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#### AN EXPLORATION OF BREAST CANCER SURVIVORS' LIVED EXPERIENCES OF PHYSICAL ACTIVITY.

LEANNE LIVSEY

A thesis submitted to the University of Huddersfield in partial fulfilment of the requirements for the degree of Doctor of Philosophy

The University of Huddersfield

September 2018

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#### ABSTRACT

Existing literature suggests that numerous factors influence cancer survivors' physical activity (PA) levels, for example receiving specific PA information from health care professionals. Interestingly. research also suggests that health care professionals fail to promote PA to cancer patients due to a variety of reasons. However, qualitative research exploring how these factors impact or influence PA levels amongst cancer survivors and PA promotion amongst health care professionals is sparse. In addition to this, no known research has utilised an interpretative phenomenological approach which includes both breast cancer survivors and breast cancer nurses. This research study utilises an interpretative phenomenological approach to explore breast cancer survivors' lived experiences of physical activity (PA) and breast cancer nurses' perspectives and experiences of promoting PA. By utilising a phenomenological approach and involving both groups, I aim to illuminate the multiple perspectives of PA and understand the meanings of the participants' experiences of either participating in PA or promoting PA.

This research involved two separate phases. During Phase One, I interviewed ten breast cancer survivors individually, using semi-structured interviews; exploring their individual lived experiences of PA. The findings were analysed using interpretative phenomenological analysis (IPA) approach; the aim here was to illuminate the participants' individual experiences and meanings of PA.The themes identified were: 'losing and regaining control of the body', 'experiences and perceptions of support', 'the meaning of PA' and 'the importance of being with *other people who were in the same boat*'.

During Phase Two, I interviewed five breast cancer nurses individually, using semi-structured interviews; exploring their perspectives and experiences of promoting PA. Template analysis was the method chosen to analyse the findings, the main themes identified were: 'Perceived responsibility for promoting PA', 'External services and resources', 'Nurse-survivor relationship' and 'Perceptions of breast cancer survivors' characteristics'.

In Phase One: Varied experiences and meanings of PA amongst the breast cancer survivors are illuminated; however, it appeared that they utilised PA as a tool to help make sense of and adapt to their 'new normal'. In Phase Two: Differences amongst the breast cancer nurses with regards to their attitudes and perceptions of their roles and PA promotion were identified; it appeared that these differences caused inconsistencies with PA promotion. The findings from both phases of the research study were synthesised and explored further. The key findings which emerged across the two phases were: utilising PA as a tool to make sense of and adapt to a 'new normal', the importance of relationships and limited PA advice. The key findings illuminate the differences between the breast cancer survivors' and the breast cancer nurses' perceptions and attitudes. For example, the breast cancer survivors' meanings of PA were related to gaining a sense of 'normality' and control over their overall health and well-being. Whereas, the majority of the breast cancer nurses' focused on the medical benefits of PA, rather than focusing on the benefits of PA holistically.

The unique insight into both sample groups, provides a deeper understanding of their experiences and meanings of PA and promoting PA. These findings may support and improve future research and PA promotion within oncology. It is recommended that more research is needed to develop further understanding of this phenomena which a) utilises interpretative phenomenological methods b) includes both sample groups, c) involves diverse sample groups such as; age, ethnicity, job roles etc. Further, it is suggested that specific education and training for breast cancer nurses with regards to their role and responsibility to promote PA, should be available as it may overcome specific issues relating to perception of their roles and PA promotion.

#### **DISSEMINATED FINDINGS**

Publications

Livsey, L. & Lewis, K. (2017). Breast cancer survivors' perceptions of participating in a supervised exercise intervention: An exploratory review of the literature. *Women & Health.* 

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#### 1. Introduction

I was prepared to feel tired, exhausted even, and it did happen. I had read that walking would be good for increasing my energy levels and for boosting my immunity so I started walking every day. Some days I did not feel at all like going out, but I would make myself take at least a few steps. The countryside around me is so beautiful that it made me happy to be there, outside and away from thoughts about treatment. Sometimes I would feel rubbish and say to my husband, 'I don't think I can go that far today.' But as I walked I began to feel as though concrete bricks were falling off my shoulders. Even if we didn't walk far I often felt better. Walking helped me so much both mentally and physically, and doing something like Breast Cancer Care's Pink Ribbon Walk would have been perfect. (Fran, 'Five things that helped me move forward after treatment' Breast cancer care, April 4<sup>th</sup> 2018).

