception (Melzack & Wall, 1988). For example, factors such as stress and tension, mental factors (e.g. preoccupied and focused on pain) and lack of activity (e.g. exercise) may result in the 'gate' staying open, which increases pain perception (Melzack & Wall, 1988). Therefore, this theory is based on the notion that non-pharmacological interventions can be used to help patients close the 'gate', reducing their experience of pain.

1.9.2 Multidimensional nature of cancer pain

Research has started to adopt the multidimensional model as a way of understanding cancer-related chronic pain (Caffo et al., 2003). It has been found that psychosocial factors play an important role in pain experienced by cancer patients and survivors, with associations between high levels of pain and increased depression, anxiety and reduced HRQoL being reported (Galloway et al., 2012; Novy & Aigner, 2014; Zoëga,

Fridriksdottir, Sigurdardottir, & Gunnarsdottir, 2013). In two studies exploring the development of chronic pain amongst breast cancer patients, it was found that psychosocial factors, such as depression, anxiety, somatisation and catastrophising in response to pain, could explain persistent post-mastectomy pain (Schreiber et al., 2013), and this was experienced up to 3 years after surgery (Belfer et al., 2013). In both studies, the pain reported by participants was not associated with medical and disease-related factors (e.g. tumour size, type of treatment), which suggests that psychological factors may provide better insight into chronic pain experienced by this population, in comparison to disease or treatment factors. Research has also found associations between higher levels of cancer pain and reduced social support (Zaza & Baine, 2002). The causal relationship has not been well established, and it has not been concluded whether these psychosocial factors influence the experience of pain or whether they impact on a patient's willingness to comply with treatment to manage pain, or whether psychosocial problems develop as a result of having pain (Wool & Mor, 2005). The complex nature of cancer and large heterogeneity in this population makes understanding cancer pain complex (Chwistek, 2017). Nevertheless, this evidence highlights the importance of viewing cancer pain from a multidimensional perspective. Therefore, consideration for these interacting biopsychosocial dimensions is important in the assessment and treatment of cancer pain (Wool & Mor, 2005).

1.9.3 Cancer pain beliefs

A multidimensional perspective of cancer pain allows a process by which a person's beliefs and attitudes about their condition can have an impact on pain experience and management (Chen, Tang, & Chen, 2012; Guo, 2014). Whilst some cognitions and beliefs may help patients to cope with their pain, others may contribute to increased pain and levels of distress (Tavoli et al., 2008). The presence of pain may be a continuous reminder for patients of both their treatment and cancer, which consequently results in increased distress and fear of cancer recurrence (Caffo et al., 2003). Studies have found that breast cancer survivors who experience chronic pain are more likely to report higher levels of pain catastrophising, which is linked to greater emotional distress (Bishop & Warr, 2003; Edwards et al., 2013). In several cross-sectional studies (patients with different cancer diagnoses), the belief that pain was inevitable has been associated with severe pain intensity (Bağçivan, Tosun, Kömürcü, Akbayrak, & Özet, 2009; Deshields et

al., 2010) and higher levels of pain interference (Valeberg et al., 2009), as measured using the BPI-SF (Guo, 2014). However, other studies have not found this association (Edrington et al, 2009; Potter et al, 2003), though this could be due to smaller sample sizes (N <100) (Guo, 2014). It may be that other confounding factors need to be considered to explain this relationship.

Research has shown how personal beliefs about cancer pain can act as barriers to pain management, which has included: belief that cancer pain is inevitable and uncontrollable; concerns about adverse effects of medication; belief that pain is a sign of disease progression and fear of addiction to medication (Cohen et al., 2008; Deshields et al., 2010; Guo, 2014; Sherwood, Adams-McNeill, Starck, Nieto, & Thompson, 2000). These barriers are related to a patient's coping efforts and subsequent outcomes including pain severity and well-being (Ward et al., 2008). For example, research has found that holding the belief that pain is understandable is associated with better treatment compliance, whereas the belief that pain is mysterious is associated with catastrophising, which is associated with poorer outcomes (Tavoli et al., 2008; Williams & Keefe, 1991). Similarly, having the perception of living with chronic pain was strongly associated with poorer pain outcomes and medication use (Bao et al., 2018). Although more research is needed, the evidence does suggest that a person's beliefs and attitudes can impact on pain experience and management. This also highlights the importance of patients being provided with sufficient support and information to understand and manage their pain (Hovind et al., 2013). Furthermore, identifying the beliefs and cognitions that cancer patients hold may help explain variability in the prevalence of chronic pain experienced within this population.

1.10 Leventhal's Common Sense Model (CSM) of self-regulation

The Common Sense Model (CSM) of self-regulation provides an empirically validated model which helps us understand how people make sense of and cope with an illness (Leventhal & Brissette, 2012; Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz & Steele, 1984). According to the CSM, when an individual is faced with an illness they will attempt to make sense of both illness and treatment by constructing internal representations which have both cognitive and emotional content (Ashley et al., 2015). According to the CSM, illness representations are formulated around the following dimensions: identity (label of illness and symptoms associated); cause(s); timeline (acute,

chronic or cyclical); controllability of the illness; consequences; and coherence (individual's understanding of the illness) (Hopman & Rijken, 2015; Weinman, Petrie, Moss-Morris, & Horne, 1996). The individual will also develop emotional representations, such as anxiety or depression or fear, which will guide how they respond to an illness (Moon, Moss-Morris, Hunter, & Hughes, 2017).

Illness representations can be formed based on information from several sources, including personal and past experience with the illness, information from health care professionals, friends, family, and the media (Anagnostopoulos & Spanea, 2005). The CSM proposes that these cognitive and emotional representations act as a framework for the development of coping strategies, which will be adopted as a way of trying to manage the illness (Moon et al., 2017). Through an appraisal process, the individual will assess the effectiveness of their chosen coping strategies, which can subsequently impact how they perceive their illness and the coping strategies that they have been using to manage (Hagger & Orbell, 2003; McCorry et al., 2013a). Figure 1 below demonstrates how the CSM is conceptualised.

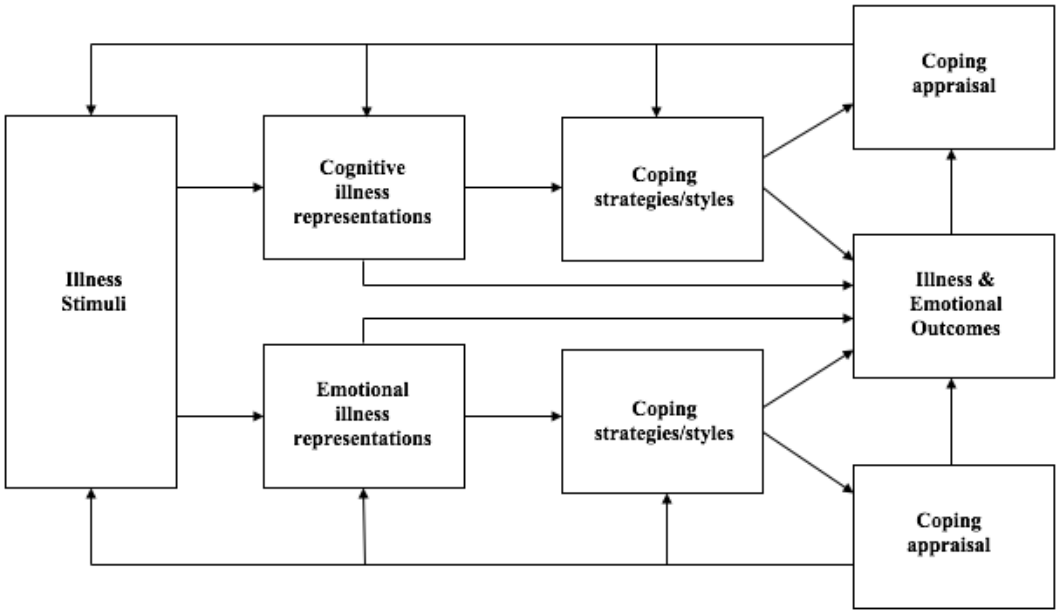


Figure 1. A conceptualisation of the CSM (adapted from Hagger & Orbell, 2003).

According to the CSM, illness representations and the coping strategies associated with them are linked with outcomes related to physical and psychological well-being (Dempster et al., 2011). Although research has attempted to understand the specific

factors underlying the variation in pain prevalence experienced by breast cancer survivors, the evidence is inconclusive. Research has, however, indicated that beliefs are associated with the experience of pain, and a logical next step would be to explore the utility of the CSM in explaining this variation.

1.10.1 Measuring illness representations

In order to evaluate illness representations, the Illness Perceptions Questionnaire (IPQ) was created (Weinman et al., 1996), with a shorter version (Brief Illness Perceptions Questionnaire; Brief IPQ) developed for when time is limited or for specific patients (e.g. people very unwell) (Broadbent, Petrie, Main, & Weinman, 2006). As the CSM evolved to expand the dimensions initially thought to be included in the model, so did the tools to assess it, with the Revised Illness Perceptions Questionnaire (IPQ-R) being published in 2002 (Moss-Morris et al., 2002). The IPQ-R measures 9 dimensions of illness representations outlined by the most recent version of the CSM and consists of 3 domains. The first, illness identity, lists 14 generic symptoms (e.g. fatigue, headache) for which participants are asked to indicate each one they associate with their illness. The second domain, referred to as the beliefs domain, covers 7 dimensions: timeline acute/chronic; timeline cyclical; consequences; controllability; curability; emotional representations, and illness coherence. The third domain lists 18 possible causes that an individual may identify as being the cause of their condition. For each dimension in the second and third domain, the responder rates their level of agreement on a five-point likert scale (Leysen et al., 2015). Several studies have demonstrated that the IPQ-R has good internal reliability and test-retest reliability, as well as predictive validity (Moon et al., 2017; Moss-Morris et al., 2002).

The IPQ-R was originally developed as a generic scale that could be used for a variety of illness groups. This means that the questionnaire may not cover beliefs, symptoms or causes that may be unique to a specific illness or patient group (Moon et al., 2017). The authors of the IPQ-R have recommended that the scale be modified by adapting the questions so that it can be used in different contexts with different illnesses (Moss-Morris et al., 2002). Several studies have done this and modified the IPQ-R for a specific group; however, there is little evidence validating such modified versions (Moon et al., 2017). Think-aloud studies have demonstrated that when modifying the IPQ-R, patients often have difficulty understanding items and sometimes misunderstood some of

the questions (Aujla, Vedhara, Walker, & Sprigg, 2018; McCorry, Scullion, McMurray, Houghton, & Dempster, 2013b; Van Oort, Schröder, & French, 2011). Therefore, it seems important to ensure that when modifying the IPQ-R, there is evidence to support that it has face validity for that particular illness or patient group.

Several studies have used the IPQ-R with breast cancer survivors, and it seems important to understand the illness representations of this patient group due to the ongoing difficulties experienced after completing all active treatment. However, as breast cancer survivors have completed all active treatment, they may no longer consider themselves as being ill and may struggle to answer the questions on the IPQ-R as they relate to their illness (Moon et al., 2017). Therefore, it seems important that when using the IPQ-R with this patient group, a modified version is used. A recent study exploring the modification and validation of the IPQ-R for use with breast cancer survivors reassures that a modified version remains valid and reliable (Moon et al., 2017).

1.11 Illness representation studies

1.11.1 Illness representations, coping strategies and illness outcomes

Research has consistently demonstrated robust associations between illness representations and outcomes (Stewart, 2020). According to the CSM, illness representations predict coping strategies, which subsequently impact on illness outcomes such as HRQoL and return to work (Leventhal et al., 1980). The CSM has been used to investigate links between illness representations and a range of psychological and physical outcomes in a variety of health conditions, including: cardiovascular disorders (Schoormans et al., 2014); asthma (Halm, Mora, & Leventhal, 2006); musculoskeletal disorders (van Wilgen, van Ittersum, Kaptein, & van Wijhe, 2008); lower back pain (Foster et al., 2008); chronic kidney disease (CKD) (Nah et al., 2019); chronic fatigue syndrome (CFS) and rheumatoid arthritis (Moss-Morris & Chalder, 2003); HIV (Keller, 1993); and many others. Hagger and Orbell (2003) conducted the first meta-analytic review in this area and reported that the dimensions of consequence, control/cure, identity and timeline were valid constructs that could be linked to illness outcomes and coping strategies for many different illness types.

Several studies have demonstrated a link between illness representations and coping strategies. For example, viewing an illness as controllable has been linked to active coping, whereas viewing an illness as uncontrollable and chronic has been linked to avoidance and denial coping (Corbett et al., 2016). This was demonstrated for patients with CFS, whereby the identity and cure/control dimensions correlated significantly with active coping, seeking social support and behavioural disengagement (Moss-Morris, Petrie, & Weinman, 1996). Similarly, Chilcot, Wellsted, and Farrington (2010) found that among hemodialysis patients, those who were non-adherent to treatment held significantly lower timeline perceptions, indicating that they held weaker perceptions regarding the chronicity of their illness. In two studies by Heijmans (1998b; 1999) with patients with CFS and Addison's disease, illness representations such as a belief that the illness is uncontrollable or negative perceptions regarding chronicity of the illness, significantly correlated with the use of passive and avoidant coping strategies, rather than more problem-focused coping strategies. Furthermore, Kemp, Morley, and Anderson (1999) found that for epilepsy patients, perceived controllability over their illness was significantly associated with problem-focused coping such as exercise, whereas viewing their illness as having severe consequences was significantly associated with avoidance.

Several systematic reviews and meta-analytic reviews have demonstrated the relationship between illness representations and illness outcomes (Aujla et al., 2016; Rivera, Corte, DeVon, Collins, & Steffen, 2020). Illness representations have been found to be related to a variety of illness outcomes, including psychological functioning, return to work, physical functioning and HRQoL (Ashley et al., 2015). A recent meta-analytic review found that illness representations were associated with psychological distress experienced across a range of physical health conditions, with illness representations accounting for 25-30% of the variance (Dempster, Howell, & McCorry, 2015). Similarly, Knowles, Wilson, Connell, and Kamm (2011) found that illness representations had a significant direct link with psychological outcomes, such as depression and anxiety. Stafford, Berk, and Jackson (2009) found that for patients with coronary heart disease, negative illness representations were significantly predictive of depression, whereas positive illness representations were associated with better HRQoL. Similarly, for patients with alopecia, it was found that having a strong illness identity (attributing more symptoms to be a result of their illness), belief that their illness has serious consequences and viewing their illness as having considerable emotional impact, were linked to reduced

HRQoL (Cartwright, Endean, & Porter, 2009). In two studies with patients with chronic conditions such as CFS, Addison's disease, psoriasis and rheumatoid arthritis, it was found that illness representations such as having a strong illness identity, holding negative perceptions regarding the chronicity of the illness and viewing the illness as having severe consequences were linked to worse outcomes on measures of physical and social functioning (Heijmans & de Ridder, 1998a; Scharloo et al., 1998).

Illness representations have also been shown to be associated with chronic pain outcomes. For example, for patients with orofacial pain, holding negative beliefs around personal control, the consequences and chronicity of their illness, were found to be predictors of outcomes including pain-related disability, anxiety and depression (Galli, Ettlin, Palla, Ehlert, & Gaab, 2010). Similarly, for patients with lower back problems, negative illness representations on dimensions of consequence, control/cure and timeline, predicted worse clinical outcomes at six months (Foster et al., 2008). Norton et al. (2014) found that for patients with rheumatoid arthritis, those who attributed more symptoms to their illness and had stronger perceptions of the consequences, chronicity and cyclicality of their condition reported higher levels of pain, functional disability and distress. In another study amongst chronic pain patients, having a strong illness identity, viewing their illness as having a strong emotional impact and holding negative beliefs regarding the chronicity and consequences of their illness correlated with pain severity, physical disability and emotional distress (Gillanders, Ferreira, Bose, & Esrich, 2013). Furthermore, in a six year longitudinal study of patients with osteoarthritis, changes in illness representations were associated with changes in outcomes over time (Kaptein et al., 2010). For example, dimensions of timeline (chronic), personal control and illness coherence became more negative, and outcomes such as functional disability and pain intensity got worse (Kaptein et al., 2010). However, it is difficult to establish the causal direction as it is possible that the patient's osteoarthritis worsened and could have accounted for changes in outcomes. Overall, the evidence provides support for the CSM by demonstrating the relationship between illness representations, coping and illness outcomes, for a variety of health conditions.

1.11.2 Illness representations, coping strategies and illness outcomes in cancer

Research exploring illness representations in relation to cancer has not always focused on the perceptions of patients who have experienced cancer (Hopman & Rijken, 2015). For example, Hagger and Orbell (2006) explored illness representations following an abnormal screening for cervical and colorectal cancer and found that the dimensions of identity, consequences and cause were linked to an individual's emotional reactions. Similarly, studies have also focused on people's lay perceptions of cancer (Figueiras & Alves, 2007). Del Castillo, Godoy-Izquierdo, Vázquez, and Godoy (2011) explored lay perceptions of cancer and found that individuals who had family experience of cancer reported significantly more symptoms and stronger emotional impact. Although this research provides useful insight into understanding how people view cancer, the majority of research has focused on exploring the perceptions of patients who have experienced cancer.

Most research in this area has been cross-sectional and has been conducted on patients who have a specific cancer diagnosis (Stewart, 2020). This has included patients with the following types of cancer: head and neck (Llewellyn, McGurk, & Weinman, 2007); breast (Millar, Purushotham, McLatchie, George, & Murray, 2005); prostate (Traeger et al., 2009); ovarian (Lancastle, Brain, & Phelps, 2011); gastrointestinal (Miceli et al., 2019); and lung (Hoogerwerf, Ninaber, Willems, & Kaptein, 2012). Findings have been inconsistent, with some studies demonstrating that negative illness representations and maladaptive coping are associated with worse psychological and physical outcomes, and others finding weaker relationships (Stewart, 2020). Ashley et al. (2015) found that amongst patients with a diagnosis of breast, colorectal and prostate cancer, illness representations were an independent predictor of HRQoL 15-months post diagnosis. However, in a study of patients with head and neck cancer, it was found that none of the illness representation dimensions predicted QoL or anxiety, though a link between timeline (acute) and depression was found (Llewellyn et al., 2007). In one study exploring the relationship between pain and illness representations among Taiwanese patients with lung and colorectal cancer, it was found that patients with more negative beliefs around consequences and treatment control reported higher levels of pain (Guo, 2014). In a study

of cancer survivors, Zhang et al. (2016) found that negative illness representations were associated with greater physical symptom distress and lower levels of optimism.

There is a limited amount of research exploring the relationship between illness representations and coping behaviours amongst cancer patients and the current evidence has produced inconsistent results (Hopman & Rijken, 2015). Nevertheless, Llewellyn et al. (2007) did find a relationship between illness representations and coping strategies, 6-8 months post-treatment. Richardson et al. (2017) carried out a meta-analysis and systematic review on 54 studies exploring illness perceptions, coping and illness outcomes in patients with cancer (mainly breast, prostate and head and neck cancer). They found that stronger emotional representations were associated with maladaptive coping styles (avoidance and denial), whereas stronger personal control beliefs were associated with adaptive coping styles (problem-focused). Stronger held beliefs around identity and more negative beliefs around consequences were associated with higher levels of psychological distress and lower levels of functioning and QoL (Richardson et al., 2017). Overall, the evidence does support the applicability of the CSM in understanding illness perceptions, coping and illness outcomes in patients with cancer; however, as some of the evidence is inconsistent, more research is needed.

1.11.3 Illness representations, coping strategies and illness outcomes in breast cancer

Several studies have explored lay women's perceptions of breast cancer. For example, Anagnostopoulos and Spanea (2005) found that women without breast cancer held strong beliefs surrounding the role of environmental factors in the development of breast cancer and overestimated the consequences of having a diagnosis. Anagnostopoulos et al. (2012) found that women who had not had a mammograph held more negative illness representations, as they reported fewer benefits to regular screening and held more negative emotional representations of breast cancer. Similarly, delays in seeking medical attention following the discovery of a potential symptom of breast cancer was associated with negative illness representations, particularly on the dimensions of identity and consequences of having breast cancer (Hunter, Grunfeld, & Ramirez, 2003). It is important to identify the illness representations of lay women, as negative beliefs could have implications for women attending regular screening and impact on how breast

cancer is viewed in society and the media; therefore, addressing these perceptions could have positive outcomes.

As discussed, women with breast cancer are often faced with numerous long-term difficulties, such as psychosocial problems, reduced physical functioning and HRQoL (Hopman & Rijken, 2015). There is a growing body of research which has explored the utility of the CSM in helping to understand illness representations for patients with breast cancer (Kaptein et al., 2013). Identifying the illness representations that these women hold, and the potential consequences of those representations, will aid in the development of interventions that can help to target and improve these symptoms (Moon et al., 2017). Several studies and a recent systematic review exploring illness representations of breast cancer patients in active treatment and those in survivorship have found that illness representations can predict a number of illness outcomes, such as psychological distress, fear of recurrence and HRQoL (Charlier et al., 2012; Kaptein et al., 2015; Thuné-Boyle, Myers, & Newman, 2006). Fear of recurrence has been considered a particular problem for those who have survived breast cancer. In two separate studies exploring the relationship between illness representations and fear of recurrence, it was found that breast cancer survivors who reported more negative emotional representations and had more negative representations on the dimensions of identity, timeline and consequences of their illness reported higher levels of fear of recurrence (Corter, Findlay, Broom, Porter, & Petrie, 2013; Freeman-Gibb, Janz, Katapodi, Zikmund-Fisher, & Northouse, 2017; Rabin, Leventhal, & Goodin, 2004).