The introductory excerpt above illustrates the lived experience of being physically active after breast cancer treatment. Fran (2018) highlights the difficulties faced when contemplating "going out" and going for a walk. But despite feeling exhausted she made herself go out for a walk every day, she creates the image of escaping her thoughts about treatment, which resulted in a weight being lifted from her shoulders. This short extract of Fran's meaning of her lived experience of physical activity (PA), sets the scene for the thesis and my interests.

#### 1.1 My interest

My passion for and interest in PA and breast cancer survivors began in 2013, during my undergraduate degree. During my final year, I completed assignments and a review of literature for my undergraduate applied research module, which all focused heavily on the health aspects of PA, nutrition and breast cancer . During the summer of 2014, as a volunteer I attended a weekly exercise class for breast cancer survivors at the university, to gain experience working with and alongside breast cancer survivors in an exercise setting. During this time, I began a Level 4 Cancer and Exercise Rehabilitation course, of which I completed and was successfully awarded in January 2015. Since completing my undergraduate degree and gaining my Level 4 exercise qualification, I have continued to deliver the weekly exercise class for breast cancer survivors and deliver talks on PA and exercise for Breast Cancer Care (BCC), which is a UK charity. The discussions that I had with the women who participated in the exercise class, and during the talks for BCC, heightened my interest and desire to gain a deeper understanding of breast cancer survivors' lived experiences of PA. Through these discussions, it became evident to me that some breast cancer survivors felt the need for further guidance and provision for PA after completing adjuvant treatment. My dual role as an exercise instructor and researcher is acknowledged throughout the research process. I discuss and explore in more depth my relationship with the participants and data, and how this influences the different stages of the research within chapter four.

Throughout my undergraduate research and role as a specialist exercise instructor, I became aware of the importance of PA for breast cancer survivors and the surprisingly low levels of PA amongst breast cancer survivors. However, when searching for the literature it became apparent that a high amount of the research used quantitative methods and those, which used qualitative methods, focused heavily on specific exercise interventions. It was evident to me that within the literature, the voices of breast cancer survivors and their lived experiences of PA are under-represented and this is something, which I am passionate about and want to understand in a greater depth. Therefore, this motivated me to undertake this research study, which explored breast cancer survivors lived experiences of PA, to gain understanding and insight into their experiences. With the acknowledgement of the issues and feelings, which arose from previous discussions above, I wondered if and how the information provided from health care professionals (HCP), had affected their experiences of PA. I was particularly interested in the views and perceptions of HCP's, concerning PA and breast cancer survivors.

#### 1.2 Reflexivity

It is important to address the question of reflexivity, as mentioned in the previous section, my role and relationship with the breast cancer survivors, could potentially influence the research process and findings. I questioned myself whether I could 'bracket' my experiences of an exercise instructor and previous knowledge gained throughout this role. On one hand, I believe this is possible to an extent, as I believe that each individual has their own story, which is based on their lived experiences and therefore, it is important to approach the research with an open mind and 'place my presumptions to one side' and document these in an audit trail. This ensures that the individual has the opportunity to provide their personal account of their experiences freely. On the other hand, I think that it is impossible to 'bracket' out or remove oneself completely from our previous experiences and knowledge; as these are embedded into how we make sense of the world. However, it is important as a researcher, to be aware of one's preunderstandings and how these may influence the research process; therefore, these should be made transparent throughout by engaging in 'researcher reflexivity' (Finlay, 2009, p. 13). To do this I have kept a reflexive journal throughout my research journey and documented my feelings and experiences, which I think may have affected the data collection and analysis process. Throughout the thesis I will be using extracts from the reflexive journal, to provide examples of when my preunderstandings and experiences may have impacted the research.

#### 1.3 Background

Breast cancer is the most common cancer in females; approximately 45, 656 females were diagnosed with new cases of invasive breast cancer in 2016 (Office for National Statistics, 2018) and an estimated 1.67 million newly diagnosed cases worldwide in 2012 (Ferlay J et al., 2013). In 2015, one-year survival for women; aged 15-99 years with breast cancer, was approximately 96.7% in England (Statistics & England, 2017). According to Cancer Research UK (n.d.) breast cancer survival rates have almost doubled in the last forty years, from 40% to 78% (Cancer Research UK, n.d.). The increase in survival 17

rates are acknowledged as a trend across most developed countries and it is suggested that these trends are a result of earlier detection, diagnosis and advances in treatment (Allemani et al., 2015).

Although breast cancer survival rates are increasing, there are still common adverse side effects of treatment such as: breast cancer related fatigue, chronic pain, impaired physical function, changes in physical appearance, comorbidities and therefore, impact health related quality of life (HRQoL) and mortality (Casla et al., 2015; Cramer et al., 2017; Schmitz, DiSipio, Gordon, & Hayes, 2015). PA has been demonstrated as an effective and safe strategy to alleviate many of the side effects; it is recommended that women after adjuvant treatment participate in regular PA to improve their HRQoL (Lahart, Metsios, Nevill, & Carmichael, 2018). Despite these beneficial effects of engaging in regular PA, research indicates that many cancer survivors do not meet the current PA recommendations and appear to engage in more sedentary behaviours such as sitting (Casla et al., 2015; Phillips et al., 2015; Pinto, Dunsiger, & Stein, 2017). Qualitative literature exploring breast cancer survivors' lived experiences of PA is scarce, therefore to increase further understanding of what PA is like for breast cancer survivors further research is important. Thus, providing the rationale for this thesis. This will be explored in more depth within chapter two.

I am going to introduce this chapter by describing my interest in the phenomenon under investigation and my reflections as the researcher. I will then discuss the definitions of breast cancer survivors and PA and state which definitions I will use in this thesis. I will discuss areas around these concepts and provide an outline of the thesis structure.

#### 1.4 Definitions of cancer survivors

The term 'cancer survivor' is used extensively across many individuals and disciplines such as clinical and academic settings, as the definition of the term remains open to debate (Mayer, Nasso, & Earp, 2017). 'Cancer survivorship' is a term which is frequently used interchangeably with the term 'cancer survivor' and overlap between the terms often occur (Hebdon, Foli, & McComb, 2015). There appears to be no universally accepted definition for what is a 'cancer survivor' and the widespread use of the term amongst different populations has caused problems for policy makers and people who are affected by cancer (Nada F. Khan, Rose, & Evans, 2012). The various definitions associated with the terms 'cancer survivor' and outcomes (Nada F. Khan et al., 2012; Marzorati, Riva, & Pravettoni, 2017).

Fitzhugh Mullen, a physician who survived cancer himself (Mullan, 1985), first articulated the term 'cancer survivor' in 1985, when he wrote an article which was a reflection of his cancer experience. Mullen believed that the concept of "cure" did not capture the whole cancer experience and therefore, he proposed that the concept of 'survival' was more appropriate (N. F. Khan, Harrison, Rose, Ward, & Evans, 2012). In his article, Mullen also proposed the "stages of survival" which involved three stages: acute, extended and permanent. The different stages of survival are defined as: the acute stage reflects