Further studies have found that negative illness representations held by survivors of breast cancer were associated with worse functional status, as reflected in physical and psychological outcomes (Rozema, Völlink, and Lechner (2009). According to Fischer et al. (2012), the level of distress experienced following breast cancer was worse for women who believed that the timeline of their illness was chronic and cyclical and for those who held more negative beliefs regarding the effectiveness of treatment and the severity of consequences that it would have on their life. Similarly, believing that the timeline of their breast cancer was chronic or cyclical was associated with higher reports of anxiety and depression (Rabin et al., 2004). Millar et al. (2005) found that a patient's perception of the impact of the symptoms and timeline of their breast cancer reliably predicted the variation in psychological morbidity reported one year post surgery. Silva, Moreira, and

Canavarro (2012) found that negative illness representations regarding the impact of breast cancer predicted higher emotional distress and impaired physical and psychosocial functioning. They also found that post-traumatic growth (positive psychological change as a result of adversity) following breast cancer acted as a moderator on the relationship between illness representations and illness outcomes, which led them to argue that in order to promote adjustment following breast cancer, an intervention is needed that can promote post-traumatic growth, which will help aid recovery and promote wellbeing post-diagnosis (Silva et al., 2012).

The majority of research exploring illness representations in women with breast cancer has focused on illness outcomes; however, there are some studies which have explored the relationship between illness representations and coping behaviours. For example, McCorry et al. (2013a) found that patients who engage in more positive and active coping strategies following their breast cancer report lower levels of distress. Similarly, breast cancer survivors who hold more negative illness representations regarding the consequences of their cancer and who believed that the development and prevention of recurrence could be caused by health or stress reported improvement in behaviours such as diet, physical exercise and a reduction in alcohol use (Costanzo, Lutgendorf, & Roeder, 2011). In another study it was found that those treated with chemotherapy had more negative illness representations regarding the timeline, consequences and cause of their breast cancer, and were more likely to engage in coping behaviours such as mental disengagement and restraint, in comparison to those treated with radiotherapy, who engaged in more acceptance (Buick, 1997). Likewise, avoidance and missing treatment sessions have been associated with more negative illness perceptions (Iskandarsyah, de Klerk, Suardi, Sadarjoen, & Passchier, 2014). However, Rozema et al. (2009) explored coping strategies of breast cancer patients and found a weak relationship between illness representations and coping strategies, identifying one relationship between the perception of breast cancer having a chronic timeline and the use of avoidance. Overall, the findings appear inconsistent and much more evidence is needed to establish the relationship.

There have also been studies that have explored illness representations and breast cancer in terms of the wider impact of representations on factors such as decision making about treatment. For example, Duric et al. (2007) found that patient preference for

adjuvant chemotherapy was determined by the way they represented their illness on the dimensions of identity and consequences. Likewise, the decision to undergo a bilateral mastectomy was associated with a patient's causal beliefs about breast cancer, particularly those who identified it as having a genetic or hormonal cause (Petrie, Myrtveit, Partridge, Stephens, & Stanton, 2015). Thomson et al. (2014) explored what factors patients thought caused their breast cancer and identified that causal beliefs were related to stress and lifestyle. Furthermore, Royer, Phelan, and Heidrich (2009) explored older breast cancer survivors' (>65) symptom beliefs and by using the CSM were able to identify that these women often describe breast cancer symptoms as chronic, having several negative consequences and that it could not be cured or controlled. McCorry et al. (2013a) found that illness perceptions remained stable during a 6 month follow-up, and one criticism of much recent research is that it has not considered the change of illness representations over time. Therefore, more longitudinal research may be needed in the future.

Overall, the CSM seems to provide a useful model for understanding the perceptions of patients who have had breast cancer, which can impact on a range of factors such as decisions regarding treatment, illness outcomes and coping behaviours. However, there is currently a lack of research exploring the relationship between illness representations and pain outcomes amongst this population. In one study, Rozema et al. (2009) did find that negative illness representations held by breast cancer survivors were associated with worse physical health outcomes. They used the 36-item short form health survey (SF-36), which measures HRQoL and includes 2 pain items. However, they were not able to specifically report whether illness representations were associated with chronic pain. Therefore, to the author's knowledge, there is currently a gap in the research.

1.12 Summary and rationale for the current study

As discussed within this literature review, cancer survival rates are increasing; however, 75% of cancer survivors are faced with negative health-related consequences, including chronic pain (Corbett et al., 2016). Chronic pain is a common and distressing symptom following a cancer diagnosis, which can impact on a variety of outcomes, such as HRQoL, psychological and physical functioning. Chronic pain affects 25-60% of breast cancer survivors which represents a major clinical problem that is not well

understood (Andersen & Kehlet, 2011). Despite research attempting to understand the underlying factors that may explain the variation in chronic pain experienced by breast cancer survivors, the evidence is inconclusive. The CSM has been widely used with a variety of health conditions. When patients are faced with a health threat, they develop internal representations as a way of trying to make sense of their illness and treatment (Leventhal & Brissette, 2012; Leventhal et al., 1984), and it has been demonstrated that these representations are associated with a variety of illness outcomes and coping behaviours across several conditions (Hagger & Orbell, 2003).

The CSM has been applied to cancer patients, demonstrating promising results with regard to identifying a relationship between illness representations, coping strategies and illness outcomes (Richardson et al., 2017); this has also been studied in breast cancer patients and survivors (Kaptein et al., 2015). Previous studies have demonstrated that illness representations can be used to understand pain experienced following an illness (Norton et al., 2014); however, to the author's knowledge, no studies have explored this association amongst breast cancer survivors. Therefore, although there is a large body of research which has documented a relationship between illness representations and a variety of illness outcomes among breast cancer patients and survivors, there is currently a lack of evidence exploring the impact that these illness representations can have on chronic pain experienced by those who survive breast cancer.

There is also a gap in the literature in terms of understanding factors that might explain the variation in chronic pain experienced by this population. Considering the high prevalence rates of women who develop chronic pain following breast cancer and its treatment, and the negative impact this can have on HRQoL, psychological and physical functioning, it seems important to explore this relationship. Therefore, given the robust evidence surrounding illness representations, it seems reasonable to consider this as a potential way of understanding and explaining the level of pain experienced by breast cancer survivors. Identifying a possible relationship would mean that interventions could be developed to target any representations held by these women, which could be useful in reducing rates of chronic pain following breast cancer.

1.13 Research aims and hypotheses

Given the information outlined above, the aims of the current study were to explore the association between illness representations, HRQoL and pain in women who have survived breast cancer. The current study attempts to answer the following questions:

1. What is the relationship between illness representations and pain severity in women who have survived breast cancer?

2. What is the relationship between HRQoL and pain severity in women who have survived breast cancer?

Based on these aims and research questions, the current study has two specific hypotheses:

1. Participants who report more negative illness representations will be more likely to report moderate or severe pain.

1. Participants who report reduced HRQoL will be more likely to report moderate or severe pain.

Chapter 2: Methodology

This chapter begins by outlining the research design and ethical clearance for the current study. The sample selection and recruitment strategy are then discussed, before outlining the procedure and measures used. The chapter then goes on to describe how the IPQ-R was adapted for the current study. Finally, the chapter finishes by outlining the data available, before describing the process of data preparation and analysis.

2.1 Design

The current study used a cross-sectional online survey. Participants were required to complete questionnaires that captured data on demographics, illness-related clinical information, illness representations, pain, HRQoL, and mood. Participants were stratified into one of four pain categories based on their level of pain severity. All data are summarised for total sample and by pain category.

2.2 Ethical Clearance

This study was approved by the School of Medicine Research Ethics Committee (SoMREC) in July 2020 (MREC 19-059) (Appendix A).

2.3 Participants and procedure

2.3.1 Sample

The literature review presented in Chapter 1 revealed no published datasets on the relationship between illness representations and pain outcomes for breast cancer survivors. However, there are similar studies that have adopted a cross-sectional design to explore the relationship between illness representations, coping strategies and illness outcomes with breast cancer patients and/or survivors (Corter et al., 2013; Freeman-Gibb et al., 2017; Rozema et al., 2009; Silva et al., 2012). The focus of this study was chronic pain experienced by breast cancer survivors. Therefore, using the following studies (Bredal et al., 2014; Caffo et al., 2003; Gärtner et al., 2009; Jensen et al., 2010; Katz et al., 2005), it was possible to calculate an average prevalence of chronic pain for this population, which was found to be 45%. To establish a sufficient sample size, Statulator was used to compute a power calculation (Dhand & Khatkar, 2014). Assuming that 45% of the participants in the population would have the factor of interest (pain), the study

would require a sample size of (n=182) for estimating the expected proportion with 7.23% precision and 95% confidence (Dhand & Khatkar, 2014).

2.3.2 Recruitment

In order to support the recruitment process, several different charities and organisations were contacted, including: Breast Cancer Haven; Breast Cancer Now; Maggie Centre; Cancer Research UK; Yorkshire Cancer Community; and Yorkshire Cancer Research. Macmillan Cancer Support were contacted but, due to GDPR restrictions, they were unable to support with recruitment. The other charities and organisations were able to support recruitment in the current study in two different ways:

1. Recruitment via email – Breast Cancer Now were able to send an invitation email to their mailing list. The email included a summary of the research and a link to access the survey (Appendix B).
2. Recruitment via poster – A poster was created, which provided a summary of the research and a link to access the survey (Appendix C). Charities/organisations were able to advertise this on different online platforms including their website, an online forum, and their Twitter and Facebook pages. The advertisement was re-posted 3 months later.

2.3.3 Inclusion and exclusion criteria

In order to take part in the study the following inclusion and exclusion criteria were agreed:

Inclusion criteria. To be eligible to complete the survey, participants were required to be: female; aged over 18; fluent in English and able to understand the questionnaires; previously received a diagnosis of breast cancer; and finished all active hospital-based treatment for breast cancer.

Exclusion criteria. Participants were not eligible to complete the survey if they were: male; under the age of 18; unable to understand English sufficiently to answer the questionnaires; had cognitive impairment that would prevent them from answering the questionnaires; or were receiving ongoing hospital-based treatment for breast cancer.

The rationale for excluding men was differences in the epidemiology of breast cancer for males and females, and less than 1% of breast cancer diagnoses are in men (Breast Cancer Now, 2021). The decision to exclude individuals under 18 is because illness representations and the psychological needs of those under 18 will be different in comparison to working age adults. Whilst this study recognises the importance of making reasonable adjustments to promote inclusivity, due to limited resources and this survey being completed online, it was difficult to make adjustments for those who would require the survey to be translated into a different language or would require extra support due to an impairment to complete the survey. Finally, as this study was interested in the experiences of breast cancer survivors, any women who were receiving ongoing hospital-based treatment were excluded.

2.3.4 Procedure

Participants were required to complete a series of questionnaires presented in an online format using 'Online Surveys' (Appendix D). Participants were first presented with the information sheet and were given the option to provide consent to participate in the survey by clicking the 'next' button. Participants were then presented with a screening question to ensure that they met the inclusion criteria. Participants were next required to complete questions about demographic and illness-related characteristics, after which they were asked to complete a set of standardised questionnaires which assessed illness representations, pain, HRQoL and mood. Table 1 provides a list of the questionnaires used in this study.

Table 1. *List of standardised questionnaires used in the online survey.*

Measure	Construct	Reference
Illness perception questionnaire – revised (IPQ-R)	Illness representations	(Moss-Morris et al., 2002)
Brief pain inventory – short form (BPI-SF)	Pain severity and interference	(Cleeland & Ryan, 1991)
EuroQol-5 dimension (EQ-5D)	Quality of Life	(Brooks, 1996)
Patient health questionnaire (PHQ-8)	Depression	(Kroenke, Spitzer, & Williams, 2001)
Generalised anxiety disorder scale (GAD-7)	Anxiety	(Spitzer, Kroenke, Williams, & Löwe, 2006)

2.4 Measures

2.4.1 Demographic and illness-related information

All participants were asked to report their age (years), sex (male/female), ethnicity (White / White mixed / Black or Black British / Asian or Asian British / Other), relationship status (married / single / widowed / divorced / civil partnership / in a relationship / other), employment status (employed - full-time / employed - part-time / unemployed / self-employed / retired / disabled, not able to work / other), education level (GCSEs or equivalent / A-Levels or equivalent / university undergraduate degree or higher) and whether they had any dependent children (yes/no). Participants were also required to provide illness-related information about their breast cancer. This included the number of times they have been diagnosed with breast cancer (number), how long ago they were diagnosed with breast cancer (years), the type of treatment they had received for their breast cancer (radiotherapy / chemotherapy / surgery / hormone therapy / other), the type of surgery they had received for their breast cancer (if applicable) (lumpectomy / single mastectomy / double mastectomy / breast reconstruction / lymph node dissection / unsure / other), and how long ago they had finished hospital-based treatment (less than 1 year ago / 1-2 years ago / 3-4 years ago / 5+ years ago).

2.4.2 Standardised participant reported outcome measures

Illness Perception Questionnaire - Revised (IPQ-R). Illness representations were measured using the IPQ-R. As recommended in the literature (Moss-Morris et al., 2002), for the purpose of this study, the questionnaire was modified and adapted for use with participants who were survivors of breast cancer (Appendix E). The questionnaire is a quantitative measure of eight cognitive and emotional representations of illness. A score is obtained from a number of statements rated on five-point likert scales, with the points varying from "strongly disagree" to "strongly agree". The items are: Timeline Acute/Chronic, Timeline Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence and Emotional Representation. In addition, an identity score is calculated from a number of symptoms listed that the participant attributes to their illness and is answered using a yes/no format. The identity scale originally includes 14 common symptoms; however, as indicated by previous research (Rozema et al., 2009), symptoms can be taken out and added when they are or are not related to the illness. Therefore, the following symptoms were removed: sore throat; sore eyes; and wheeziness. The following symptoms were added to the original list: feeling down and anxiety. The final list of symptoms can be found in Appendix D. The IPQ-R has been assessed in a range of illness populations (asthma, diabetes, chronic and acute pain, cancer, and HIV infection), with all domains demonstrating good internal consistency, with Cronbach alpha levels ranging from 0.79 to 0.89 (Moss-Morris et al., 2002).

Higher scores on the identity, timeline, consequences and cyclical dimensions represent strongly held beliefs about the number of symptoms attributed to the illness, the chronicity of the condition, the negative consequences of the illness and the cyclical nature of the condition. Lower scores on the personal control, treatment control and coherence dimensions represent negative beliefs surrounding the controllability of the illness and less personal understanding of the illness.

There is a third section that addresses the participants' perception regarding the cause of their illness and includes factors related to behavioural, biological and psychological causes. The original list includes 18 possible causes; however, as highlighted in previous research (Moon et al., 2017; Rozema et al., 2009), an additional breast cancer-related causal factor was included which was 'hormonal influence'.

Brief Pain Inventory – Short Form (BPI-SF). The BPI-SF is a 12-item self-report questionnaire designed to evaluate pain severity and pain interference. The BPI-SF is considered a powerful tool that has demonstrated reliability and validity across studies (Kumar, 2011). The BPI-SF was originally developed to assess cancer pain (Tang & Tanco, 2021), and has been used in studies that have focused on pain following breast cancer (Bredal et al., 2014; Jensen et al., 2010).

The first question on the BPI-SF established the presence/absence of chronic pain by asking participants whether they have experienced pain (specific to their breast cancer and/or treatment) for the past 3 months or longer. Participants responding "no" to this question were categorised as the "no pain" group and did not complete any more of the BPI-SF questions. Participants responding "yes" to this question were then presented with the remaining BPI-SF items.

Pain severity was assessed by four items asking participants to rate their pain at its "worst in the last 24 hours", "least in the last 24 hours", "average in the last 24 hours", and "now". Each item was scored on an 11-point likert scale anchored 0 "no pain" and 10 "pain as bad as you could imagine". Pain severity score was calculated as the average response across these four items. Using the pain severity score, participants were categorised into one of three categories: mild pain (0-3), moderate pain (4-6) and severe pain (7-10). These pain categories (including the no pain group described above) were used as the primary outcome variables for the descriptive and inferential analyses.

Pain relief was assessed by asking participants to rate how much relief they have got from medication to manage their pain, on a scale anchored at 0% indicating "no relief" and 100% indicating "complete relief".

Pain interference was assessed by seven items asking about what extent pain interferes with general activity, mood, walking ability, normal work, relations with other people, sleep, and enjoyment of life. Each item was scored on an 11-point likert scale anchored 0 "does not interfere" and 10 "completely interferes". Pain interference score was calculated as the average response across these seven items.

EuroQol-5 Dimension (EQ-5D). The EQ-5D allows participants to classify their own health status into five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression with five levels of severity (no problems, slight,

moderate, severe and extreme problems). There are 3,125 possible health states that can be identified based on participants' responses, ranging from 11111 (full health) to 55555 (worst health) (McCaffrey, Kaambwa, Currow, & Ratcliffe, 2016). The health state is then converted into a single index 'utility' score using a scoring algorithm. The measure also includes a visual analogue scale (EQ-VAS), which allows participants to provide a single rating of self-perceived health, with 0 indicating "the worst health you can imagine" and 100 indicating "the best health you can imagine". Research has supported the validity and reliability of using the EQ-5D within a cancer population (Davies et al., 2020; Pickard, Wilke, Lin, & Lloyd, 2007).

Patient Health Questionnaire depression module (PHQ-8). The PHQ-8 was used instead of the PHQ-9 to avoid the item on the PHQ-9 asking about thoughts about suicide. As the information was collected using an online survey whereby anonymity is maintained, it would not be possible to address risk related to any disclosure. The PHQ-8 is a self-report questionnaire consisting of eight items which are scored on a numerical rating scale of 0-3 that measures the frequency of depression symptoms (e.g. feeling hopeless, little interest or pleasure in doing things, negative self-evaluation). Overall scores range from 0-24, and are classified as "mild" (5-9), "moderate" (10-14), "moderately severe" (15-19) and "severe" (20-24).

Generalised Anxiety Disorder Scale (GAD-7). A self-report questionnaire consisting of seven items, which are scored on a numerical rating scale of 0-3 that measures the frequency of generalised anxiety symptoms (e.g. feeling nervous, being able to stop or control worrying, becoming easily annoyed or irritable). Overall scores range from 0-21, and are classified as "mild" (5-9), "moderate" (10-14) and "severe" (15-21).

2.5 Adaptation of the IPQ-R for the current study

As stated, the IPQ-R has been widely used alongside different health conditions, including breast cancer. The IPQ-R is often used to assess current perceptions of an illness; however, as participants were survivors of breast cancer, it did not feel appropriate to assess current perceptions of their illness, as they may well no longer consider themselves to be unwell. Therefore, the current study aimed to use the IPQ-R to retrospectively explore participants' illness perceptions about their breast cancer and treatment. To the author's knowledge, no previous research had used the IPQ-R in this

way. Therefore, the author contacted John Weinman, a psychologist who has been prominent in the field of health psychology and who developed the original IPQ (Weinman et al., 1996), to see whether this seemed like an appropriate way of using the questionnaire. Although he had not used the IPQ retrospectively, he suggested that, by re-wording the questions, this seemed appropriate; however, he recommended piloting the version with survivors of breast cancer, using a cognitive interview approach to ensure it made sense. He also recommended contacting Zoe Moon, who had modified the IPQ-R as part of her PhD (Moon et al., 2017) and she also agreed with John Weinman that a cognitive interview would be beneficial to ensure the questionnaire made sense to participants.

2.5.1 Cognitive Interview

After item modification on the IPQ-R (Appendix E), a short cognitive interview approach was used to ensure that items on the modified IPQ-R were being understood and interpreted in the expected way. Cognitive interviews encourage participants to verbalise their thought processes whilst they answer the questionnaire, and similar methods have been used in other studies to examine questionnaires that assess illness perceptions (Moon et al., 2017; Van Oort et al., 2011). The author contacted two breast cancer survivors who were known to him prior to undertaking the study, and both agreed to take part in the cognitive interview. The first was a 48 year old, white British female, who had finished hospital-based treatment 6 years ago. The second was a 66 year old, Eurasian female, who had finished hospital-based treatment 13 years ago. Due to restrictions surrounding COVID-19, the cognitive interview was conducted over the telephone. Both participants were sent the modified version of the IPQ-R and were asked to complete this and verbalise everything that they were thinking as they completed the questionnaire. The cognitive interviews showed that both women could understand the questionnaire and were able to think back to when they had breast cancer. They both felt that it was appropriate and relevant to utilise the questionnaire in this way. The questionnaire was also shared with a Clinical Psychologist (qualified for +1 year) working in oncology services. He also felt that the modified questionnaire seemed applicable and relevant to be used in this way.

2.7 Data available

Once participants completed the survey, their responses were stored securely on 'Online Surveys'. As highlighted above, participants completed a number of questionnaires. Table 2 below summarises the data that were available following completion of all the questionnaires. Pain severity was the primary outcome of interest. Data collected on illness representations and HRQoL were explored as predictors of pain severity. All other available data, such as demographics, illness-related variables and psychological factors (e.g. depression and anxiety), were treated as confounders.

Table 2. *Summary of data available*.

Concept / Domain	Measure	Data Type	Outcome	Predictor	Confounder
Demographic	Age	Continuous/categorical			
	Relationship status	Categorical			
	Ethnicity	Categorical			
	Children	Dichotomous			
	Employment status	Categorical			
	Education status	Categorical			
Illness-related variables	Number of diagnoses	Dichotomous			
	Years since diagnosis	Continuous/categorical			
	Treatment – Radiotherapy	Dichotomous			
	Treatment – Chemotherapy	Dichotomous			
	Treatment – Surgery	Dichotomous			
	Treatment – Hormone Therapy	Dichotomous			
	Total amount of treatment	Categorical			
	Surgery – Lumpectomy	Dichotomous			
	Surgery – Single mastectomy	Dichotomous			
	Surgery – Double mastectomy	Dichotomous			
	Surgery – Breast reconstruction	Dichotomous			
	Surgery – Lymph node dissection	Dichotomous			
	Total amount of surgery	Categorical			
	Time since finished treatment	Categorical			
Brief Pain Inventory	Pain severity	Continuous/categorical			
	Pain interference	Continuous/categorical			
Illness perception	Identity	Count			
	Timeline (acute/chronic)	Continuous			
	Consequences	Continuous			
	Personal Control	Continuous			

Concept / Domain	Measure	Data Type	Outcome	Predictor	Confounder
	Treatment Control	Continuous			
	Illness Coherence	Continuous			
	Timeline (cyclical)	Continuous			
	Emotional representation	Continuous			
	Causes – Stress	Continuous			
	Causes – State of Health	Continuous			
	Causes – Lifestyle	Continuous			
	Causes – Biology	Continuous			
	Causes – Factors out of my control	Continuous			
Quality of Life	EQ-VAS score	Continuous			
Anxiety	Overall score	Continuous/categorical			
Depression	Overall score	Continuous/categorical			

Note: Colours have been used for the purpose of a visual aid.

2.8 Data extraction

Once recruitment was finished, all available data were downloaded from 'Online Surveys' onto an Excel spreadsheet, from which they were imported into SPSS version 26 (SPSS, 2020).

2.9 Data Cleaning

Data cleaning is an important process that involves preparing data for analysis by removing or modifying data that is incorrect, incomplete, duplicated or improperly formatted (Pallant, 2016). A full summary of the data cleaning process is provided in Appendix F. The following data was removed or modified:

Demographics. For the question regarding relationship status, two participants responded with 'other' and using their qualitative responses, they were re-coded into two existing categories and the category 'other' was removed. For the employment status question, nine participants responded with 'other'. Using their qualitative responses, two new employment status categories were created: 'carer' and 'home parent', and all nine were re-coded into one of the new or existing categories, which meant that the category 'other' was removed.

Due to the limited variation in responses to the ethnicity item, this data was summarised descriptively, but was not included in the inferential statistical analysis. Similarly, low variance was observed for responses to the relationship status and employment status items. Therefore, the original response data to these two items are summarised descriptively, however, for the purposes of the infernal analyses, some categories were collapsed to create new, larger categories more suited to inferential analysis. For relationship status, the categories 'married', 'civil partnership' and 'in a relationship' were recoded as 'in a close confiding relationship.' The categories 'single', 'widowed' and 'divorced' were recoded as 'not in a close confiding relationship.' For employment status, the categories 'employed (full-time)', 'employed (part-time)' and 'self-employed' were recoded as 'working'. The categories 'unemployed', 'disabled – not able to work', 'home parent' and 'carer' were recoded as 'not in paid working'. The category 'retired' was not recoded.

Illness-related information. Participants were required to provide the approximate amount of years since they were diagnosed with breast cancer, which was reported in a free-text box. There were inconsistencies in how participants reported this, with some providing the number of years (e.g. 2 years), the year (e.g. 2018), and the number of months (e.g. 9 months ago). Therefore, in order to have a consistent format, it was decided that participants' responses to this item would be rounded down to the nearest year. Some examples include: '6 months ago' became 0 years (i.e. less than a year), '15 months ago' became 1 year, and '5.5 years' became 5 years, etc. Participants were also asked to report the type of treatment that they had received for their breast cancer. Sixteen participants responded with 'other' and for 3 of those participants, using their qualitative responses, their response was able to be re-coded into one of the existing categories. Participants were also required to report the type of surgery that they had received (if applicable). Eighteen participants responded with 'other', of which eleven of those participants were re-coded into one of the existing categories, based on their qualitative responses. Some examples include: 'nipple reconstruction' became 'breast reconstruction' and 'mammoplasty' became 'breast reconstruction'. Finally, participants were asked to report the number of times they had been diagnosed with breast cancer; however, due to low variation in responses, this data was summarised descriptively but not included in the inferential statistical analysis.

Standardised participant reported outcome measures. One of the questions on the BPI-SF required participants to report how much relief they get from medication to manage their pain. This study was focused on perceptions of breast cancer and aimed to identify links between illness representations and chronic pain. As this study was not focused on pain management it was decided that this data point was not directly associated with the research questions or hypotheses; therefore, it was not included in the analysis.

The EQ-5D is used in large population health surveys and provides a health state classification, whereas the EQ-VAS allows participants to provide a self-rating of their perceived health. To ensure construct validity the EQ-5D and EQ-VAS were both administered; however, as shown in previous studies (Feng, Parkin & Devlin, 2014), the data can be analysed and reported using either the EQ-5D single index score or the EQ-VAS. The EQ-5D and EQ-VAS have been shown to both be reliable and valid in

predicting HRQoL (Whynes, 2008). It was therefore decided to only include the EQ-VAS data in the current study. The EQ-VAS is arguably a useful tool that measures overall health, which is close to the patient's perspective (Feng et al., 2014), and in one study was argued to be more responsive than EQ-5D index scores (Stark, Reitmeir, Leidl, & König, 2010). The EQ-VAS has also been shown to be a reliable and valid measure within cancer populations (Davies et al., 2020; Pickard et al., 2007). Therefore, only the EQ-VAS data are reported in the analyses (Chapter 3).

2.9.1 Missing or incomplete data

For the question that required participants to report the approximate number of years since they were diagnosed with breast cancer, two participants had made errors in what they had reported. Both of these were regarded as missing or incomplete data. However, as the rest of the data provided by these participants was complete, their data was included in the study.

2.9.2 Factor analysis

The third section of the IPQ-R addresses participants' perceptions regarding the cause of their illness. Moss-Morris et al. (2002) suggest that when there is a large enough sample size (i.e. $n \geq 85$), factor analysis should be used to group together causal beliefs, which can then be used as sub-scales (Moss-Morris et al., 2002). The term 'factor analysis' encompasses different but related techniques, with one of the main distinctions being between principal component analysis (PCA) and factor analysis (FA). Whilst these techniques are both similar, Stevens (1996) expresses a preference for PCA, as it is psychometrically sound and avoids some of the potential problems with 'factor indeterminacy' associated with FA (Pallant, 2016). PCA is also recommended when an empirical summary of the data set is needed (Tabachnick & Fidell, 2018). Therefore, the 19 items on the causal section of the IPQ-R were subjected to PCA using SPSS version 26.

Prior to performing the PCA, the suitability of the data for PCA was checked (Pallant, 2016). The correlation matrix revealed the presence of many coefficients of .3 and above. The Kaiser-Meyer-Olkin value was 0.84, which exceeds the recommended value of 0.6, and Bartlett's Test of Sphericity reached statistical significant ($p<0.001$), supporting the factorability of the correlation matrix (Pallant, 2016).

PCA revealed the presence of five components with eigenvalues exceeding 1 and an inspection of the screeplot revealed a break after the fifth component (Appendix G). Therefore, it was decided to retain five components for further investigation. The five-component solution explained a total of 61.6% of the variance, with component 1 contributing 30.6%, component 2 contributing 10.4%, component 3 contributing 8.7%, component 4 contributing 6.2%, and component 5 contributing 5.6% of the variance. Looking at the component correlation matrix, there was a weak correlation between each of the components (below .3) (Appendix G). However, the correlation between component 1 and 2 was reported as (r = .36). Therefore, to aid in the interpretation of these five components, oblimin rotation was performed. The rotated solution revealed that all five components had a number of strong loadings with all variables loading substantially on one component (Appendix G).

Based on the results from this analysis, five components were identified and included the following:

1. Stress (included 5 variables) – My emotional state, family problems, stress or worry, my mental attitude and overwork.
2. State of Health (included 5 variables) – Germ or virus, altered immunity, poor medical care, my personality and accident or injury.
3. Lifestyle (included 5 variables) – Alcohol, diet or eating behaviours, smoking, my own behaviour and pollution in the environment.
4. Biology (included 2 variables) – ageing and hormonal influence.
5. Factors out of my control (included 2 variables) – chance or bad luck and hereditary.

These five causal factors were used as sub-scales moving forward with further analysis.

2.10 Data analysis

The data were analysed using SPSS version 26 (SPSS, 2020). The data were explored using descriptive statistics (means, standard deviations, minimum and maximum values, 5% trimmed means), histograms, box plots, normal Q-Q plots, and estimates of skewness and kurtosis (Appendix H). The purpose of this was to examine the distribution of the data. This was undertaken for the following data: age, illness

perceptions, pain, HRQoL and mood. For all variables, the data were observed to be normally distributed. However, for one continuous variable 'approximate number of years since diagnosis', it was found that the data was positively skewed and a number of outliers were identified, which meant that normality could not be assumed. Therefore, a square root (SQRT) transformation was used on the original data. The transformed variable 'approximate number of years since diagnosis SQRT' was found to be sufficiently normally distributed, and was used for the inferential analysis (Appendix H).

Descriptive statistics were calculated for all variables. Means and standard deviations were calculated for continuous variables. Dichotomous and categorical variables were summarised using frequency count and proportion. Descriptive statistics were calculated for the overall sample and stratified by the four pain categories (no pain, mild pain, moderate pain and severe pain). Pearson's Chi^2 tests and one-way between groups analysis of variance (ANOVA) tests were used to explore differences between the pain categories on demographics, illness-related variables, illness representations, pain, HRQoL and psychological factors. Any variables that were found to have a significant relationship were then taken forward into the ordinal regression analyses.

Ordinal logistic regression models were used to quantify the relationship between illness representations and HRQoL (predictor variables) and the four pain categories (outcome variable), adjusted for demographic factors, illness-related factors, and psychological factors (cofounder variables, see Figure 2). As per Kleinbaum and Klein (2010), ordinal logistic regression models were used because of the ordered nature of the primary outcome variable (i.e. no pain, mild, moderate, severe pain). Preliminary checks showed that there was no multicollinearity and there were proportional odds, which meant that the data were suitable for ordinal logistic analysis (Kleinbaum & Klein, 2010). The -2 Log Likelihood statistic (-2LL) assessed model fit, with a statistically significant Chi^2 statistic ($p<0.05$) indicating that the final model gives a significant improvement over the baseline intercept-only model. A Chi^2 goodness-of-fit test was also computed with a non-significant statistic ($p>0.05$) indicating that the data and model predictions are similar, suggesting that the data and model are a good fit.

Six ordinal logistic regression models quantified the relationship between illness representations, HRQoL, demographic factors, illness related factors, and psychological factors as predictors of pain categories. Outputs from each model are presented as odds

ratio (OR) and 95% confidence intervals (CI), p-values of ≤ 0.05 were considered statistically significant. Odds ratios of greater than one represent positive effects and odds ratios between zero and one represent negative effects.

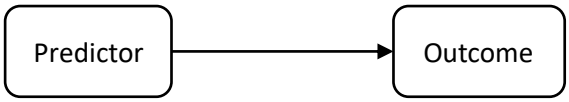
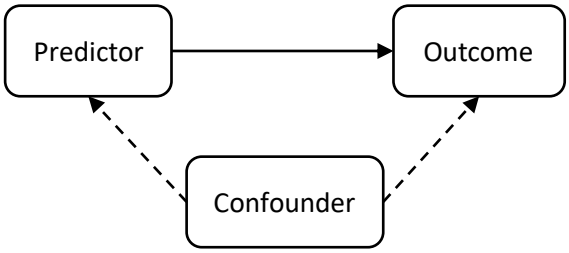
Simple predictor model	
Simple predictor model with cofounders	

Figure 2. Theoretical models of association to be tested using ordinal logistic regression modelling.

Finally, to explore the relationship between illness symptoms and chronic pain in breast cancer survivors, frequency count and proportion were used to describe the prevalence of the 13 symptoms listed on the IPQ-R identity domain for the overall sample and stratified by the four pain categories.

Chapter 3: Results

This chapter presents the study's findings. It starts by presenting descriptive statistics for demographic and illness characteristics of the overall sample. Participants were then grouped into four pain categories (no pain, mild pain, moderate pain, severe pain) and descriptive statistics for demographics, illness-related characteristics, illness representations, pain, HRQoL and psychological factors will be presented. Pearson's Chi-square tests and one-way between groups ANOVA tests were used to explore differences between the four pain categories. Ordinal logistic regression models are then used to assess the impact of illness representations and HRQoL on pain severity. Finally, the chapter concludes by presenting descriptive statistics for the symptoms listed on the identity domain of the IPQ-R.

3.1 Demographic and illness characteristics of overall sample

Between July 2020 and November 2020, a total of 182 women who were survivors of breast cancer completed the online survey. Participants were aged between 33-84 (M= 55.14, SD= 9.93). As shown in Table 3, participants were predominantly white (97.8%). Seventy-three percent were married, 9.3% single, 3.8% widowed, 4.9% divorced, 1.6% in a civil partnership, and 7.1% in a relationship. Thirty-one percent were in full-time employment, 22% in part-time employment, 5.5% unemployed, 8.2% self-employed, 28% retired, 1.1% home parents, 1.6% carers, and 2.6% were disabled or unable to work. Sixty percent had achieved a university degree or higher, 21.4% had GCSEs or equivalent, and 18.1% had A-Levels or equivalent. Seventy percent of participants had no dependent children, in comparison to 30.2% who had dependent children.

All participants identified as being survivors of breast cancer and the years since diagnosis ranged from 0-27 (M=5.44, SD=4.79). The majority of the sample had been diagnosed with breast cancer on one occasion (95.1%); 4.9% had been diagnosed with breast cancer on two occasions. The type of treatment participants had received included the following: radiotherapy (73.1%), chemotherapy (65.4%), surgery (96.2%), and hormone therapy (65.9%). Seven percent of participants selected 'other' treatment, which included bisphosphonate treatment (zometa infusions) and immunotherapy (herceptin). The type of surgery participants underwent included: lumpectomy (54.4%), single mastectomy (44.5%), double mastectomy (14.8%), breast reconstruction (32.4%), and

lymph node dissection (55.5%). Four percent of participants selected 'other' surgery, which included sentinel node biopsy. Twenty-one percent of participants had finished hospital-based treatment less than 1 year ago, 25.8% 1-2 years ago, 15.9% 3-4 years ago, and 37.4% 5+ years ago.

3.1.1 Prevalence of chronic pain

As shown in Table 3, IPQ-R data indicated that 77.5% of participants reported pain at some point following their diagnosis, and 70.9% felt that this pain was associated with their breast cancer or treatment. Data from the BPI-SF indicated that 66% of participants reported experiencing ongoing chronic pain, which they believe to be a consequence of their breast cancer or treatment.

Table 3. *Characteristics of overall sample*.

Sample Characteristics	**All (n=182)**
Age	
Min-Max	33-84
Mean (SD)	55.14 (9.93)
Ethnicity (%)	
White	178 (97.8)
Asian or Asian British	2 (1.1)
Black or Black British	1 (0.5)
Other	1 (0.5)
Relationship status† (%)	
Married	133 (73.1)
Single	17 (9.3)
Widowed	7 (3.8)
Divorced	9 (4.9)
Civil Partnership	3 (1.6)
In a relationship	13 (7.1)
Employment Status† (%)	
Employed (full-time)	56 (30.8)
Employed (part-time)	40 (22)
Unemployed	10 (5.5)
Self-employed	15 (8.2)
Retired	51 (28)
Disabled, not able to work	5 (2.7)
Home parent	2 (1.1)
Carer	3 (1.6)
Education status (%)	
GCSEs or equivalent	39 (21.4)
A-Levels or equivalent	33 (18.1)
University undergraduate degree or higher	110 (60.4)
Dependent Children (%)	
Yes	55 (30.2)
No	127 (69.8)
Number of times diagnosed with breast cancer (%)	
Once	173 (95.1)
Twice	9 (4.9)
Women who experienced pain since their breast cancer* (%)	
Yes	141 (77.5)
No	41 (22.5)
Women who have experienced pain that they think is associated with their breast cancer or treatment* (%)	
Yes	129 (70.9)
No	53 (29.1)
Women who experience ongoing pain in relation to their breast cancer or treatment^ (%)	
Yes	120 (65.9)
No	62 (34.1)

Note: Due to small numbers for ethnicity and number of times diagnosed with breast cancer, this prevented any further statistical analysis.

†These variables were collapsed to create new categories, to allow further statistical analysis.

*These variables were derived from the identity section on the IPQ-R, following participants' response to 'pain' as a symptom.

^This variable was created using participants' response to the screening question on the BPI-SF.

3.2 Characteristics for pain categories

Using the BPI cut-points for categorising pain into different levels, participants were grouped into the following categories: no pain (34.1%), mild pain (35.7%), moderate pain (25.3%) and severe pain (4.9%) (Table 4). Pearson's Chi-square tests and one-way between groups ANOVA tests were used to explore differences between the no pain, mild pain, moderate pain, and severe pain categories on demographics, illness-related characteristics, illness representations, pain, HRQoL and psychological factors.

As shown in Table 4, no significant differences were found between participants across pain categories for the following variables: relationship status, dependent children and education status. There was a significant difference between the mean ages of women $F(3,178) = 3.52$, $p = 0.016$, with the mean age of women being lower in the severe pain category than those in the no pain and mild pain categories. A significant difference was found for employment status, $\chi^2\ (6, N=182) = 45.09$, $p < 0.001$ across the pain categories; the proportion of participants working full- or part-time declined from 64% in the no pain group to 33% in the severe pain group. There was a significant difference between the average number of years since diagnosis, $F(3,176) = 3.75$, $p = 0.005$, with the average being lower in the severe pain category, in comparison to those in the no pain category. A significant difference was found for the amount of time since participants had finished hospital-based treatment, $\chi^2\ (9, N=182) = 23.37$, $p = 0.005$, with 44% of women in the severe pain category having finished hospital-based treatment less than a year ago, compared with 60% of women in the no pain category finishing 5+ years ago.

There were no significant differences found for type or total amount of treatment between participants across pain categories (Table 4). However, there were trends towards a higher proportion of women in the severe pain category who had received chemotherapy or radiotherapy in comparison to those in the no pain category; however, these differences did not reach statistical significance. Similarly, 67% of women in the severe pain category had received 4-5 different anti-cancer treatments, in comparison to 35% in the no pain category; however, this also did not reach statistical significance. There were no significant differences for type or total amount of surgery between participants across pain categories (Table 4). However, there were trends in the data suggesting that a higher proportion of women in the severe pain category underwent a

double mastectomy and lymph node dissection, in comparison to the no pain category, but this did not reach statistical significance.

With regard to illness representations, there were no significant differences found across the four pain categories for the following dimensions: personal control, illness coherence and emotional representations (Table 4). Significant differences were found for the following IPQ factors: identity $F(3, 178) = 15.93$, $p < 0.001$; timeline (acute/chronic) $F(3, 178) = 5.14$, $p = 0.002$; consequences $F(3, 178) = 4.84$, $p = 0.003$; and timeline (cyclical) $F(3, 178) = 4.39$, $p = 0.005$. For each significant IPQ factor, mean scores were higher in the severe pain category, in comparison to the no pain category. Conversely, a significant difference was found for treatment control $F(3, 178) = 5.57$, $p = 0.001$, where the mean score was lower in the severe pain category, in comparison to the no pain category. These findings indicate that as pain severity increases, participants were more likely to have a strong illness identity (attributing more symptoms to be a result of their illness), hold negative perceptions regarding the chronicity and cyclicality of their illness, view their illness as having significant consequences and have negative perceptions of treatment control.

As shown in Table 4, in terms of the 'causes' domain on the IPQ-R, there were no significant differences for 'lifestyle', 'biology' and 'factors out of my control'. Significant differences were found for stress $F(3, 178) = 5.65$, $p < 0.001$ and state of health $F(3, 178) = 12.85$, $p < 0.001$; mean scores were higher in the severe pain category, in comparison to the no pain category. These findings indicate that as pain severity increases, participants were more likely to attribute factors associated with stress and state of health, as the cause of their breast cancer.