the beginning stage of cancer, which is the diagnosis and treatment, the extended stage, reflects the phase after the end of treatment, when the patient is in remission, and the permanent stage is defined as being roughly equated to cure (Mullen, 1985). According to the Department of health (2010), the term 'cancer survivorship' has different definitions. However, within The National Cancer Survivorship Initiative [NCSI] Vision document, 'survivorship' is defined as "those who are undergoing primary treatment, those who are in remission following treatment, those who are undergoing primary treatment, those who are in remission following treatment, those who are cured and those with active or advanced disease" (Department of Health, Macmillan Cancer Support, & NHS Improvement, 2010, p. 21). Similarly, the National Cancer Institute [NCI] defines the term 'survivor' within a cancer context as "a person is considered to be a survivor from the time of diagnosis until the end of life" (National Cancer Institute, 1996-2014). Whereas, the NCI defines the term 'survivorship' within a cancer context as "survivorship focuses on the health and life of a person with cancer post treatment until the end of life" (National Cancer Institute, 1996-2014b). Additionally, individuals who have lived more than 3-5 years from diagnosis, or end of treatment, without evidence of disease, are defined as cancer survivors (Surbone, Annunziata, Santoro, Tirelli, & Tralongo, 2013).

For the purpose of this thesis the definition which will be used is: "a person is considered to be a survivor from the time of diagnosis until the end of life" (National Cancer Institute, 1996-2014). This term is commonly used and accepted in the cancer field, despite the ongoing debates, as it covers all aspects of the cancer trajectory. Regardless of which definition is most appropriate for this thesis, experiences of cancer vary from person to person and interpretations of the term are very subjective (Nada F. Khan et al., 2012). Therefore, the focus is not on which definition fits all or defines the participants within the current study, rather which term can be best applied as an umbrella term for the phenomena under investigation.

#### 1.5 Breast cancer and treatment

Breast cancer begins when cells in the breast become abnormal; the cells begin to divide and make more abnormal cells, these form a lump which is known as a tumour (Breast cancer care, n.d.-b; Macmillan Cancer Support, 2017). There are different types of breast cancer, which are often split into two categories: non-invasive and invasive breast cancer. Non-invasive breast cancer (ductal carcinoma in situ, DCIS) this is the earliest form of breast cancer and the cells have not spread outside the breast (Breast cancer care, n.d.-b). The second type being invasive breast cancer, this is when the cells start in the ducts or lobes and spread into the surrounding breast tissue (Macmillan Cancer Support, 2016b). Invasive ductal breast cancer (of no special type, NST), is the most common type of breast cancer; the cancer cells start in the ducts of the breast and spread into the breast tissue. This type can spread outside the breast cancer care, n.d.-b; NHS, 2016). Invasive lobular breast cancer, is the second most common type of breast cancer care, n.d.-b; NHS, 2016). Invasive lobular breast cancer, is the second most common type of breast cancer care, n.d.-b; NHS, 2016). Invasive lobular breast cancer, is the second most common type of breast cancer care, n.d.-b; NHS, 2016). Invasive lobular breast cancer, is the second most common type of breast cancer care, n.d.-b; NHS, 2016). Invasive lobular breast cancer, is the second most common type of breast cancer care, n.d.-b; NHS, 2016). Invasive lobular breast cancer which are known as a "special type" or

uncommon, these include: Inflammatory breast cancer and Paget's disease of the breast (Macmillan Cancer Support, 2016b).

The main treatments for breast cancer include: surgery, radiotherapy, chemotherapy, hormone therapy and targeted therapy. Factors such as; the stage, grade and type of breast cancer affects the decision about which treatment is most appropriate for the individual (Cancer Research UK, 2017a). For the majority of women, they usually begin their treatment for breast cancer with surgery. The different types of surgery are: lumpectomy or a wide local excision, which involves removing the cancer and some surrounding breast tissue. The other type is a mastectomy, which involves removal of the whole breast. The option to have a breast reconstruction at the same time as a mastectomy, or at a later time is available (Cancer Research UK, 2017a). Additional treatments are usually combined with surgery, these are known as adjuvant treatment and they may include: radiotherapy, chemotherapy, hormone therapy and targeted therapy.