There was a significant difference in pain interference across the four pain categories $F(2, 109) = 29.69$, $p < 0.001$. As expected, the mean interference score was significantly higher in the severe pain category, in comparison to the mild pain category (Table 4). A significant difference was also found for HRQoL scores across the four pain categories $F(3, 178) = 19.89$, $p < 0.001$. Mean HRQoL scores were significantly lower in the severe pain category, in comparison to the no pain and mild pain categories. Likewise, significantly higher depression and anxiety scores were found in the severe pain category, in comparison to the no pain and mild pain categories $F(3, 178) = 14.41$, $p < 0.001$; $F(3, 178) = 4.88$, $p = 0.003$, respectively.

Table 4. *Participant characteristics according to BPI-SF cut-points for categorising pain into different levels*.

			Pain Categories				
Variables	**Level**	**All (n=182)**	**No pain N=62 (34.1)**	**Mild Pain N=65 (35.7)**	**Moderate Pain N=46 (25.3)**	**Severe Pain N=9 (4.9)**	**P value**
Demographic variables							
Age	Min-Max	33-84	33-84	34-73	38-82	36-58	0.016[b]
	Mean (SD)	55.14 (9.93)	56.56 (11.02)	52.88 (9.01)	57.52 (9.05)	49.56 (8.48)	
Relationship Status	In a close relationship	149 (81.9)	51 (82.3)	54 (83.1)	37 (80.4)	7 (77.8)	0.972[a]
	Not in a close relationship	33 (18.1)	11 (17.7)	11 (16.9)	9 (19.6)	2 (22.2)	
Dependent Children	Yes	55 (30.2)	17 (27.4)	24 (36.9)	10 (21.7)	4 (44.4)	0.256[a]
	No	127 (69.8)	45 (72.6)	41 (63.1)	36 (78.3)	5 (55.6)	
Employment Status	Working	111 (61)	40 (64.5)	50 (76.9)	18 (39.1)	3 (33.3)	<0.001[a]
	Not in paid work	20 (11)	2 (3.2)	1 (1.5)	12 (26.1)	5 (55.6)	
	Retired	51 (28)	20 (32.3)	14 (21.5)	16 (34.8)	1 (11.1)	
Education status	GCSEs	39 (21.4)	9 (14.5)	13 (20)	14 (30.4)	3 (33.3)	0.211[a]
	A-Levels	33 (18.1)	11 (17.7)	14 (21.5)	5 (10.9)	3 (33.3)	
	University degree	110 (60.4)	42 (67.7)	38 (58.5)	27 (58.7)	3 (33.3)	
Illness related variables							
Years since diagnosis	Min-Max	0-27	0-19	0-18	0-27	1-7	0.005[b]
	Mean (SD)	5.44 (4.79)	6.80 (4.75)	4.40 (4.03)	5.67 (5.69)	2.78 (2.16)	
Radiotherapy	Yes	133 (73.1)	39 (62.9)	48 (73.8)	38 (82.6)	8 (88.9)	0.088[a]
	No	49 (26.9)	23 (37.1)	17 (26.2)	8 (17.4)	1 (11.1)	
Chemotherapy	Yes	119 (65.4)	39 (62.9)	37 (56.9)	35 (76.1)	8 (88.9)	0.080[a]
	No	63 (34.6)	23 (37.1)	28 (43.1)	11 (23.9)	1 (11.1)	
Surgery	Yes	175 (96.2)	62 (100)	61 (93.8)	43 (93.5)	9 (100)	0.150[a]
	No	7 (3.8)	-	4 (6.2)	3 (6.5)	-	
Hormone Therapy	Yes	120 (65.9)	42 (67.7)	40 (61.5)	32 (69.6)	6 (66.7)	0.820[a]
	No	62 (34.1)	20 (32.3)	25 (38.5)	14 (30.4)	3 (33.3)	
Total treatment (count)	1-2	48 (26.4)	19 (30.6)	20 (30.8)	8 (17.4)	1 (11.1)	0.328[a]
	3	64 (35.2)	21 (33.9)	24 (36.9)	17 (37)	2 (22.2)	
	4-5	70 (38.5)	22 (35.5)	21 (32.3)	21 (45.7)	6 (66.7)	
Surgery – Lumpectomy	Yes	99 (54.4)	31 (50)	41 (63.1)	22 (47.8)	5 (55.6)	0.353[a]
	No	83 (45.6)	31 (50)	24 (36.9)	24 (52.2)	4 (44.4)	

Variables	Level	All (n=182)	Pain Categories				P value
			No pain N=62 (34.1)	Mild Pain N=65 (35.7)	Moderate Pain N=46 (25.3)	Severe Pain N=9 (4.9)	
Surgery – Single mastectomy	Yes	81 (44.5)	34 (54.8)	21 (32.3)	22 (47.8)	4 (44.4)	0.079[a]
	No	101 (55.5)	28 (45.2)	44 (67.7)	24 (52.2)	5 (55.6)	
Surgery – Double mastectomy	Yes	27 (14.8)	7 (11.3)	9 (13.8)	8 (17.4)	3 (33.3)	0.342[a]
	No	155 (85.2)	55 (88.7)	56 (86.2)	38 (82.6)	6 (66.7)	
Surgery – Breast reconstruction	Yes	59 (32.4)	23 (37.1)	20 (30.8)	14 (30.4)	2 (22.2)	0.751[a]
	No	123 (67.6)	39 (62.9)	45 (69.2)	32 (69.6)	7 (77.8)	
Surgery – Lymph node dissection	Yes	101 (55.5)	31 (50)	35 (53.8)	28 (60.9)	7 (77.8)	0.365[a]
	No	81 (44.5)	31 (50)	30 (46.2)	18 (39.1)	2 (22.2)	
Total surgery (count)	1-2	132 (72.5)	42 (67.7)	51 (78.5)	34 (73.9)	5 (55.6)	0.361[a]
	3-4	50 (27.5)	20 (32.3)	14 (21.5)	12 (26.1)	4 (44.4)	
Finished hospital-based treatment	Less than 1 year ago	38 (20.9)	6 (9.7)	16 (24.6)	12 (26.1)	4 (44.4)	0.005[a]
	1-2 years ago	47 (25.8)	12 (19.4)	19 (29.2)	14 (30.4)	2 (22.2)	
	3-4 years ago	29 (15.9)	7 (11.3)	12 (18.5)	8 (17.4)	2 (22.2)	
	5+ years ago	68 (37.4)	37 (59.7)	18 (27.7)	12 (26.1)	1 (11.1)	
IPQ-R variables							
Identity	Min-Max	0-13	0-10	0-13	0-13	6-12	<0.001[b]
	Mean (SD)	5.84 (3.22)	4.03 (2.74)	6.03 (2.93)	7.39 (3.14)	8.89 (2.02)	
Timeline (acute/chronic)	Min-Max	6-28	6-28	8-25	10-28	17-26	0.002[b]
	Mean (SD)	17.47 (4.19)	16.16 (3.93)	17.48 (4.23)	18.63 (4.06)	20.56 (3.39)	
Consequences	Min-Max	10-30	10-30	13-29	13-29	20-30	0.003[b]
	Mean (SD)	22.42 (3.96)	21.05 (4.16)	22.69 (3.64)	23.43 (3.64)	24.67 (3.90)	
Personal Control	Min-Max	6-29	6-27	6-27	7-29	9-20	0.302[b]
	Mean (SD)	16.57 (4.76)	16.32 (4.96)	16.18 (4.87)	17.67 (4.53)	15.33 (3.20)	
Treatment Control	Min-Max	9-25	9-25	9-25	13-24	12-20	<0.001[b]
	Mean (SD)	19.16 (3.15)	20.16 (3.18)	18.69 (3.25)	19.07 (2.48)	16.22 (3.03)	
Illness Coherence	Min-Max	5-25	5-25	8-25	9-25	10-25	0.728[b]
	Mean (SD)	18.40 (4.11)	18.69 (4.49)	18.55 (3.67)	17.96 (4.03)	17.56 (5.24)	
Timeline (cyclical)	Min-Max	4-19	4-19	4-16	4-16	8-15	0.005[b]
	Mean (SD)	9.61 (3.15)	8.63 (3.39)	9.63 (2.75)	10.70 (3.08)	10.67 (2.69)	
Emotional Representations	Min-Max	7-30	9 -30	12-30	7-30	12-30	0.677[b]
	Mean (SD)	23.85 (5.01)	23.32 (4.61)	24.22 (5.01)	24.22 (5.25)	23 (6.72)	
Causes – Stress	Min-Max	5-25	5-20	5-22	5-25	5-20	<0.001[b]
	Mean (SD)	12.27 (4.49)	10.94 (3.84)	11.95 (4.36)	14.28 (4.85)	13.56 (4.53)	

Variables	Level	All (n=182)	Pain Categories				P value
			No pain N=62 (34.1)	Mild Pain N=65 (35.7)	Moderate Pain N=46 (25.3)	Severe Pain N=9 (4.9)	
Causes – State of Health	Min-Max	5-21	5-15	5-15	5-21	8-17	<0.001[b]
	Mean (SD)	9.10 (3.47)	7.90 (2.75)	8.46 (3.02)	10.87 (3.75)	12.89 (3.75)	
Causes – Lifestyle	Min-Max	5-24	5-18	5-23	5-24	5-18	0.369[b]
	Mean (SD)	11.28 (3.79)	10.76 (3.26)	11.20 (3.77)	11.87 (4.39)	12.44 (3.94)	
Causes – Biology	Min-Max	2-10	2-10	2-10	2-10	3-9	0.211[b]
	Mean (SD)	6.31 (1.96)	5.95 (1.85)	6.34 (1.46)	6.76 (2.13)	6.22 (1.85)	
Causes – Factors out of my control	Min-Max	2-10	4-9	3-10	2-10	3-8	0.880[b]
	Mean (SD)	6.37 (1.48)	6.37 (1.28)	6.46 (1.46)	6.28 (1.72)	6.11 (1.76)	
Pain, QoL and mood variables							
Pain Severity	Min-Max	0.5-9	-	0.5-3.75	4-6.75	7-9	<0.001[b]
	Mean (SD)	3.70 (2.03)	-	2.13 (0.89)	5.08 (0.73)	8 (0.78)	
Pain Interference	Min-Max	0.14-10	-	0.14-7.71	0.86-10	4.86-9.57	<0.001[b]
	Mean (SD)	4.11 (2.70)	-	2.63 (2.16)	5.33 (2.32)	7.31 (1.55)	
EQ-5D VAS score	Min-Max	2-100	33-100	4-100	2-95	20-50	<0.001[b]
	Mean (SD	70.09 (19.09)	78.10 (15.57)	73.23 (17.32)	60.65 (17.74)	40.56 (12.36)	
Depression (PHQ-8)	Min-Max	0-24	0-20	0-23	1-24	8-24	<0.001[b]
	Mean (SD)	7.42 (5.80)	4.68 (4.59)	7.31 (5.30)	9.89 (5.79)	14.44 (6.24)	
Anxiety (GAD-7)	Min-Max	0-21	0-21	0-21	0-21	3-18	0.003[b]
	Mean (SD)	6.45 (5.62)	4.68 (5.10)	6.58 (5.49)	7.83 (5.65)	10.56 (6.34)	

[a] *p* values were derived from Pearson's Chi-Square tests.

[b] *p* values were derived from one-way between-groups ANOVA tests.

3.3 Illness representations and quality of life as predictors of pain severity

Ordinal logistic regression models were used to quantify the association between illness representations and HRQoL across the four pain categories. Based on the descriptive statistics (Table 4), predictor and cofounder variables (Table 2) that were significantly associated with the outcome variable (i.e. $p<0.05$ on Chi-squared or ANOVA tests) were taken forward into the regression models.

One of the assumptions of ordinal logistic regression models is that there is no multicollinearity between independent variables. The variables 'years since diagnosis' and 'time since finished hospital-based treatment' were hypothesised to potentially have multicollinearity, as they are in essence measuring a similar duration. A one-way between-groups ANOVA was used to explore the relationship between the two variables. Participants were divided into four groups according to the time since they finished hospital based treatment (less than one year ago, 1-2 years ago, 3-4 years ago and 5+ years ago). The ANOVA revealed a significant, positive relationship between time since diagnosis and time since completed treatment ($F(3,176) = 103.7$, $p = <0.001$). This suggested that there was multicollinearity between these variables. Therefore, 'time since completing treatment' was taken forward in the regression models, as it was the more closely associated (temporally) with the primary outcome variable (pain severity).

Six ordinal logistic regression models compared illness representations and HRQoL as predictors of pain category:

1. Model 1 – univariate (unadjusted) main effects model
2. Model 2 – multivariate model, adjusted for illness representations and HRQoL
3. Model 3 – multivariate model, adjusted for demographic factors: age and employment status
4. Model 4 – multivariate model, adjusted for illness related factors: time since finished hospital-based treatment
5. Model 5 – multivariate model, adjusted for psychological factors: depression and anxiety
6. Model 6 – multivariate model, all factors included, a fully adjusted model

These models are referred to as model 1, 2, 3, 4, 5 and 6, respectively, in the text and reported in Table 5.

Model 1 (Table 5) indicates that for each additional symptom participants identified with their breast cancer (IPQ-R identity domain), the odds of being in a higher pain category increased by 34% (OR 1.34, CI 1.22-1.47, p<0.001). Table 4 shows that mean identity score in the 'no pain' group was 4.03 (SD 2.74) compared with 8.89 (2.02) in the severe pain group. This relationship became slightly attenuated but persisted when adjusted for other illness representation dimensions and HRQoL in Model 2 (OR 1.26, CI 1.12-1.41, p<0.001), demographics in Model 3 (OR 1.25, CI 1.11-1.41, p<0.001), illness-related factors in Model 4 (OR 1.21, CI 1.07-1.36, p=0.002), depression and anxiety symptoms in Model 5 (OR 1.27, CI 1.12-1.43, p<0.001). In the final fully adjusted model (Model 6) IPQ-R identity remained a significant independent predictor of being in a higher pain category compared to the no pain group (OR 1.21, CI 1.07-1.37, p=0.003). Overall, these data suggest that the IPQ-R identity domain was an independent and significant predictor of pain severity.

Model 1 also showed that for a unit increase in scores on the timeline (acute/chronic) domain, the odds of being in a higher pain category increased by 13% (OR 1.13, CI 1.06-1.21, p<0.001). Model 1 also showed that a unit increase in score on the consequences domain, the odds of being in a higher pain category increased by 14% (OR 1.14, CI 1.06-1.23, p<0.001). Finally, Model 1 showed that a unit increase in score on the timeline (cyclical) domain increased the odds of being in a higher pain category by 18% (OR 1.18, CI 1.08-1.29, p<0.001). In contrast to the previous findings, Model 1 showed that a lower score on the treatment control domain increased the odds of being in a higher pain category by 13% (OR 0.87, CI 0.80-0.95, p=0.003). The relationships between these four domains and the pain categories became attenuated and non-significant when adjusted for other illness representation dimensions and HRQoL (Model 2), demographics (Model 3), illness-related factors (Model 4), psychological factors (Model 5) and in a fully-adjusted model (Model 6) (Table 5).

Model 1 showed that a higher score on the IPQ-R cause sub-category 'stress', increased the odds of being in the higher pain category by 12% (OR 1.12, CI 1.06-1.93, p<0.001). This relationship attenuated and became non-significant when adjusted for other factors in all other models (Models 2-6, Table 5). A higher score on the IPQ-R cause

sub-category 'state of health', was associated with a 25% increase in the odds of being in a higher pain category (OR 1.25, CI 1.15-1.36, p<0.001). Model 2 shows that the relationship persisted and remained significant when adjusted for other illness representation dimensions and HRQoL, with little change to the estimate (OR 1.15, CI 1.04-1.27, p=0.006). However, this relationship attenuated and became non-significant when adjusted for demographics in Model 3, illness-related factors in Model 4, depression and anxiety symptoms in Model 5 and in the fully adjusted model, Model 6 (Table 5).

The regression modelling also demonstrated a significant negative association between HRQoL and the pain categories (Table 5). Model 1 indicated that a unit reduction in HRQoL score was associated with a 5% increase in the odds of being in a higher pain category (OR 0.95, CI 0.93-0.96, p<0.001). This relationship slightly attenuated but persisted and remained significant after adjusting for illness representations (Model 2), demographics (Model 3), illness-related factors (Model 4), psychological factors (Model 5), and in a fully adjusted model (Model 6) (Table 5). This indicates that HRQoL remains an independent and significant predictor of pain severity.

The main effect models in Table 5 (Model 1) show variation in the relationships between demographic factors and pain severity categories. There was no significant relationship between age and pain categories (OR 0.99, CI 0.96-1.02, p=0.571); however, not being in paid work was associated with a 14-fold increase in the odds of being in a higher pain category (OR 15.77, CI 5.48-45.34, p<0.001), compared to participants who were working. However, the wide CI indicates that the effect is not estimated precisely; likely due to the small number of participants in the severe pain category (Table 4). Nevertheless, this relationship remained significant when entered simultaneously with illness representations, HRQoL and other demographics (Model 3) (OR 7.28, CI 2.33-22.77, p=0.001) and in a fully adjusted model (Model 6) (OR 5.92, CI 1.84-19.05, p=0.003); this suggests that not being in paid work is strongly associated with being in a higher pain category.

Compared to respondents who completed treatment five or more years ago, those that completed 3-4 years ago or 1-2 years ago had a 2-fold increase likelihood of being in a higher pain category (OR 3.19, CI 1.41-7.24, p=0.005; OR 2.98, CI 1.47-6.03, p=0.002 respectively). Respondents who completed treatment less than 1 year ago had an almost 4-fold increase in the odds of being in a higher pain category (OR 4.71, CI 2.20-10.07,

p<0.001). The relationship for 3-4 years and 1-2 years attenuated and became non-significant when entered simultaneously with illness representations and HRQoL (Model 4, Table 5) and in a fully adjusted model (Model 6, Table 5). The relationship for less than 1 year ago became slightly attenuated but persisted in Model 4 (OR 3.63, CI 1.44-9.16, p=0.006); however, this became non-significant in Model 6 (OR 2.79, CI 1.00-7.81, p=0.050).

The main effects model in Table 5 (Model 1) shows that higher scores on measures of depression and anxiety increased the odds of being in a higher pain category by 17% (OR 1.17, CI 1.11-1.23, p<0.001) and 10% (OR 1.10, CI 1.04-1.15, p<0.001) respectively. However, this relationship attenuated and become non-significant when entered simultaneously with illness representations and HRQoL (Model 5, Table 5) and in a fully adjusted model (Model 6, Table 5).

Table 5. *Ordinal logistic regression models to predict pain severity (no pain; n=62; mild pain; n=65; moderate pain; n=46; severe pain; n=9).*

	Model 1 OR (95%CI)	**Model 2** OR (95%CI)	**Model 3** OR (95%CI)	**Model 4** OR (95%CI)	**Model 5** OR (95%CI)	**Model 6** OR (95%CI)
IPQ-R Dimensions						
Identity	1.34 (1.22-1.47)*	1.26 (1.12-1.41)*	1.25 (1.11-1.41)*	1.21 (1.07-1.36)†	1.27 (1.12-1.43)*	1.21 (1.07-1.37)†
Timeline (acute/chronic)	1.13 (1.06-1.21)*	0.99 (0.92-1.09)	0.99 (0.90-1.08)	1.06 (0.96-1.17)	1.00 (0.92-1.09)	1.04 (0.94-1.14)
Consequences	1.14 (1.06-1.23)*	1.03 (0.94-1.13)	1.01 (0.92-1.12)	1.01 (0.91-1.11)	1.03 (0.93-1.14)	1.00 (0.90-1.11)
Treatment control	0.87 (0.80-0.95)†	0.94 (0.85-1.04)	0.93 (0.84-1.02)	0.94 (0.85-1.04)	0.93 (0.84-1.03)	0.93 (0.84-1.03)
Timeline (cyclical)	1.18 (1.08-1.29)*	1.03 (0.93-1.14)	1.05 (0.95-1.17)	1.02 (0.92-1.14)	1.03 (0.93-1.13)	1.05 (0.94-1.17)
Causes - Stress	1.12 (1.06-1.93)*	0.99 (0.92-1.07)	0.99 (0.91-1.07)	0.99 (0.92-1.08)	0.99 (0.92-1.08)	0.99 (0.91-1.08)
Causes – State of Health	1.25 (1.15-1.36)*	1.15 (1.04-1.27)†	1.13 (1.02-1.25)	1.14 (1.03-1.27)	1.14 (1.03-1.27)	1.12 (1.00-1.24)
Quality of Life						
EQ-5D VAS	0.95 (0.93-0.96)*	0.96 (0.94-0.98)*	0.96 (0.94-0.98)*	0.96 (0.94-0.98)*	0.96 (0.94-0.98)*	0.97 (0.95-0.99)*
Demographics						
Age	0.99 (0.96-1.02)		1.00 (0.96-1.04)			1.00 (0.96-1.05)
Employment status						
Working	1		1			1
Not in paid work	15.77 (5.48-45.34)*		7.28 (2.33-22.77)†			5.92 (1.84-19.05)†
Retired	1.24 (0.67-2.32)		1.02 (0.42-2.49)			1.08 (0.42-2.75)
Illness-related						
Finished hospital based treatment						
Less than 1 year ago	4.71 (2.20-10.07)*			3.63 (1.44-9.16)†		2.79 (1.00-7.81)
1-2 years ago	2.98 (1.47-6.03)†			1.98 (0.88-4.48)		1.60 (0.65-3.92)
3-4 years ago	3.19 (1.41-7.24)†			2.84 (1.14-7.05)		2.32 (0.89-6.03)
5+ years ago	1			1		1
Psychological factors						
Depression (PHQ-8)	1.17 (1.11-1.23)*				1.10 (1.00-1.20)	1.11 (1.00-1.22)
Anxiety (GAD-7)	1.10 (1.04-1.15)*				0.91 (0.84-0.99)	0.91 (0.83-1.00)

*p<0.001, †p<0.05

3.4 Further analysis of IPQ-R identity domain

The data presented in Table 5 show that the IPQ-R identity dimension remained an independent and significant predictor of pain severity when adjusted for all other variables (Model 6). The IPQ-R identity dimension is a count variable consisting of 13 symptoms related to participants' breast cancer or cancer treatment. To further understand the relationship between pain and the IPQ-R identity, descriptive statistics were produced to describe the prevalence of each of the IPQ-R identity symptoms across the four pain categories (Table 6).