#### 1.6 Breast cancer treatment side effects

According to Breast cancer care (n.d.-b), different types of treatment can cause both temporary and long term side effects. After breast surgery, many people experience pain and stiffness around the area of the operation. Other side effects are bruising, burning like sensation and numbness, these usually last for several weeks but for some the pain can last longer. Radiotherapy causes immediate side effects such as: skin reactions, swelling, pain, tiredness and fatigue, and lymphoedema. These can occur during treatment and up to six months after the completion of treatment. Chemotherapy can affect people in very different ways, however some of the most common side effects are: increased risk of infection, hair loss, nausea, fatigue, weight gain, changes to the menstrual cycle, anaemia and osteoporosis. The most common side effects of hormone therapy are: hot flushes, night sweats, joint pain and stiffness, nausea, mood changes, fatigue and osteoporosis. The common side effect of targeted therapy for breast cancer are: headache, fever and feeling sick. These are almost instant while receiving the therapy, or up to four hours after (Breast cancer care, n.d.-c; Macmillan Cancer Support, 2016a).

#### 1.7 PA and breast cancer

There has been a large amount of research examining the benefits of PA amongst cancer survivors. For the purpose of this thesis I will provide a summary of the findings from research, which involved breast cancer survivors.

A pilot study by Reis et al. (2018), evaluated the effects of a twelve week combined exercise programme on breast cancer patients, who were undergoing breast cancer treatment. The programme consisted of three sessions per week of aerobic, resistance and flexibility exercises. 28 participants completed the study, they were split into a control group and an exercise group. Findings from this study showed that 20 those who participated in the exercise programme, had a significant reduction in pain intensity and how pain interfered with the participant's life, compared to those who were in the control group. Additionally, those in the exercise group showed significant improvements in maximum oxygen uptake, flexibility and static strength, compared to those who were in the control group (Reis et al., 2018). A cross sectional study, which included 231 participants with stages 1-3 breast cancer, found breast cancer survivors who reported higher levels of PA, reported lower levels of fatigue and pain, compared to those who reported lower levels of PA (Shin et al., 2017). PA was assessed using a questionnaire, which involved the type, duration and frequency, a metabolic equivalent (MET) value was given to each activity reported (Shin et al., 2017). A review which accessed the effects of PA interventions for women, who have completed adjuvant treatment for breast cancer, reported that PA interventions have beneficial effects (Lahart, Metsios, Nevill, & Carmichael, 2018). This review reported improvements from baseline to the end of interventions scores in: health related quality of life (HRQoL), emotional function, perceived physical function, anxiety and cardiorespiratory fitness. Whereas, smaller improvements in: cardiorespiratory fitness, fatigue and self-reported PA were sustained for three months or more post intervention. Similarly, a review concluded that exercise interventions are effective at alleviating breast cancer treatment side effects such as; fatigue, depression and anxiety, improving physical abilities and fitness, improving HRQoL and improving body image (Palesh et al., 2018).

Research has paid particular attention to the relationship between PA and all-cause mortality and cancer specific mortality. However, there appears to be debate regarding the effect of PA on all-cause and breast cancer related mortality, with relation to; disease stage, oestrogen receptor status, body mass index, and the duration, type and intensity of activity (K. S. Courneya et al., 2014; Li et al., 2016). A recent meta-analysis reported a correlation between PA and cancer mortality. Those who participated in higher levels of PA, reduced the risk of cancer mortality (Li et al., 2016). Findings from Li et al. (2016), are consistent with the findings from other research (Veal et al., 2017; Zhong et al., 2014). Zhong et al. (2014), found associations with PA levels both pre-diagnosis and post-diagnosis and breast cancer specific and all-cause mortality. The review concluded that those who had higher PA levels, had a decreased risk of breast cancer-specific and all-cause mortality. Similarly, a prospective observational study found that women who participated in at least 150 minutes of moderate intensity activity per week, a year before their diagnosis decreased their risk of death by 31% compared with those who were inactive. Whereas, those who participated in at least 150 minutes of moderate intensity activity per week, during the second year of diagnosis, decreased their risk of death by 67% compared with those who were inactive (Melinda L Irwin et al., 2008). Whereas, a Norwegian study had conflicting findings to those from Zhong et al. (2014), conclusions from the study indicated that PA levels pre-diagnosis were not associated with all-cause or breast cancer specific mortality (Borch, Braaten, Lund, & Weiderpass, 2015). Additionally, a review conducted by Brenner, Neilson, Courneya and Friedenreich (2014), summarised that PA during breast cancer treatment has not been reported to have a significant association with survival, in observational studies particularly. However, Brenner et al. (2014), reviewed a study which showed that resistance training during chemotherapy treatment led to improvements in the participant's adherence to chemotherapy (K. S. Courneya et al., 2014). They suggested that the 21

improvements in treatment adherence may cause survival and recurrence benefits (Brenner, Neilson, Courneya, & Friedenreich, 2014).

A study, which reviewed the findings from lifestyle intervention studies, which examined the effects of certain lifestyle factors on breast cancer recurrence and mortality, reports that the relationship between exercise and breast cancer recurrence is under speculation, however clinical evidence is lacking (Dieli-Conwright, Lee, & Kiwata, 2016). They concluded that regular exercise may have beneficial effects on breast cancer recurrence, due to the benefits on health outcomes, which are biologically connected to recurrence. A review conducted in 2012 (Loprinzi, Cardinal, Winters-Stone, Smit, & Loprinzi, 2012), involved two studies which investigated the relationship between PA and breast cancer recurrence. Loprinzi et al. (2012), stated that both of these studies reported a non-significant effect between PA levels and breast cancer recurrence risk. Similarly, findings from another study showed that PA did not have a significant influence on the risk of breast cancer recurrence (Sternfeld et al., 2009).

#### 1.8 Defining PA

According to the World Health Organization ([WHO], 2018), PA is defined as "any bodily movement produced by skeletal muscles that requires energy expenditure". There are different terms which are associated with PA such as exercise and fitness; subsequently, these terms are often misused or used interchangeably (Caspersen, Powell, & Christenson, 1985). Exercise is described as a subset of PA, which is planned and structured, with the aim to improve physical fitness (World Health Organization, 2018). Whereas, Casperson et al. (1985, p.126) defines fitness as "a set of attributes that are either health or skill related". Most research which explores breast cancer survivors' experiences of PA generally focuses on their experiences of participating in a specific exercise intervention, usually as part of a randomised controlled trial. However, the focus of my research is on PA. Specifically, my focus is on <u>self-initiated</u> PA, which for the purpose of this thesis refers to <u>any type of PA which is initiated by the individual</u>, rather than a programme into which an individual is routinely enrolled as part of treatment or through a research trial. For brevity, this will be shortened to 'PA' throughout the thesis. When using extracts from the participants' transcripts, I will use the term which they use to describe PA, to ensure that I capture the language and true meaning of their experience.

#### **1.9 PA guidelines**

The current PA guidelines recommends adults 19-64 and older people to; participate in at least 150 minutes of moderate to vigorous intensity aerobic activity, or 75 minutes of vigorous aerobic activity each week, and at least two days of strength based exercises a week (Bull, 2010; NHS, 2015). Adults are advised to engage in 150 minutes of PA, in bouts across the week, for example; at least 30 minutes on five days or more (Bull, 2010). There are no specific guidelines for PA after cancer, it is recommended that people living with and after cancer avoid inactivity and build up to the general population guidelines of at least 150 minutes per week (Cancer Research UK, 2015; K.S Courneya, 22

2017; Stevinson, Campbell, Cavill, & Foster, 2017). However, it has been reported that up to 70% of breast cancer survivors are not meeting the American College of Sports Medicine (ACSM) guidelines for people living with cancer (M. L. Irwin, 2009; Pullen et al., 2018). These guidelines recommend that people living with cancer undertake 150 minutes of moderate intensity of aerobic exercises per week and 20-30 minutes of moderate intensity strength based exercises at least twice a week (Palesh et al., 2018)

#### 1.10 Current study

This research study utilises an interpretative phenomenological approach to explore the lived experiences of PA and the experiences of PA promotion. This thesis involves two phases:

#### Phase One

Aims to explore breast cancer survivors' lived experiences of PA; interpretative phenomenological analysis was the method of analysis chosen to interpret and illuminate the findings.