On the IPQ-R identity dimension, participants were required to indicate whether or not they had experienced each symptom since completing their breast cancer treatment (yes/no). They were then asked to indicate whether or not they felt that symptom was related to their breast cancer and/or its treatment (yes/no); the latter information is presented in Table 6. The data in Table 6 are summarised as frequency count and proportion and describe the prevalence of the 13 symptoms across the four pain categories. These data capture participants' views on symptoms associated with their breast cancer and/or treatment since their diagnosis rather than current symptoms.

As shown in Table 6, there were common trends in the data suggesting that a higher proportion of women in the moderate and severe pain category experienced multiple symptoms that they related to their breast cancer and/or treatment, which was found for the following symptoms: pain, breathlessness, fatigue, stiff joints, headaches, sleep difficulties, dizziness, loss of strength, feeling down and anxiety. In contrast, proportions of these symptoms for women in the no pain and mild pain categories were lower and similar to the overall group means. This was not true of all symptoms – weight loss and nausea, for example, showed little difference between the pain categories.

Table 6. *Symptoms on the IPQ-R that participants had experienced and related to their breast cancer and/or treatment*.

Symptoms on IPQ-R identity domain	All (n=182)	Pain Categories			
		No pain 62 (34.1%)	Mild Pain 65 (35.7%)	Moderate Pain 46 (25.3%)	Severe Pain 9 (4.9%)
Pain					
Yes	129 (70.9%)	27 (43.5%)	52 (80%)	41 (89.1%)	9 (100%)
No	53 (29.1%)	35 (56.5%)	13 (20%)	5 (10.9%)	-
Nausea					
Yes	41 (22.5%)	9 (14.5%)	18 (27.7%)	13 (28.3%)	1 (11.1%)
No	141 (77.5%)	53 (85.5%)	47 (72.3%)	33 (71.7%)	8 (88.9%)
Breathlessness					
Yes	48 (26.4%)	6 (9.7%)	14 (21.5%)	21 (45.7%)	7 (77.8%)
No	134 (73.6%)	56 (90.3%)	51 (78.5%)	25 (54.3%)	2 (22.2%)
Weight Loss					
Yes	22 (12.1%)	2 (3.2%)	6 (9.2%)	13 (28.3%)	1 (11.1%)
No	160 (87.9%)	60 (96.8%)	59 (90.8%)	33 (71.7%)	8 (88.9%)
Fatigue					
Yes	141 (77.5%)	38 (61.3%)	55 (84.6%)	39 (84.8%)	9 (100%)
No	41 (22.5%)	24 (38.7%)	10 (15.4%)	7 (15.2%)	-
Stiff Joints					
Yes	118 (64.8%)	32 (51.6%)	41 (63.1%)	36 (78.3%)	9 (100%)
No	64 (35.2%)	30 (48.4%)	24 (36.9%)	10 (21.7%)	-
Headaches					
Yes	41 (22.5%)	5 (8.1%)	18 (27.7%)	13 (28.3%)	5 (55.6%)
No	141 (77.5%)	57 (91.9%)	47 (72.3%)	33 (71.7%)	4 (44.4%)
Upset Stomach					
Yes	30 (16.5%)	5 (8.1%)	10 (15.4%)	11 (23.9%)	4 (44.4%)
No	152 (83.5%)	57 (91.9%)	55 (84.6%)	35 (76.1%)	5 (55.6%)
Sleep Difficulties					
Yes	113 (62.1%)	26 (41.9%)	44 (67.7%)	35 (76.1%)	8 (88.9%)
No	69 (37.9%)	36 (58.1%)	21 (32.3%)	11 (23.9%)	1 (11.1%)

Symptoms on IPQ-R identity domain	All (n=182)	Pain Categories			
		No pain 62 (34.1%)	**Mild Pain 65 (35.7%)**	**Moderate Pain 46 (25.3%)**	**Severe Pain 9 (4.9%)**
Dizziness					
Yes	39 (21.4%)	6 (9.7%)	16 (24.6%)	14 (30.4%)	3 (33.3%)
No	143 (78.6%)	56 (90.3%)	49 (75.4%)	32 (69.6%)	6 (66.7%)
Loss of Strength					
Yes	104 (57.1%)	25 (40.3%)	36 (55.4%)	34 (73.9%)	9 (100%)
No	78 (42.9%)	37 (59.7%)	29 (44.6%)	12 (26.1%)	-
Feeling down					
Yes	118 (64.8%)	31 (50%)	43 (66.2%)	37 (80.4%)	7 (77.8%)
No	64 (35.2%)	31 (50%)	2 (33.8%)	9 (19.6%)	2 (22.2%)
Anxiety					
Yes	118 (64.8%)	38 (61.3%)	39 (60%)	33 (71.7%)	8 (88.9%)
No	64 (35.2%)	24 (38.7%)	26 (40%)	13 (28.3%)	1 (11.1%)

Chapter 4: Discussion

This final chapter will first provide a summary of the main findings presented in Chapter 3. These findings will be discussed in relation to the study aims and existing literature. Strengths and limitations of the current study will then be discussed. Finally, implications for clinical practice will be considered, before highlighting possible avenues for future research, followed by overall conclusions.

4.1 Summary of main findings

The aim of this thesis was to explore the association between illness representations, HRQoL and pain in women who have survived breast cancer. To the author's knowledge, this study is the first to examine the relationship between illness representations and chronic pain experienced by women who have survived breast cancer. The findings of this study suggest that components of illness representations are associated with, and predictive of, pain severity. These findings are in accordance with the assumptions of the CSM, whereby perceptions of a condition can be associated with physical and psychological outcomes (Leventhal & Brissette, 2012; Leventhal et al., 1980; Leventhal et al., 1984). The present study also demonstrated that reduced HRQoL is associated with, and predictive of, increased pain severity. An additional finding was that employment status was also found to have a significant, direct relationship with pain severity. These findings will now be discussed in the context of the existing literature, highlighted in chapter one.

4.1.1 The prevalence of chronic pain

This study found that 71% of participants had experienced pain at some point following their diagnosis, which they felt was related to their breast cancer and/or treatment. The BIP-SF data highlighted that 66% of participants were experiencing ongoing persistent pain that they perceived as being a consequence of their breast cancer and/or treatment. This is slightly higher than the reported prevalence of chronic pain in this population from previous studies, which ranges from 25-60% (Andersen & Kehlet, 2011; Bredal et al., 2014; Caffo et al., 2003; Gärtner et al., 2009; Jensen et al., 2010; Katz et al., 2005; K. Wang et al., 2018). This could be due to factors such as sample size and inconsistent use of pain measurement tools across studies. Nevertheless, the current study

supports previous findings highlighting that chronic pain is a major clinical problem experienced by breast cancer survivors. It is also important to note that only a small proportion of women (5%) who had experienced pain following their breast cancer and/or treatment (71%), did not progress to experience persisting, chronic pain (66%). This highlights a significant issue whereby a large proportion of women experienced an unmet clinical need.

With regard to the severity of pain experienced, the present study classified participants into four categories: no pain (34%), mild pain (36%), moderate pain (25%), and severe pain (5%). These prevalence rates are similar to those reported in previous studies (Bredal et al., 2014; Forsythe et al., 2013; Jensen et al., 2010), and suggest that the prevalence of severe pain is less common in breast cancer survivors, compared to rates of mild-moderate pain.

4.1.2 Demographic and illness-related factors associated with pain severity

Demographic factors such as relationship status, having dependent children and education status were not found to be associated with pain severity. There was a significant difference in the average age of women across the pain categories, suggesting that younger age was associated with being in a higher pain category (Table 4). These data appear to support previous findings (e.g. Poleshuck et al., 2006; L. Wang et al., 2016), suggesting that younger age is associated with an increased risk of developing chronic pain. However, results from the main-effect model (Table 5) found that the relationship between age and pain severity was non-significant. Therefore, whilst some previously published data suggest there may be an association with younger age and higher pain severity in breast cancer survivors, this study supports previous findings (Bredal et al., 2014; Gärtner et al., 2009), which have found that age is not associated with any variation in pain severity experienced by this population.

The findings presented in this thesis suggest that employment status is associated with pain severity. In an unadjusted model it was found that not being in paid work was associated with a 14-fold increase in the odds of being in a higher pain category (Table 5), compared to women who were working. When entered simultaneously with illness representations, HRQoL and other demographics, and in a fully adjusted model, the relationship between not being in paid work and experiencing more severe pain remained

significant (Table 5). It is important to note that the confidence intervals for these odds ratios were large, indicating that the effect was imprecisely estimated. Nevertheless, these findings suggest that not being in paid work has a significant, direct relationship with pain severity. However, this study is cross-sectional and therefore it is not possible to establish a temporal relationship between pain and employment status. It is logical to assume that breast cancer survivors are less likely to be in employment because of high levels of chronic pain associated with having had breast cancer. However, because of the cross-sectional nature of this data it cannot be ruled out that not being in paid work is a risk factor for the onset of chronic pain in breast cancer survivorship. The former argument would support the current literature, as chronic pain has been found to disrupt many aspects of an individual's life, including employment status (Davison & Jhangri, 2005; de Sola, Salazar, Dueñas, Ojeda, & Failde, 2016; Grant, Rees, Underwood, & Froud, 2019); however, being unemployed has also been considered a risk factor for developing chronic pain (Mills et al., 2019). Similarly, Smith et al. (2001) found that employment status was independently associated with severe chronic pain in the more general population. It could be concluded that the relationship between chronic pain and employment status is bidirectional. Nevertheless, the results from this study and previous findings suggest that employment status is an important factor to consider when planning the management of chronic pain in breast cancer survivors.

Contrary to previous research, (e.g. Divella et al., 2020; Ferreira et al., 2014; Gärtner et al., 2009; Peuckmann et al., 2009), in the present study, illness-related factors such as type of treatment and surgery were not found to be significantly associated with chronic pain experienced in this population. There were some trends in the data suggesting that those in a higher pain category were more likely to have had chemotherapy, radiotherapy, double mastectomy and lymph node dissection; however, these did not reach statistical significance. These findings suggest that the type of treatment and/or surgery a woman receives is not a risk factor that can be used to understand chronic pain experienced in this population. It may be that other variables such as psychological factors (e.g. stress, anxiety, depression), having a pre-morbid condition (e.g. arthritis, fibromyalgia), post-surgical complications, or the severity of acute post-operative pain (e.g. Bao et al., 2018; Divella et al., 2020; Dominick et al., 2012; L. Wang et al., 2016) need to be considered when interpreting findings from previous studies.

The current study did show that compared to women who completed treatment five or more years ago, those that completed treatment between 1 and 4 years ago had a 2-fold increased likelihood of being in a higher pain category (Table 5). Women who completed treatment less than 1 year ago had a 4-fold increase in the odds of being in a higher pain category (Table 5). The relationship between pain and treatment completion 1-4 years ago became attenuated and non-significant when entered simultaneously with other factors. However, the relationship with treatment less than 1 year ago remained significant when entered with illness representations and HRQoL, but became non-significant in a fully-adjusted model. Similar to previous findings, these results do suggest that chronic pain can persist years after treatment has finished (Gärtner et al., 2009; Mols et al., 2005); however, they suggest that the severity of pain may be better understood based on the length of time that has passed since hospital-based treatment has finished. For instance, pain severity improves as more time passes after treatment has ended, which may be explained by pain fading over time or women habituating to their pain. However, as this relationship became non-significant in a fully adjusted model, it may be that other factors (e.g. employment status) are ultimately a better predictor of pain severity reported among this population.

4.1.3 Physical and psychological factors associated with pain severity

The current findings showed a significant relationship between pain interference and pain severity, as women in a higher pain category were more likely to score higher on pain interference. This finding was expected and is similar to those reported in previous studies, highlighting that more severe pain is associated with higher levels of pain interference (Galli et al., 2010; Guo 2014; Norton et al., 2014). This present study used pain severity rather than pain interference to stratify participants into different categories. Previous studies have frequently used pain severity as a measure to quantify pain experienced by breast cancer survivors (Bredal et al., 2014; Gärtner et al., 2009; Jensen et al., 2010). Therefore, it felt appropriate to use pain severity as a way of quantifying the pain experienced by participants, because it was important that the current results were comparable to previous studies, as the purpose of the study was to try to understand and explain factors that may be associated with high chronic pain prevalence in breast cancer survivors.

Psychological factors such as depression and anxiety have been found to correlate with chronic pain in people with a variety of health conditions (e.g. de Heer et al., 2018; Mills et al., 2019), including breast cancer survivors (e.g. Bredal et al., 2014; L. Wang et al., 2016). However, it has often been argued that this association is weak and the casual relationship is difficult to establish. The findings from the present study show that higher scores on measures of depression and anxiety are associated with a 1.2 and 1.1 times greater odds of being in a higher pain category, respectively (Table 5). However, when entered simultaneously with other factors, this relationship became attenuated and non-significant, suggesting that there is no significant direct relationship between anxiety and depression and pain severity in this population. This is similar to findings reported in previous studies which have demonstrated that whilst there is an association, psychological factors may not in themselves predict chronic pain (e.g. Bredal et al., 2014; L. Wang et al., 2016). Therefore, other risk factors need to be considered.

4.1.3 Illness representations and pain severity

One of the aims of this study was to explore the relationship between illness representations and pain severity among breast cancer survivors, whilst controlling for demographics, illness-related factors and psychological factors. Analysis in Table 4 and 5 showed that there was a significant association between illness representations and pain severity for the following domains: identity, timeline (acute/chronic), consequences, timeline (cyclical), and treatment control. These findings suggest that women in a higher pain category were more likely to have a strong illness identity (attributing more symptoms to be a result of their illness), hold negative perceptions regarding the chronicity and cyclicality of their illness, view their illness as having significant consequences, and have negative perceptions surrounding treatment control. These results support previous research reporting that dimensions of consequence, control, identity and timeline can be used to understand illness outcomes and coping behaviours (Hagger & Orbell, 2003). Within the breast cancer population, these domains have been found to be associated with numerous illness outcomes, including fear of recurrence (e.g. Corter et al., 2013; Freeman-Gibb et al., 2017), mental health (e.g. anxiety and depression) (e.g. Rabin et al., 2004), higher levels of distress (e.g. Fischer et al., 2012; Silva et al., 2012), HRQoL (e.g. Ashley et al., 2015) and physical status (e.g. Rozema et

al., 2009). However, this is the first study to demonstrate an association between these domains and pain severity among breast cancer survivors.

The current study also found a significant association between pain severity and two causal beliefs: 'stress' and 'state of health'. Women who were in a higher pain category were more likely to attribute the cause of their breast cancer to these two factors. This finding has not been demonstrated in previous studies; however, factors such as stress and lifestyle have been noted as common causal beliefs that breast cancer survivors feel were the cause of their breast cancer (Thomson et al., 2014). Causal beliefs have not previously been linked to pain outcomes in this population, but have been linked to factors such as decision making around treatment (Petrie et al., 2015). Likewise, in another study it was found that women who believed that cancer recurrence could be caused by health or stress reported improvement in behaviours such as diet and physical exercise (Constanza et al., 2011). It could be that causal factors provide insight into different ways that breast cancer survivors cope with or manage their chronic pain; however, this finding has not been demonstrated in previous research and would need to be explored in future studies.

Results from the logistic regression analysis showed that after adjusting for other factors, the relationship between pain severity and timeline (acute/chronic), consequences, timeline (cyclical), treatment control, and causal beliefs 'stress' and 'state of health' became non-significant. Therefore, whilst the results demonstrated that these domains were associated with pain severity, none of them were found to be independent predictors. Similar results were found in a study with adults who experience general chronic pain (Gillanders et al., 2013). They found that though negative beliefs surrounding the chronicity and consequences of their illness correlated with pain severity, these domains did not predict pain severity; however, they did find that beliefs around consequences mediated the relationship between pain severity and physical disability (Gillanders et al., 2013).

The results from the current study contradict some previous research which found that these domains do predict pain outcomes. For example, in a study with orofacial pain patients, it was found that the IPQ-R consequences domain was a predictor of pain-related disability, explaining 35% of its variance (Galli et al., 2010). In another study with patients with a diagnosis of rheumatoid arthritis, it was found that patients who had more

negative beliefs surrounding the consequences, chronicity and cyclicality of their condition reported higher levels of pain and functional disability (Norton et al., 2014). However, it is important to acknowledge differences between these studies and the current study. Firstly, Galli et al. (2010) used pain-related disability as the primary outcome, whereas the current study used pain severity. Secondly, Norton et al. (2014) reported that IPQ-R domains could predict higher levels of pain; however, they used the EQ-5D singular pain item to measure pain, whereas the current study used the BPI-SF. Finally, both of these studies were conducted with non-cancer populations. These differences could account for the contradiction in findings.

In a main-effect model, higher scores on the IPQ-R identity domain were found to be associated with 1.3 times greater odds of being in a higher pain category (Table 5). This relationship remained significant even after adjusting for other factors, and in a fully-adjusted model was found to be almost as high (1.2 times greater odds; Table 5). These findings suggest a predictive relationship between illness identity and pain severity, demonstrating that a strong illness identity is an important predictor which is directly associated with pain severity among breast cancer survivors. A similar relationship between a strong illness identity and higher levels of pain and functional disability has been found in other studies in different populations including rheumatoid arthritis (Norton et al., 2014), adults experiencing chronic widespread pain (Järemo, Arman, Gerdle, Larsson, & Gottberg, 2017) and orofacial pain patients (Galli et al., 2010). However, as previously highlighted, there were differences in the primary outcomes used in previous studies and the assessment tools utilised to assess chronic pain. The majority of other studies have also been with participants from non-cancer populations and therefore this study is the first to demonstrate this relationship for breast cancer survivors. Gillanders et al. (2013) conducted a similar study with chronic pain patients and obtained similar findings to this study. They found that having a strong illness identity was associated with lower acceptance and more catastrophising, and that these variables were closely related to pain intensity, and outcomes of physical disability and emotional distress, which has also been demonstrated in other studies (e.g. Galli et al., 2010). The only other study to focus on cancer patients produced different findings; however, Guo (2014) found that negative beliefs around consequences and treatment control in Taiwanese patients with lung and colorectal cancer predicted higher levels of pain intensity. As highlighted, the relationship between the IPQ-R consequences domain and pain outcomes has been

documented in previous studies (e.g. Galli et al., 2010; Norton et al., 2014). However, Guo (2014) found that the IPQ-R treatment control domain was also predictive of pain intensity which has not previously been documented.

The finding that illness identity is a significant predictor of pain severity may be better understood within the context of the chronic pain literature. Chronic pain can cause major disruption in an individual's life (Davison & Jhangri, 2005). It has been linked to factors such as sleep difficulties, emotional distress and reduced physical functioning (Arnold et al., 2016). It has been reported that chronic pain can impact on identity (Morley, Davies, & Barton, 2005). Therefore, it is possible that some people become extremely enmeshed with their illness (e.g. breast cancer) and this can have a negative impact on their pain. As highlighted in chapter 3, the identity domain required participants to report which symptoms they have experienced and associate with their breast cancer and/or treatment. Symptoms reported by participants in the higher pain category included pain, stiff joints, breathlessness, fatigue, headaches, upset stomach, sleep difficulties, dizziness, loss of strength, feeling down and anxiety (Table 6). Many of these symptoms are similar to those reported by other chronic pain populations (Arnold et al., 2016; Foster et al., 2008). Therefore, it could be that chronic pain experienced by breast cancer survivors is not necessarily unique in terms of its underlying mechanisms. It has previously been argued that the factors underlying chronic pain experienced by cancer patients may be different to those underlying chronic pain experienced by non-cancer patients (Turk & Fernandez, 1990). However, it has also been argued that there may be more similarities than differences (Bishop & Warr, 2003). The findings from the present study may further support this theory and have important clinical implications which will be discussed later in this chapter.

Pain catastrophising has been shown to be a robust predictor of perceived pain (Craner et al., 2017; Roth et al., 2012) and has been associated with various outcomes such as pain intensity, disability and distress for both non-cancer (Burns et al., 2015; Craner et al., 2017; Scott et al., 2016) and cancer populations (Bishop & Warr, 2003; Edwards et al., 2013). Although pain catastrophising was not addressed in the current study, it could be that this factor mediates the relationship between illness identity and pain severity. Therefore, exploring coping behaviours among breast cancer survivors who

experience chronic pain may be important. Future avenues for research will be discussed later in this chapter.

4.1.4 HRQoL and pain severity

Another aim of the study was to explore the relationship between HRQoL and pain severity among breast cancer survivors, whilst controlling for demographics, illness-related factors and psychological factors. Analysis showed that HRQoL was a significant, independent predictor of pain severity. Those in a higher pain category were more likely to report lower scores on HRQoL, as measured using the EQ-5D-VAS. The relationship between the presence of chronic pain and reduced HRQoL has been well-documented in the literature. This has been demonstrated for non-cancer populations (e.g. Hadi, McHugh, & Closs, 2019) and cancer populations (e.g. Paice & Ferrell, 2011), including breast cancer patients and survivors (e.g. Akechi et al., 2001; Caffo et al., 2003). Whilst the results from this study support previous findings, it is important to note that it is difficult to establish causality. Although the findings show that HRQoL is an independent predictor of pain severity, it is difficult to conclude whether breast cancer survivors have reduced HRQoL which predicts pain severity, or whether increasing pain severity predicts reduced HRQoL. It is also difficult to establish whether participants had any pre-morbid or co-morbid health conditions that could have contributed to lower scores on HRQoL. Nevertheless, the findings from this study highlight an unmet clinical need, whereby this population are experiencing reduced HRQoL associated with a high prevalence of moderate to severe chronic pain.

It is also important to note here that difficulties such as fatigue, sleep disturbance and psychological factors (e.g. anxiety and depression) have been associated with reduced HRQoL (Bower, 2008; Cvetković & Nenadović, 2016). As demonstrated within this study, women in a higher pain category reported experiencing several symptoms that they felt were a consequence of their breast cancer and/or treatment (as captured by the IPQ-R identity domain). This provides support for the hypothesis that women in a higher pain category are more likely to have a strong illness identity, which could be associated with both reduced HRQoL and pain severity.

4.1.5 Impact of COVID-19

This project took place during the COVID-19 pandemic and it is important to consider any potential impact that this may have had on the day-to-day project management, participant recruitment and responses to the survey questions. As the study was conducted online, no adaptations to the delivery methods were needed to enable breast cancer survivors to participate in the study. Recruitment for this project was affected in the following ways: (1) a delay in the intended start date by 4 months due to delays in gaining ethical approval; and (2) recruitment strategies to use posters in the reception areas of some of the charities and organisations was not possible due to COVID-19 restrictions. This recruitment strategy would have provided participants who do not use online communities and services with the opportunity to participate. Accessibility of this survey will be acknowledged in the limitations of this thesis. The overall recruitment rate did not appear to be adversely affected by the pandemic, as the study managed to obtain 182 survey responses in 5 months of the survey being open.

Due to restrictions surrounding COVID-19, it is important to consider the impact that this could have had on participants, particularly on self-reported measures of pain, HRQoL and psychological factors. Participants may have experienced difficulties accessing medical care and may have been unable to utilise coping behaviours (e.g. physiotherapy, going to the gym, social support etc.) that previously helped to manage their physical and mental wellbeing. This could have had a negative impact on self-reported outcomes such as pain, HRQoL, depression and anxiety. The prevalence of chronic pain reported in this study (66%) is similar to prevalence rates reported in previous studies (25-60%). This suggests that the COVID-19 pandemic is unlikely to have had a significant impact on self-reported chronic pain prevalence rates. Likewise, several studies exploring the severity and impact of chronic pain among breast cancer survivors have shown that worse pain outcomes are associated with reduced HRQoL and psychological functioning (e.g. Caffo et al., 2003; Bredal et al., 2014; Jensen et al., 2010). Similar findings were produced in the current study.

The current study found that employment status had a significant, direct relationship with pain severity, as those in a higher pain category were less likely to be in paid employment. During the COVID-19 pandemic, unemployment rates have increased slightly (Watson, 2020); therefore, it is difficult to determine the impact that this had on

participants. However, previous studies have found that employment status is independently associated with pain outcomes (e.g. Smith et al., 2001), which supports the findings of this study. Therefore, whilst it is important to acknowledge the potential impact of COVID-19, based on the findings from previous studies, it is unlikely to have had a significant impact on the current findings.

4.2 Strengths and Limitations

4.2.1 Strengths

To the author's knowledge, this study was the first to address illness representations, HRQoL and pain severity among breast cancer survivors. Therefore, this study provides a contribution to the CSM and illness representations literature.

This study included a sample size sufficiently large to meet the estimated prevalence of chronic pain in breast cancer survivors, as determined by a power calculation with 7.23% precision and 95% confidence (Dhand & Khatkar, 2014). This ensured that a sufficient number of women participated to accurately estimate the primary outcome measure, pain severity, which was measured using the BPI-SF.

A strength of the study was the use of an online survey, which helped to ensure that the sample was as inclusive and generalisable as possible. Seven breast cancer and cancer charities and organisations were contacted and asked to distribute the survey on multiple online platforms (e.g. online forums and notice boards hosted by breast cancer and cancer charities). By engaging with charities and organisations in this way, the survey was accessible to as broad a segment of the target population as possible. Likewise, an online survey meant that it was possible to reach a larger number of individuals within a shorter amount of time, compared with paper-based versions of the survey. Another strength of using an online survey is that it is flexible; participants are able to complete it at a time that is convenient for them (Evans & Mathur, 2005). Furthermore, the data from the study went through a rigorous preparation process, which enabled robust analysis.

Another strength of the study are the standardised outcome measures that were included. Standardised measures that have previously demonstrated good reliability and validity, particularly within a cancer population, were selected. As highlighted in chapter 2, the present study modified the IPQ-R to be used with breast cancer survivors. In order

to ensure that the modified IPQ-R was being understood and interpreted in the correct way, attempts were made to validate this modified version. A cognitive interview approach was used with two individuals, who both reported that the modified IPQ-R was clear and comprehensible. Finally, the causes section of the IPQ-R went through the process of FA to establish sub-scales of causal beliefs, which allowed for more robust analysis.

4.2.2 Limitations

The current study has several limitations, which should be considered when interpreting the results.

4.2.2.1 Recruitment and Sampling

The study recruited participants through several different cancer and breast cancer charities and organisations; however, this meant that the study was susceptible to selection bias, whereby only participants who accessed those charities and organisations would be able to complete the survey. Likewise, it is important to consider self-selection bias, whereby a certain group of individuals may be more likely to dedicate their time to participate in a survey.

Using online methods to recruit participants creates issues around accessibility (Wright, 2005). The survey would have only been accessible to participants who have internet access and are online literate. For example, it was difficult to make reasonable adjustments for individuals who may have required support completing the questionnaire (e.g. those who would require the survey to be translated into a different language or would require extra support due to an impairment). This potentially excludes specific groups of individuals, and considering the highlighted issues around accessibility, the survey may have been less accessible to more marginalised groups (e.g. those from a lower socio-economic background). This raises issues around generalisability, as participants are a specific group of individuals who are able to access and use online communities and services (Wright, 2005).

Whilst this study recruited the target sample size, issues around generalisability are highlighted in the sample demographic data (Table 2). The sample was predominately white British (98%). National prevalence data shows that approximately 65% of breast

cancer patients are white British (NCIN, n.d.), which means the current estimate of 98% is much higher. It is difficult to conclude why the majority of participants in the current study were white British; however, research has shown that individuals from minority ethnic backgrounds can experience difficulty accessing cancer support (MacMillan Cancer Support, n.d.). Whilst this could suggest that women from ethnic minority backgrounds may be less likely to have accessed support via the charities and organisations that helped to recruit participants in the current study, this cannot be verified.

4.2.2.2 Design

One of the limitations of utilising a cross-sectional design is that it is not possible to establish temporal or causal relationship between variables (Sedgwick, 2014). However, a number of associative relationships between pain severity and illness representations and HRQoL were identified. Using an online survey means that participants are not given the opportunity to ask any questions or clarify instructions. Therefore, it is possible that participants could have misinterpreted instructions, which could result in response bias (Evans & Mathur, 2005). Furthermore, the survey was relatively long and required participants to answer a variety of questions. Therefore, participants could have been susceptible to respondent fatigue, whereby participants' motivation and attention could have reduced towards the latter part of the survey (Schmidt, Gummer, & Roßmann, 2020).

Another limitation with the design of the study is that participants may not have accurately reported demographic and illness-related characteristics (Wright, 2005). Participants were survivors of breast cancer and whilst the inclusion criteria required participants to have finished all hospital-based treatment, this could have been misinterpreted. It is common for women to have hormone therapy for 5 years or more once hospital-based treatment has finished (NHS UK, 2020). These women may not consider themselves to be 'cancer free' and survivors, and are therefore less likely to participate in the study despite finishing hospital-based treatment. After completing the survey, some participants contacted the author via email to provide feedback about completing the survey. Consent was obtained from these participants to include their feedback in this thesis. As highlighted below, some questions and feedback from

participants highlight the ambiguity around what it means to have finished hospital-based treatment and be considered a 'survivor':

"After 5 years of hormone treatment that had horrible side effects, I thought at last I was cancer free… well maybe I was free of breast cancer, but what was substituted in its place was horrific."

"I have finished my chemotherapy, but still have monthly injections for 5 years. Can I complete the survey?"

A further limitation is that the current study did not require participants to report whether they had experienced any pre-morbid or co-morbid health conditions (e.g. arthritis) or how long they had experienced pain for. Therefore, it is impossible to determine whether participants were able to accurately reflect on pain that was a consequence of their breast cancer and/or treatment. Therefore, the study may have been susceptible to recall bias, as it is difficult to determine whether the exposure (breast cancer diagnosis) or outcome (chronic pain) came first (Ben-Zeev, Young, & Madsen, 2009). Attempts were made to direct participants to answer the questions on the IPQ-R and BPI-SF reflecting on pain that they experience in relation to their breast cancer and/or treatment. However, some individuals may have experienced chronic pain due to multiple causes, and this survey did not differentiate between or account for multi-comorbid chronic pain. This is supported based on the findings of this study. For example, when answering the IPQ-R, participants were required to select whether 'pain' was a symptom that they had experienced and relate to their breast cancer and/or treatment (yes/no). On the BPI-SF participants were then required to select whether they were experiencing ongoing pain in relation to their breast cancer and/or treatment (yes/no), which was then used to stratify participants into the different pain categories. As shown in chapter 3 (Table 6), only 80% of participants in the mild pain category and 90% in the moderate pain category selected 'yes' on the IPQ-R, stating that they had experienced pain at some point that they relate to their breast cancer and/or treatment. Based on the fact that these participants selected 'yes' on the BPI-SF to experiencing ongoing pain in relation to their breast cancer and or treatment (evidenced by them being in the mild or moderate pain category), it would have been expected that 100% of those participants selected 'yes' on the IPQ-R pain as a symptom question. Therefore, this suggests that either participants

had difficulty understanding the instructions or they were experiencing pain as a consequence of multiple causes and struggled to differentiate between this.

Finally, one of the limitations of utilising a quantitative design rather than a qualitative design is that participants may not have been able to fully express the challenges and experience of being a breast cancer survivor. This was reflected in feedback from one participant:

"The lived experience of 'my breast cancer' is complex and multi-faceted, both physically and mentally. When I describe 'my breast cancer', it is not just one thing, it is an ongoing process".

4.2.2.3 Standardised outcome measures

Whilst the findings of the present study show a relationship between illness representations and pain severity, only one of the domains (identity) on the IPQ-R was found to be a significant, independent predictor. This highlights a limitation of the CSM as an explanatory model for pain severity within this population. However, this could be due to limitations regarding the way the present study utilised the IPQ-R. Firstly, whilst attempts were made to validate the modified IPQ-R used in the present study for the target population, it is important to acknowledge the limitations to this. Two individuals participated in the cognitive interview to ensure that the modified version of the IPQ-R was understood and interpreted as intended. However, as there were only two individuals, it may be difficult to generalise this to other survivors of breast cancer. Likewise, as both individuals were known to the author prior to undertaking the study, there may have been some response bias in terms of them wanting to give positive feedback. Based on some feedback emailed by two participants, it was evident that some of the items on the IPQ-R did not make sense to them. Within the current study, the IPQ-R was used to retrospectively explore participants' illness perceptions about their breast cancer and treatment. This could have resulted in retrospective recall bias (Ben-Zeev et al., 2009). For example, if participants are experiencing ongoing difficulties as a result of their breast cancer and/or treatment, it could result in them reporting more past adversity. Therefore, it may be difficult for some participants to retrospectively think of their illness representations at the time when they had breast cancer and were undergoing active hospital-based treatment, due to ongoing difficulties influencing perceptions of their

illness. Likewise, if participants are not experiencing difficulties in survivorship, this may result in more positive representations of their illness.

Finally, the EQ-VAS was used in the current study. This is a vertical visual analogue scale that requires participants to mark on the scale their self-perceived health. As the study was completed online, it was not possible for participants to do this, so instead participants were shown a picture of the visual analogue scale and asked to provide a number (0-100) as to where they would rate their current health. This could have potentially reduced the validity of the scale.

4.3 Implications for clinical practice

Several implications for clinical practice can be outlined following the findings from this study. The study supports previous findings that chronic pain is a significant clinical problem for breast cancer survivors. The association between reduced HRQoL and chronic pain within this population also highlights that pain management is an unmet clinical need for survivors of breast cancer. In order to improve pain management for this population, several factors needed to be addressed. Firstly, there is currently a lack of agreement on a standard pain assessment tool for this population. Therefore, guidance is needed regarding a standard assessment tool that should be incorporated into routine clinical practice, to ensure that pain is being adequately identified. Secondly, although pharmacological interventions are frequently used to manage acute pain following breast cancer treatment, studies have found that negative personal beliefs around cancer pain and/or treatment can act as a barrier to effective pain management (e.g. Cohen et al., 2008; Guo, 2014). Research has also found that breast cancer survivors experiencing chronic pain reported that they had not received any information about managing pain at any point following their treatment (Hovind et al., 2013). This highlights a clinical need for more information and support to be provided to breast cancer patients and/or survivors surrounding pain management. Psychoeducation surrounding breast cancer and associated symptoms, such as pain, will help increase a patient's understanding and knowledge of their illness. This could help to minimise negative beliefs surrounding cancer pain and/or treatment that act as a barrier to effective pain management and may help to empower patients to utilise helpful coping strategies to manage their pain.

Chronic pain is a complex, multidimensional experience. It is important that services do not rely solely on pharmacological interventions to support cancer patients to manage their pain. Several research studies have been conducted to examine the effectiveness of psychosocial interventions that may be useful in supporting breast cancer patients and/or survivors to manage their pain (e.g. Bender et al., 2008; Tatrow & Montgomery, 2006). Psychosocial interventions have been found to be beneficial for this population in managing pain when they reduce preoperative stress (Bender et al., 2008), target unhelpful cognitions and beliefs surrounding their illness (Tatrow & Montgomery, 2006), and incorporate stress management and acceptance techniques (Johanssen et al., 2013). Whilst psychosocial interventions may be an effective way of managing pain for this population, the results are considered preliminary, as more evidence is needed. Overall there is currently a lack of evidence-based guidance on the management of cancer-related pain (Hamood et al., 2018), which highlights a clinical need for more guidance to ensure adequate pain management for this population.

Results from this study suggest that components of illness representations are associated with pain severity among breast cancer survivors. Previous findings have reported that within this population, illness representations are associated with several other illness outcomes, including physical disability, emotional distress and reduced HRQoL (e.g. Charlier et al., 2012; Rozema et al., 2009). Therefore, routine assessment of illness representations for this population would be recommended. Clinical resources could be utilised for health professionals to conduct routine assessment for patients with breast cancer, to assess their illness representations. This would have important implications, as it may be possible to develop psychosocial interventions that would specifically address unhelpful representations (Nah et al., 2019). For example, in one study it was found that a 10-week supportive intervention improved illness perceptions of cancer patients (Pourfallahi, Gholami, Tarrahi, Toulabi, & Moghadam, 2020). This could result in more positive outcomes in survivorship.

As highlighted previously in this chapter, the finding from this study that a strong illness identity is an important predictor of pain severity among breast cancer survivors has also been demonstrated in other chronic pain populations (e.g. Gillanders et al., 2013; Järemo et al., 2017; Norton et al., 2014). Similarly, symptoms (e.g. stiff joints, anxiety, sleep difficulties etc.) reported by participants in the higher pain category are similar to

those reported by other chronic pain populations (Arnold et al., 2016). Research has previously speculated that the underlying mechanisms of chronic pain experienced by cancer patients are different from non-cancer patients (Turk & Fernandez, 1990). However, the findings from this study suggest that there may be more similarities than differences in terms of psychological representations of chronic pain, which supports other studies (e.g. Bishop & Warr, 2003). It could be argued that interventions and pain management programmes which are effective and used with non-cancer (e.g. musculoskeletal) chronic pain populations may be effective in supporting breast cancer survivors to manage their pain. Therefore, if the underlying psychological representations of chronic pain are similar in cancer and non-cancer populations, it may be possible to adapt psychological pain management treatment techniques that have been validated within non-cancer chronic pain populations for breast cancer survivors. Due to the lack of guidance surrounding the management of cancer-related pain, this is something that health professionals should consider when supporting breast cancer survivors to manage their pain. Finally, cancer pain is often underreported and undertreated (Green et al., 2011); therefore, encouraging health professionals to conduct holistic assessments will ensure that patients' needs are adequately identified and addressed.

4.4 Implications for future research

This study has identified, for the first time, the relationship between illness representations and chronic pain in breast cancer survivors. In particular, this study found that the identity domain on the IPQ-R to be a significant, independent predictor of pain severity. However, one of the symptoms listed within the domain was 'pain'. Although it may not have had a major impact on the overall regression results, a sensitivity analysis on the identity domain could be conducted with and without the 'pain' item. This would enable an evaluation of the extent to which pain as a symptom was carrying the main effect on this analysis (see Table 5, Model 1-6, IPQ-R identity variable).

Most research conducted on illness representations is cross-sectional, including this study. Considering the limitations associated with cross-sectional designs, prospective longitudinal studies would enhance our understanding of the temporal relationships between illness representations and the onset of chronic pain and other conditions that impact on QoL (Stewart, 2020). Mapping the natural history and variation in illness representations of breast cancer survivors from diagnosis, to treatment, and

recovery, would help determine how changes in illness representations over time relate to the onset of illness outcomes, such as chronic pain. This could be used to identify common stages of change in illness representations and opportunities to implement interventions that may improve health outcomes (such as chronic pain) and overall HRQoL. Though in general longitudinal research suggests that illness representations are unlikely to change over time (Dempster et al., 2015). In a six-year longitudinal study of patients with osteoarthritis, it was found that over time, illness representations become more negative, and this was associated with worse outcomes on functional disability and pain intensity (Kaptein et al., 2010). Therefore, it would be interesting to see if a similar pattern occurs with breast cancer patients and whether this could provide insight into chronic pain experienced in survivorship. Overall, more longitudinal research within this area would help to understand changes in illness representations over time.

The majority of research exploring illness representations in women with breast cancer has focused on illness outcomes. Future studies should explore whether illness representations and coping are important predictors of illness outcomes in this population, as this is a current gap in the literature. Although one study found a weak relationship between illness representations and coping behaviours of breast cancer patients (Rozema et al., 2009), there are some studies that have produced promising results (e.g. McCorry et al., 2013a). Pain catastrophising and maladaptive coping (e.g. avoidance and denial) have been found to predict worse illness outcomes, such as greater emotional distress, functional disability and pain severity (Edwards et al., 2013; Richardson et al., 2017; Schreiber et al., 2013). Therefore, future studies should determine whether illness representations predict coping behaviours, which could subsequently impact on pain outcomes among breast cancer patients and/or survivors.

The current findings show that breast cancer survivors have a strong illness identity and this is associated with chronic pain. Future research could help to develop and explore the effectiveness of psychosocial interventions in supporting these women around their illness identity, which could help to improve overall HRQoL and reduce their experience of chronic pain. Previous studies have found that pain catastrophising is an important predictor of perceived pain (Craner et al., 2017; Roth et al., 2012) and also HRQoL (Lamé, Peters, Vlaeyen, Kleef, & Patijn, 2005). The findings of this study indicate that breast cancer survivors experience reduced HRQoL and high prevalence

rates of chronic pain. Therefore, future research should explore the relationships between pain catastrophising, chronic pain and HRQoL in breast cancer survivors. By exploring whether there is a relationship, it would be possible for research to then identify interventions that may help reduce pain catastrophising that would also improve HRQoL. For example, techniques such as acceptance and mindfulness have been linked to pain catastrophising and cited as effective treatment for chronic pain (e.g. de Boer et al, 2014; Craner et al., 2017; de Boer, Steinhagen, Versteegen, Struys, & Sanderman, 2014). Therefore, it may be possible to utilise these interventions with breast cancer survivors. There is a growing body of research that has attempted to validate non-pharmacological interventions as a way of supporting breast cancer patients and/or survivors to manage their pain (Tatrow & Montgomery, 2006; Johanssen et al., 2013). Future research should continue to provide evidence to validate these interventions, as this will be crucial in supporting services to establish evidence-based guidance on the management of cancer-related pain.

Previous studies have argued that there may be more similarities than differences in the factors underlying chronic pain in cancer and non-cancer populations than previously thought (Bishop & Warr, 2003). A comparative study exploring illness representations, coping behaviours and pain outcomes in breast cancer survivors and those with chronic conditions (e.g. arthritis) would be useful. This would help to establish whether the psychological representations underlying chronic pain in breast cancer and other chronic conditions are similar or different. If there were more similarities than differences, it could be argued that interventions and pain management programmes that have a strong evidence-base, and are regularly used with non-cancer (e.g. musculoskeletal) chronic pain populations, may be effective in supporting breast cancer survivors to manage their pain. Furthermore, given that the current study has suggested that there may be more similarities in the underlying psychological representations of chronic pain for cancer and non-cancer patients, a qualitative study to further explore and understand the factors and experiences of both populations would be recommended.

As highlighted in the literature, the authors of the IPQ-R have recommended that it can be modified by adapting questions so that it can be used in different contexts with different illnesses (Moss-Morris et al., 2002). Whilst several studies have done this, there is little evidence validating such modified versions. Think-aloud studies have shown that

when answering the IPQ, patients sometimes struggle to answer or can misunderstand the questions (McCorry et al., 2013b; Van Oort et al., 2011). This highlights the importance of exploring the face validity of the IPQ with different groups of patients, particularly when a modified version is used. For example, by validating a modified version of the IPQ-R to be used with the breast cancer population, it improves the internal and external validity of the scale. Therefore, it would be useful for future research to validate these modified versions. This would be particularly useful when modifying the IPQ-R for use with certain populations who may no-longer consider themselves to be unwell, such as breast cancer survivors.

Finally, it may be useful for future research to explore health professionals' understanding of chronic pain experienced by this population. This could provide insight into what information and support is currently being given to patients, and help to identify current gaps that health professionals feel are missing in enabling adequate pain management. Previous research has reported that a shared understanding between patients and professionals is likely to have beneficial outcomes (Feeney, Tormey, & Harmon, 2018). Therefore, exploring health professionals' experiences and understanding could have a beneficial impact on clinical practice and subsequently patient outcomes.

4.5 Conclusions

This study is the first to explore the association between illness representations, HRQoL and chronic pain among breast cancer survivors. Consistent with previous research, it was found that illness representations are associated with illness outcomes. In the current study, it was found that identity, timeline (acute/chronic), consequences, timeline (cyclical), treatment control and causal factors 'stress' and 'state of health', were associated with more severe chronic pain in breast cancer survivors. However, cross-sectional ordinal logistic regression analysis found that when adjusted for other factors (e.g. demographics, illness-related factors and psychological factors), the association between illness representations and pain severity became non-significant. However, IPQ-R identity remained an independent, significant predictor of pain severity, even when adjusting for other factors. This finding is the first within the context of breast cancer survivors and chronic pain. These results are similar to those reported by studies exploring the association between illness representations and illness outcomes, within non-cancer chronic pain populations. This suggests that there may be more similarities than

differences in the underlying psychological mechanisms used to understand chronic pain in cancer and non-cancer populations than previously thought. Consequently, pain management interventions utilised in non-cancer populations may be effective in cancer populations, specifically breast cancer survivors. However, more research is needed.

HRQoL was also found to be a significant, independent predictor of pain severity among breast cancer survivors. This finding suggests that chronic pain in breast cancer survivors represents an unmet clinical need. Therefore, it is essential that consideration is given to find ways to improve HRQoL and chronic pain experienced by this population. Another interesting finding was that employment status was found to have a direct, independent relationship with pain severity, even when adjusting for other factors. The current finding that those in a higher pain category are less likely to be in paid employment supports previous findings which have reported an association between employment status and chronic pain in non-cancer populations.

Despite the methodological limitations, the findings of this study contribute to a novel area of literature. Implications for clinical practice and future research have been discussed. It is hoped that the findings of this study will inform future areas of research, which could result in a better understanding of chronic pain experienced by this population. Furthermore, the findings from this study could also inform future clinical practice, resulting in better prevention, assessment and management of pain experienced by breast cancer patients and/or survivors. This could subsequently improve overall quality of life for breast cancer survivors.

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Appendix

Appendix A – Ethical approval email

Dear Lewis

MREC 19-059 - Exploring the experiences of survivors of breast cancer. Can illness representations be used to understand pain experienced in survivorship?

NB: All approvals/comments are subject to compliance with current University of Leeds and UK Government advice regarding the Covid-19 pandemic.

I am pleased to inform you that the above research ethics application has been reviewed by the School of Medicine Research Ethics Committee (SoMREC) and on behalf of the Chair, I can confirm a favourable ethical opinion based on the documentation received at date of this email.

Please retain this email as evidence of approval in your study file.

Please notify the committee if you intend to make any amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see https://leeds365.sharepoint.com/sites/ResearchandInnovationService/SitePages/Amendments.aspx or contact the Research Ethics Administrator for further information FMHUniEthics@leeds.ac.uk if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I hope the study goes well.

Best wishes
Rachel
On behalf of Dr Naomi Quinton, co-Chair, SoMREC

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Rachel de Souza, Lead Research Ethics & Governance Administrator, The Secretariat, Room 9.29, Level 9, Worsley Building, Clarendon Way, University of Leeds, LS2 9NL, Tel: 0113 3431642, r.e.desouza@leeds.ac.uk
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Appendix B – Recruitment email

UNIVERSITY OF LEEDS

Hi,

My name is Lewis Langford, I am a Clinical Psychologist in training at The University of Leeds. I am contacting you because I am carrying out a research project exploring the experiences of people who have had breast cancer to understand the impact that this can have on quality of life.

People who experience breast cancer can be faced with several long term health-related consequences which can have an impact on their quality of life. Understanding the experiences of those who have had breast cancer can help us to identify ways to reduce the impact of any long term consequences of breast cancer on peoples' everyday lives.

We are contacting you to invite you to take part in a short online survey which will take approximately 20-30 minutes to complete. The survey is completely confidential and does not require you to disclose any identifiable information.

In order to take part in the survey you must:

1. Be female and over the age of 18.
2. Have previously had a diagnosis of breast cancer.
3. Have finished all active treatment for breast cancer.

If you are interested in taking part in the research then you can click on the link below which will take you to the online survey. You will first be presented with an information sheet which will provide you with more information about the study, so you can make a decision whether you want to take part.

https://leeds.onlinesurveys.ac.uk/exploring-experiences-of-people-who-have-had-breast-cancer-2

This study has been reviewed by the School of Medicine Research Ethics Committee, University of Leeds (MREC 19-059).

If you have any further questions you can contact me, Lewis Langford via email umlla@leeds.ac.uk. Thank you very much for taking time to read this.

Kind Regards,

Lewis Langford

Supervised by
Dr Matthew Mulvey
Dr Gary Latchford

Appendix C – Recruitment poster

UNIVERSITY OF LEEDS

Have you experienced breast cancer?

We are looking for females over 18 to take part in a short online survey which will take approximately 20-30 minutes to complete. The survey is completely confidential and does not require you to disclose any identifiable information.

Why take part?

People who experience breast cancer can be faced with several long term health-related consequences which can impact on quality of life. Understanding the experiences of those who have had breast cancer can help us to identify ways to reduce the impact of any long term consequences of breast cancer on peoples' everyday lives.

Can I take part?

You can take part if you are:

1. Female and over the age of 18
2. Have previously had a diagnosis of breast cancer.
3. Have finished all active treatment for breast cancer.

How to take part?

If you are interested in taking part in the research you can follow the link https://tinyurl.com/yyvglau3 or scan the QR code bellow which will both take you to the online survey. You will be presented with an information sheet which will provide you with more information about the study.

Who has reviewed this study?

This study has been reviewed by the School of Medicine Research Ethics Committee, University of Leeds (MREC 19-059).

If you require any further information or have any questions you can contact Lewis Langford via email: umlla@leeds.ac.uk. Thank you for taking time to read this.

Appendix D – Online survey

Exploring experiences of women who have had breast cancer

Welcome

Thank you for choosing to complete this survey which is exploring the experiences of women who have had breast cancer.

The survey is subject to ethical guidelines set out by the University of Leeds, UK, including informed consent, the right to withdraw and protection of anonymity.

Information Sheet

Please take the time to read the following information carefully to help you decide whether or not you would like to participate in the study. It is important that you understand why the research is being done and what it will involve.

What is the purpose of this study?

This study is exploring the experiences of women who have had breast cancer to understand the impact that experiencing breast cancer can have on quality of life, in particular their experiences of pain.

Why have I been invited to take part?

You have been invited to take part in our survey as a female who has had a diagnosis of breast cancer. Only over 18's are being asked to take part as this study recognises that experiences may be different for adults.

What do I have to do?

If you agree to take part you will be asked to complete an online survey. The survey involves a series of questionnaires that will ask you about pain, quality of life, mood, and a little about who you are. This survey will take approximately 20-30 minutes to complete.

Do I have to take part in the study?

Taking part in this study is entirely voluntary. If you decide to take part after reading this information sheet you will be asked to proceed to the survey questions. You can withdraw at any time during the questionnaire, by shutting down the browser. You do not have to give a reason for not participating.

What happens if I say yes but then later decide I don't want to take part?

You are able to exit the survey at any time by shutting down the browser. Any data already submitted on previous pages will already be captured by OnlineSurvey. Once data has been captured you will not be able to withdraw it from the research as the data is stored anonymously. Likewise, once the survey has been sent (by pressing the 'finish' button) you will not be able to withdraw your responses as all responses are anonymous.

What happens to the information I give?

All the information that we collect during this survey is stored anonymously on a secure University of Leeds server and will be used in the analysis of this research. After this research has been completed, the data will be kept securely for use in further research by the University of Leeds and their academic collaborators. All of the data obtained will be treated as confidential and stored securely as is required by the Data Protection Act. The data collected will be used as part of a doctoral thesis and may be written up for publication. No identifying information about you will be included in the report. For further information, please see the University of Leeds Research Privacy Notice:

https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf

Will I be contacted as a result of anything I answer in the survey?

This survey is anonymous therefore you cannot be contacted regardless of what you answer in the survey. If you require health and well-being support please contact one of the support services listed at the end of the survey.

Who has reviewed this study?

This study has been reviewed by the School of Medicine Research Ethics Committee, University of Leeds (MREC 19-059).

If I have questions about the study who can I ask?

If you require any further information please contact the Doctoral student who is completing this research, Lewis Langford (umlla@leeds.ac.uk). You can also contact the supervisors of this project, Dr Matthew Mulvey (m.r.mulvey@leeds.ac.uk) or Dr Gary Latchford (g.latchford@leeds.ac.uk).

Thank you for reading this information sheet.

By pressing the next button below you agree to participate in this study.

*****Note that once you have clicked on the CONTINUE button at the bottom of each page you cannot return to review or amend that page*****

Project title	*Document type*	*Version #*	*Date*
Exploring experiences of women who have had breast cancer	Information sheet	2	08/06/2020

Can I take part?

Please check that you meet the following criteria before you proceed with the survey.

1. Female and over the age of 18
2. Have previously had a diagnosis of breast cancer.
3. Have finished all active hospital based treatment for breast cancer.

Please select. ✱ *Required*

○ Yes ○ No

About you

These questions ask for a little background information about you. Please don't worry if you feel unable to answer any of these - just carry on with the rest of the questionnaire.

How old are you?

What is your gender?

- ☐ Female
- ☐ Male
- ☐ Other

If other please specify here.

Which of these best describes your ethnic group?

- ☐ White
- ☐ White Mixed
- ☐ Black or Black British
- ☐ Asian or Asian British
- ☐ Other ethnic group

If other please specify here.

What is your relationship status?

- [ ] Married
- [ ] Single
- [ ] Widowed
- [ ] Divorced
- [ ] Civil Partnership
- [ ] In a relationship
- [ ] Other

If other please specify here.

Do you have any dependent children?

- ( ) Yes
- ( ) No

Which of these best describes your employment status?

- [ ] Employed (Full-time)
- [ ] Employed (Part-time)
- [ ] Unemployed
- [ ] Self-employed
- [ ] Retired
- [ ] Disabled, not able to work
- [ ] Other

If other please specify here.

What is the highest level of education that you have completed?

- [ ] GCSE's or equivalent
- [ ] A-Level's or equivalent
- [ ] University undergraduate degree or higher

Questions about your Breast Cancer

The following questions will ask you for some information about your breast cancer. Please do not worry if you struggle to answer any of these questions - please just answer them as best as you can.

How many times have you been diagnosed with breast cancer?

If you have been diagnosed with breast cancer on more than one occassion, please answer the following questions thinking about your most recent diagnosis of breast cancer.

Approximately how many years ago were you diagnosed with breast cancer?

What type of treatment did you have for your breast cancer? (please select multiple if appropriate)

- ☐ Radiotherapy
- ☐ Chemotherapy
- ☐ Surgery
- ☐ Hormone Therapy
- ☐ Other

If other please specify here.

If you have had surgery, please indicate what surgey you have had? (Please select multiple if appropriate) *Optional*

- [ ] Lumpectomy
- [ ] Single mastectomy
- [ ] Double mastectomy
- [ ] Breast reconstruction
- [ ] Lymph node dissection (removal of lymph nodes)
- [ ] Unsure
- [ ] Other

If other please specify here.

When did you finish hospital based treatment (e.g. chemotherapy, radiotherapy, surgery) for your breast cancer?

- ( ) less than 1 year ago
- ( ) 1-2 years ago
- ( ) 3-4 years ago
- ( ) 5+ years ago

Illness Perceptions Questionnaire - Revised (IPQ-R)

You will now be asked some questions that require you to think about your breast cancer and breast cancer treatment. Please answer all the questions as honestly as you can.

Your views about your breast cancer

Listed below are a number of symptoms that you may or may not have experienced since your breast cancer or breast cancer treatment. Please indicate by selecting Yes or No, whether you have experienced any of these symptoms since your breast cancer, and whether you believe that these symptoms are related to your breast cancer.

	I have experienced this symptom since my breast cancer or breast cancer treatment		This symptom is related to my breast cancer	
	Yes	No	Yes	No
Pain	○	○	○	○
Nausea	○	○	○	○
Breathlesness	○	○	○	○
Weight Loss	○	○	○	○
Fatigue	○	○	○	○
Stiff Joints	○	○	○	○
Headaches	○	○	○	○
Upset Stomach	○	○	○	○
Sleep Difficulties	○	○	○	○
Dizziness	○	○	○	○
Loss of Strength	○	○	○	○
Feeling down	○	○	○	○
Anxiety	○	○	○	○

We are interested in your own personal views of how you now see and think about your breast cancer and breast cancer treatment.

Please indicate how much you agree or disagree with the following statements about your breast cancer by ticking the appropriate box.

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
My breast cancer lasted for a short time	○	○	○	○	○
At the time, I thought my breast cancer was likely to be permanent rather than temporary	○	○	○	○	○
My breast cancer lasted for a long time	○	○	○	○	○
My breast cancer passed quickly	○	○	○	○	○
At the time, I expected to have this breast cancer for the rest of my life	○	○	○	○	○
My breast cancer has improved over time	○	○	○	○	○

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
When I had breast cancer, it was a serious condition	○	○	○	○	○
My breast cancer has had major consequences on my life	○	○	○	○	○
My breast cancer has not had much effect on my life	○	○	○	○	○
My breast cancer has strongly affected the way others see me	○	○	○	○	○
My breast cancer has had serious financial consequences	○	○	○	○	○
My breast cancer caused difficulties for those who are close to me	○	○	○	○	○

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
There was a lot that I could do to control the symptoms of my breast cancer	○	○	○	○	○
What I did could have determined whether my breast cancer got better or worse	○	○	○	○	○
The course of my breast cancer depended on me	○	○	○	○	○
Nothing I did affected my breast cancer	○	○	○	○	○
I had the power to influence my breast cancer	○	○	○	○	○
My actions had no effect on the outcome of my breast cancer	○	○	○	○	○

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
There was very little that could have been done to improve my breast cancer	○	○	○	○	○
My treatment was effective in curing my breast cancer	○	○	○	○	○
The negative effects of my breast cancer were prevented (avoided) by my treatment	○	○	○	○	○
My treatment controlled my breast cancer	○	○	○	○	○
There was nothing that could have helped my breast cancer	○	○	○	○	○

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
The symptoms of my breast cancer were puzzling to me	○	○	○	○	○
My breast cancer was a mystery to me	○	○	○	○	○
I did not understand my breast cancer	○	○	○	○	○
My breast cancer did not make any sense to me	○	○	○	○	○
I had a clear picture or understanding of my breast cancer	○	○	○	○	○

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
The symptoms of my breast cancer changed a great deal from day to day	○	○	○	○	○
The symptoms of my breast cancer came and went in cycles	○	○	○	○	○
My breast cancer was very unpredictable	○	○	○	○	○
I went through cycles in which my breast cancer got better and worse	○	○	○	○	○

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
At the time, I got depressed when I thought about my breast cancer	○	○	○	○	○
At the time, when I thought about my breast cancer I got upset	○	○	○	○	○
At the time, my breast cancer made me feel angry	○	○	○	○	○
At the time, my breast cancer did not worry me	○	○	○	○	○
At the time, having breast cancer made me feel anxious	○	○	○	○	○
At the time, thinking about my breast cancer made me feel afraid	○	○	○	○	○

Possible causes of my breast cancer

We are interested in what you consider may have been the cause of your breast cancer. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your breast cancer rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your breast cancer. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
Stress or worry	○	○	○	○	○
Hereditary - it runs in my family	○	○	○	○	○
A Germ or virus	○	○	○	○	○
Diet or eating habits	○	○	○	○	○
Chance or bad luck	○	○	○	○	○
Poor medical care in my past	○	○	○	○	○
Pollution in the environment	○	○	○	○	○
My own behaviour	○	○	○	○	○
My mental attitude e.g. thinking about life negatively	○	○	○	○	○
Family problems or worries caused my illness	○	○	○	○	○
Overwork	○	○	○	○	○
My emotional state e.g. feeling down, lonely, anxious, empty	○	○	○	○	○
Ageing	○	○	○	○	○
Alcohol	○	○	○	○	○
Smoking	○	○	○	○	○
Accident or injury	○	○	○	○	○
My personality	○	○	○	○	○
Altered immunity	○	○	○	○	○
Hormonal influence	○	○	○	○	○

Do you experience any pain?

The following group of questions require you to think about any pain that you may experience as a result of your breast cancer or breast cancer treatment.

Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains and toothache). Have you had pain other than these everyday kinds of pain today?

- Yes
- No

Do you experience any pain?

If you have more than one painful area, please answer the following questions thinking about the most painful area.

	0 (No Pain)<----------(Pain As Bad As You Can Imagine) 10										
	0	1	2	3	4	5	6	7	8	9	10
Please rate your pain by marking the number that best describes your pain at its worst in the last 24 hours.	○	○	○	○	○	○	○	○	○	○	○
Please rate your pain by marking the number that best describes your pain at its least in the last 24 hours.	○	○	○	○	○	○	○	○	○	○	○
Please rate your pain by marking the number that best describes your pain on the average.	○	○	○	○	○	○	○	○	○	○	○
Please rate your pain by marking the number that tells how much pain you have right now.	○	○	○	○	○	○	○	○	○	○	○

	0% (No Relief)<---------- (Complete Relief) 100% *Optional*										
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
If you are taking any medication to manage your pain, in the last 24 hours, how much relief have pain treatments or medications provided? Please mark the percentage that most shows how much relief you have received.	○	○	○	○	○	○	○	○	○	○	○

Please mark the number that describes how, during the past 24 hours, pain has interfered with your:

	0 (Does Not Interfere)<----------(Completely Interferes) 10										
	0	1	2	3	4	5	6	7	8	9	10
General activity	○	○	○	○	○	○	○	○	○	○	○
Mood	○	○	○	○	○	○	○	○	○	○	○
Walking ability	○	○	○	○	○	○	○	○	○	○	○
Normal work (includes both work outside the home and housework)	○	○	○	○	○	○	○	○	○	○	○
Relations with other people	○	○	○	○	○	○	○	○	○	○	○
Sleep	○	○	○	○	○	○	○	○	○	○	○
Enjoyment of life	○	○	○	○	○	○	○	○	○	○	○

My health

You will now be asked some questions about your health.

Try to answer each of the questions as honestly as you can.

EQ-5D

Under each heading, please indicate which option best describes your health TODAY.

MOBILITY

- ☐ I have no problems in walking about
- ☐ I have slight problems in walking about
- ☐ I have moderate problems in walking about
- ☐ I have severe problems in walking about
- ☐ I am unable to walk about

SELF-CARE

- ☐ I have no problems washing or dressing myself
- ☐ I have slight problems washing or dressing myself
- ☐ I have moderate problems washing or dressing myself
- ☐ I have severe problems washing or dressing myself
- ☐ I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- ☐ I have no problems doing my usual activities
- ☐ I have slight problems doing my usual activities
- ☐ I have moderate problems doing my usual activities
- ☐ I have severe problems doing my usual activities
- ☐ I am unable to do my usual activities

PAIN / DISCOMFORT

- ☐ I have no pain or discomfort
- ☐ I have slight pain or discomfort
- ☐ I have moderate pain or discomfort
- ☐ I have severe pain or discomfort
- ☐ I have extreme pain or discomfort

ANXIETY / DEPRESSION

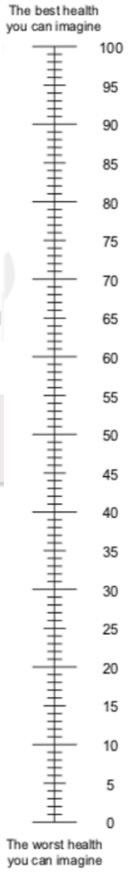
- ☐ I am not anxious or depressed
- ☐ I am slightly anxious or depressed
- ☐ I am moderately anxious or depressed
- ☐ I am severely anxious or depressed
- ☐ I am extremely anxious or depressed

We would like to know how good or bad your health is TODAY.

This scale is numbered from 0 to 100.

100 means the best health you can imagine. 0 means the worst health you can imagine.

In the box below, please write a number between 0 to 100 to indicate how you would rate your health TODAY.



My mood

You will now be asked some questions about your mood.

Have a look at the two tables below, and try to answer each of the questions as honestly as you can.

PHQ-8

Over the last 2 weeks, how often have you been bothered by any of the following:

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things?	○	○	○	○
Feeling down, depressed or hopeless?	○	○	○	○
Trouble falling or staying asleep, or sleeping too much?	○	○	○	○
Feeling tired or having little energy?	○	○	○	○
Poor appetite or overeating?	○	○	○	○
Feeling bad about yourself or that you are a failure or have let yourself or your family down?	○	○	○	○
Trouble concentrating on things, such as reading the newspaper or watching television?	○	○	○	○
Moving or speaking so slowly that other people could have noticed? Or the opposite being so fidgety or restless that you have been moving around a lot more than usual?	○	○	○	○

GAD-7

Over the last 2 weeks, how often have you been bothered by any of the following:

	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge?	○	○	○	○
Not being able to stop or control worrying?	○	○	○	○
Worrying too much about different things?	○	○	○	○
Trouble relaxing?	○	○	○	○
Being so restless that it is hard to sit still?	○	○	○	○
Becoming easily annoyed or irritable?	○	○	○	○
Feeling afraid as if something awful might happen?	○	○	○	○

Thank you!

Thank you very much for completing this survey.

Once again, please be assured all information provided is kept securely and anonymously.

As a thank you for completing the survey you have the option to enter into a prize drawer for the chance to win a £30 amazon voucher. If you would like to enter the prize drawer please enter your email below, this is completely optional.

If you decide to enter, once the survey closes we will complete the prize drawer and will contact you if you win.

Please provide your email if you wish to enter the prize drawer. *Optional*

Contact information

If you require any further information please contact the Doctoral student who is completing this research, Lewis Langford (umlla@leeds.ac.uk). You can also contact the supervisors of this project, Dr Matthew Mulvey (m.r.mulvey@leeds.ac.uk) or Dr Gary Latchford (g.latchford@leeds.ac.uk).

If you have been in any way affected by the content of the questionnaire, you can contact your GP to arrange an appointment. Below are also a list of sources of relevant support:

Breast Cancer Now Helpline: 0808 800 6000 (available Mon-Fri 9am-4pm, Sat 9am-1pm).

Macmillan Cancer Support: 0808 808 00 00 (available 7 days a week, 8am-8pm).

Samaritans: 116 123 (available 24 hours a day, 365 days a year).

Below are some websites you may also find useful:

https://www.macmillan.org.uk

https://breastcancernow.org

https://breastcancersupport.org.uk

That's all! Thank you again for taking part.

Appendix E – Adapted IPQ-R for the purpose of this study

Timeline (Acute/Chronic)

Original Item	Change
My breast cancer will last a short time	My breast cancer lasted for a short time
My breast cancer is likely to be permanent rather than temporary	At the time, I thought my breast cancer was likely to be permanent rather than temporary
My breast cancer will last for a long time	My breast cancer lasted for a long time
This breast cancer will pass quickly	My breast cancer passed quickly
I expect to have this breast cancer for the rest of my life	At the time, I expected to have this breast cancer for the rest of my life
My breast cancer will improve in time	My breast cancer has improved over time

Consequences

Original Item	Change
My breast cancer is a serious condition	When I had breast cancer, it was a serious condition
My breast cancer has major consequences on my life	My breast cancer has had major consequences on my life
My breast cancer does not have much effect on my life	My breast cancer has not had much effect on my life
My breast cancer strongly affects the way others see me	My breast cancer has strongly affected the way others see me
My breast cancer has serious financial consequences	My breast cancer has had serious financial consequences
My breast cancer causes difficulties for those who are close to me	My breast cancer caused difficulties for those who are close to me

Personal Control

Original Item	Change
There is a lot which I can do to control the symptoms of my breast cancer.	There was a lot that I could do to control the symptoms of my breast cancer
What I do can determine whether my breast cancer gets better or worse	What I did could have determined whether my breast cancer got better or worse
The course of my breast cancer depends on me	The course of my breast cancer depended on me
Nothing I do will affect my breast cancer	Nothing I did affected my breast cancer
I have the power to influence my breast cancer	I had the power to influence my breast cancer
My actions will have no effect on the outcome of my breast cancer	My actions had no effect on the outcome of my breast cancer

Treatment Control

Original Item	Change
There is very little that can be done to improve my breast cancer	There was very little that could have been done to improve my breast cancer
My treatment will be effective in curing my breast cancer	My treatment was effective in curing my breast cancer
The negative effects of my breast cancer can be prevented (avoided) by my treatment	The negative effects of my breast cancer were prevented (avoided) by my treatment
My treatment can control my breast cancer	My treatment controlled my breast cancer
There is nothing which can help my breast cancer	There was nothing that could have helped my breast cancer

Illness Coherence

Original Item	Change
The symptoms of my breast cancer are puzzling to me	The symptoms of my breast cancer were puzzling to me
My breast cancer is a mystery to me	My breast cancer was a mystery to me
I don't understand my breast cancer	I did not understand my breast cancer
My breast cancer doesn't make any sense to me	My breast cancer did not make any sense to me
I have a clear picture or understanding of my breast cancer	I had a clear picture or understanding of my breast cancer

Timeline (cyclical)

Original Item	Change
The symptoms of my breast cancer change a great deal from day to day	The symptoms of my breast cancer changed a great deal from day to day
My symptoms come and go in cycles	The symptoms of my breast cancer came and went in cycles
My breast cancer is very unpredictable	My breast cancer was very unpredictable
I go through cycles in which my breast cancer gets better and worse.	I went through cycles in which my breast cancer got better and worse

Emotional Representations

Original Item	Change
I get depressed when I think about my breast cancer	At the time, I got depressed when I thought about my breast cancer
When I think about my breast cancer I get upset	At the time, when I thought about my breast cancer I got upset
My breast cancer makes me feel angry	At the time, my breast cancer made me feel angry
My breast cancer does not worry me	At the time, my breast cancer did not worry me
Having breast cancer makes me feel anxious	At the time, having breast cancer made me feel anxious
My breast cancer makes me feel afraid	At the time, thinking about my breast cancer made me feel afraid

Appendix F - Data Cleaning

- Participant 103 answered 'other – separated' for Q5 and this was re-coded as 'divorced'.
- Participant 112 answered 'other – living with companion' for Q5 and this was re-coded as 'in a relationship'.
- For Q7 due to the answers that were given under the category 'other' two new categories were created: carer and home parent.
- Participant 7 responded with 'other – not working since breast cancer' for Q7 and this was re-coded as 'unemployed'.
- Participant 29 responded with 'other – carer for relative' for Q7 and this was re-coded as 'carer'.
- Participant 35 responded with 'other – carer' for Q7 and this was re-coded as 'carer'.
- Participant 115 responded with 'other – stay at home parent' for Q7 and this was re-coded as 'home parent'.
- Participant 119 responded with 'other – theoretically I have my own business. In reality I am not longer capable of running it' for Q7 and this was re-coded as 'unemployed'.
- Participant 127 responded with 'other – home maker' for Q7 and this was re-coded as 'home parent'.
- Participant 138 responded with 'other – full time carer' for Q7 and this was re-coded as 'carer'.
- Participant 144 responded with 'other – full time student' for Q7 and this was re-coded as 'employed (full-time)'.
- Participant 174 responded with 'other – not working/looking for work' for Q7 and this was re-coded as 'unemployed'.
- Participant 124 responded with '18' for Q9. This was changed for '1'.
- Participant 9 responded with 'less than one year' for Q10 which was changed to '0'.
- Participant 10 responded with '18 months' for Q10 which was changed to '1'.
- Participant 20 responded with '19 months' for Q10 which was changed to '1'.
- Participant 22 responded with 'September 2019' for Q10 which was changed to '1'.
- Participant 24 responded with '20 months ago' for Q10 which was changed to '1'.
- Participant 28 responded with '6 months ago' for Q10 which was changed to '0'.

- Participant 35 responded with '9 months ago' for Q10 which was changed to '0'.
- Participant 39 responded with '5.5' for Q10 which was changed to '5'.
- Participant 44 responded with '2.5' for Q10 which was changed to '2'.
- Participant 75 responded with '2.5' for Q10 which was changed to '2'.
- Participant 76 responded with '15 months ago' for Q10 which was changed to '1'.
- Participant 85 responded with '2013' for Q10 which was changed to '7'.
- Participant 94 responded with 'n/a' for Q10 which was treated as missing data.
- Participant 98 responded with '0' for Q10 and based on answers to other questions this was clearly an error and treated as missing data.
- Participant 119 responded with '5 yes 10 months' for Q10 which was changed to '5'.
- Participant 127 responded with '2019' for Q10 which was changed to '1'.
- Participant 139 responded with 'less than one year' for Q10 which was changed to '0'.
- Participant 143 responded with 'this year' for Q10 which was changed to '0'.
- Participant 163 responded with '1.5' for Q10 which was changed to '1'.
- Participant 165 responded with '11 months ago' for Q10 which was changed to '0'.
- Participant 171 responded with '1.5' for Q10 which was changed to '1'.
- Participant 50 responded with 'other – anastrozole' for Q11 which was changed to 'hormone therapy'.
- Participant 116 responded with 'other – tamoxifen' for Q11 which was changed to 'hormone therapy'.
- Participant 127 responded with 'other – ovaries removed' for Q11 which was changed to 'surgery'.
- For Q12 the 'unsure' column was removed as no participants selected this response.
- Participant 16 responded with 'other – mammoplasty' for Q12 which was re-coded as 'breast reconstruction'.
- Participant 19 responded with 'other – mammoplasty L&R' for Q12 which was re-coded as 'breast reconstruction'.
- Participant 20 responded with 'other – mammoplasty and reduction at later stage' for Q12 which was re-coded as 'breast reconstruction'.
- Participant 44 responded with 'other – Diep' for Q12 which was removed as this data was captured in Q11 by answering 'surgery'.

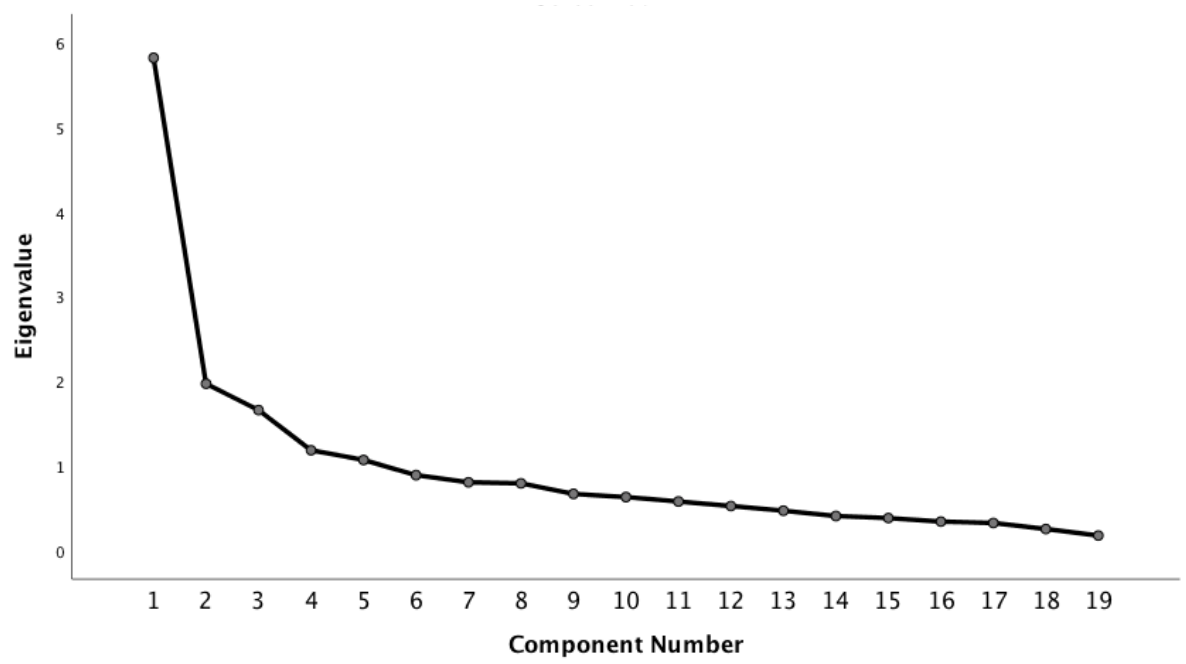
- Participant 52 responded with ‘other – nipple reconstruction and lipofill’ for Q12 which was removed as this data was captured by the participant selecting ‘breast reconstruction’.
- Participant 102 responded with ‘other – therapeutic mammoplasty’ for Q12 which was re-coded as ‘breast reconstruction’.
- Participant 103 responded with ‘other – 4 lumpectomies’ for Q12 which was removed as this data was captured by the participant selecting ‘lumpectomy’.
- Participant 107 responded with ‘other – asymmetry reduction and uplift’ for Q12 which was re-coded as ‘breast reconstruction’.
- Participant 119 responded with ‘other - removal of encapsulation, several revisions, installation of Port-a-Cath’ for Q12 which was removed as this data was captured by the participant selecting ‘breast reconstruction’ for Q12 and ‘surgery’ for Q11.
- Participant 120 responded with ‘other – mammoplasty’ for Q12 which was re-coded as ‘breast reconstruction’.
- Participant 156 responded with ‘other – segmentectomy’ for Q12 which was re-coded as ‘lumpectomy’.
- Responses to the medication relief question for the brief pain inventory were removed as this information was not required for the current study.
- Those who responded ‘no’ to the screening question for the brief pain inventory were automatically given a 0 for their pain severity and interference score.
- Responses to the EQ-5D were removed as this information was not required for the current study.

Appendix G – Factor analysis output

Component matrix (unrotated loadings) of IPQ-R causal items

	Component				
	1	**2**	**3**	**4**	**5**
My mental attitude e.g. thinking about life negatively	.749	.024	-.248	-.009	-.222
Overwork	.715	.122	-.212	.091	.070
My personality	.699	-.383	-.090	-.096	.090
My emotional state e.g. feeling down, lonely, anxious, empty	.687	.193	-.425	-.012	-.223
Altered immunity	.654	-.327	.024	.048	.270
A Germ or virus	.627	-.393	.141	.045	.332
Family problems or worries caused my illness	.623	.127	-.457	.105	-.175
Pollution in the environment	.618	.289	.027	-.120	.062
Poor medical care in my past	.596	-.293	.098	-.002	.308
Accident or injury	.586	-.423	-.022	-.319	-.063
My own behaviour	.576	.380	.353	-.081	-.128
Stress or worry	.535	.313	-.415	.172	.027
Smoking	.524	-.264	.428	-.228	-.173
Alcohol	.468	.269	.530	-.274	-.239
Diet or eating habits	.467	.417	.476	.097	-.052
Hereditary - it runs in my family	.063	-.494	.204	.604	-.141
Ageing	.314	.197	.243	.507	.176
Hormonal influence	.238	.330	.179	.419	.089
Chance or bad luck	-.051	.444	-.060	-.260	.692

Screeplot of IPQ-R causal items



Component correlation matrix for PCA following Five Factor Solution of IPQ-R causal items

Component	1	2	3	4	5
1	1.000	-.363	.297	.113	.078
2	-.363	1.000	-.297	-.056	.172
3	.297	-.297	1.000	.118	.033
4	.113	-.056	.118	1.000	.075
5	.078	.172	.033	.075	1.000

Pattern and structure matrix for PCA with oblimin rotation of Five Factor Solution of IPQ-R causal items

Item	Pattern coefficients					Structure coefficients					Communalities
	1	2	3	4	5	1	2	3	4	5	
My emotional state e.g. feeling down, lonely, anxious, empty	**.855**	.022	.066	-.082	-.050	**.853**	-.311	.301	.018	.017	.739
Family problems or worries caused my illness	**.825**	-.011	-.070	-.002	-.091	**.801**	-.306	.175	.077	-.032	.655
Stress or worry	**.736**	.015	-.106	.176	.120	**.729**	-.210	.133	.255	.189	.587
My mental attitude e.g. thinking about life negatively	**.685**	-.153	.154	-.076	-.150	**.766**	-.468	.389	.017	-.123	.673
Overwork	**.569**	-.275	.045	.131	.076	**.703**	-.489	.314	.222	.085	.584
A Germ or virus	-.047	**-.835**	-.003	.099	.028	.268	**-.817**	.243	.142	-.112	.679
Altered immunity	.110	**-.740**	-.033	.072	.020	.378	**-.770**	.228	.124	-.094	.611
Poor medical care in my past	.007	**-.731**	.022	.068	.083	.293	**-.729**	.252	.118	-.037	.545
My personality	.259	**-.666**	.006	-.150	-.069	.480	**-.765**	.260	-.088	-.174	.661
Accident or injury	.158	**-.559**	.158	-.388	-.110	.356	**-.661**	.322	-.329	-.217	.628
Alcohol	-.056	.026	**.864**	-.027	-.005	.187	-.210	**.836**	.067	.022	.704
My own behaviour	.168	.015	**.682**	.163	.061	.388	-.248	**.749**	.267	.112	.623
Diet or eating habits	.019	.036	**.654**	.378	.045	.246	.179	**.695**	.459	.103	.631
Smoking	-.136	-.399	**.553**	-.163	-.213	.138	-.541	**.605**	-.106	-.285	.609
Pollution in the environment	.348	-.160	**.349**	.061	.222	.534	-.355	**.514**	.167	.237	.484
Ageing	.032	-.134	.086	**.648**	-.039	.176	-.214	.210	**.666**	-.008	.484

Hormonal influence	.110	.059	.135	**.565**	.005	.193	-.051	.217	**.590**	.070	.381
Chance or bad luck	-.145	-.180	-.078	.086	**.879**	-.025	.042	-.028	.136	**.841**	.749
Hereditary - it runs in my family	-.151	-.248	-.195	.395	**-.644**	-.124	-.268	-.141	.320	**-.676**	.675

Appendix H – Descriptive statistics to examine the distribution of the data

	5% trimmed mean	Skewness	Kurtosis
Age	55.04	0.083	0.047
Approximate amount of years since diagnosis	4.98	1.520	2.782
SQRT – Approximate amount of years since diagnosis	2.08	0.369	-0.040
IPQ-R Identity	5.81	-0.001	-0.696
IPQ-R Timeline	17.48	-0.020	-0.269
IPQ-R Consequences	22.57	-0.509	0.040
IPQ-R Personal Control	16.60	-0.069	-0.263
IPQ-R Treatment Control	19.25	-0.395	0.341
IPQ-R Illness Coherence	18.59	-0.548	0.509
IPQ-R Timeline (cyclical)	9.55	0.248	-0.109
IPQ-R Emotional Representations	24.20	-0.828	0.366
IPQ-R Causes - Stress	12.15	0.167	-0.321
IPQ-R Causes – State of Health	8.89	0.581	-0.088
IPQ-R Causes – Lifestyle	11.15	0.342	0.364
IPQ-R Causes - Biology	6.34	-0.230	-0.496
IPQ-R Causes – Factors out of my control	6.34	0.270	0.156
Pain severity	3.61	0.520	-0.349
Pain interference	4.03	0.222	-1.047
EQ-5D VAS score	71.28	-0.886	0.851
Total PHQ-8	7.04	0.925	0.121
Total GAD-7	6.06	0.835	-0.054