#### Phase Two

Aims to explore breast cancer nurses' perspectives and experiences of promoting PA; template analysis was the method of analysis chosen.

#### 1.11 The thesis structure

This thesis is structured into ten chapters:

Chapter two contains a review of existing literature, related to PA amongst cancer survivors. The first section draws upon literature examining factors which may influence cancer survivors' adherence to and participation in exercise interventions and self-initiated PA. The second section focuses on the qualitative literature exploring breast cancer survivors' experiences of PA. This chapter concludes with a rationale for research thesis to be undertaken.

Chapter three involves a description of my own epistemological and ontological assumptions and how my philosophical assumptions informed the choice and development of the methodology used for this research. I then describe some phenomenological approaches and provide a justification for using an interpretive phenomenological approach.

Chapter four contains the methods utilised for Phase One of the research. I present the aims of this phase of the research and provide details of the design and methods utilised. I conclude the chapter with ethical considerations and some personal reflections regarding my position as a researcher.

Chapter five contains the findings from Phase One of the research. Written descriptions of my interpretations and quotes from the participants are presented to illuminate the findings.

Chapter six contains a discussion of the research findings from this current study and findings from existing research and theory. Similarities and differences amongst the findings are explored and discussed. I conclude with a discussion of the strengths and limitations and a personal reflection of Phase One of the research.

Chapter seven describes the methods and sample used for Phase Two of the research. I present the aims of this phase of the research and I provide a rationale for choosing an alternative method of analysis. I detail the methods and procedures of this phase and reflect upon the challenges faced.

Chapter eight contains the findings from Phase Two of the research. Written descriptions of my interpretations and quotes from the participants are presented to illuminate the findings.

Chapter nine, I discuss the main findings from Phase Two and compare them to findings from existing literature. I discuss the strengths and limitations of this phase of my research. Finally, reflect on my experience of utilising template analysis (TA) throughout the analysis stage.

Chapter ten, concludes with an integrate discussion of the key findings from both phases of the research study, to illuminate the overall meaning of the phenomenon. This includes comparisons to existing literature. I discuss the quality of the study and the implications of these findings. I will also consider the strengths and limitations of this research, and provide some suggested recommendations for future research and practice.

#### 2. Literature review

In this chapter I will discuss existing literature around the influential factors of PA amongst cancer survivors. This chapter will explore and discuss the literature from a variety of methodological approaches and perspectives, to gain a holistic understanding of the phenomenon and to identify gaps in the literature. The purpose of this literature review to obtain a broad understanding of the existing literature which has been conducted on this phenomenon. The literature included in this literature review, will be viewed and critiqued through an interpretivist lens, as my epistemological and ontological position underpins how I view the existing literature, make sense of it and therefore, interpret it. Consequently, I argue against critically appraising the quality of the studies included in the review and limiting the studies included with regards to the methods used. For the purpose of this review, both quantitative and qualitative studies are included and a critical discussion, in relation to whether they can be applied and used to understand this phenomenon will be provided throughout.

#### 2.1 Literature review structure

The first section will discuss the literature examining factors which may influence cancer survivors' adherence and participation to exercise interventions and self-initiated PA. The second section will discuss the qualitative literature exploring breast cancer survivors' experiences of PA. The third section focuses on exploring literature which examines health care professionals' PA promotion behaviour. For the final section of this chapter, I will provide a clear rationale for the current research and methodological approach undertaken within this thesis. However, throughout this chapter I will argue the rationale for the need to explore the meanings of PA, to obtain a deeper understanding of people's experiences of PA and promoting PA. Therefore, I will argue that utilising an interpretative phenomenological approach is valuable to the contribution of existing research and knowledge in this field.

# 2.2. Quantitative systematic reviews; investigating the determinants and predictors of exercise adherence to exercise interventions among multiple cancer populations.

There have been numerous systematic reviews, which have investigated the determinants and predictors of exercise adherence to exercise interventions among multiple cancer populations. The terms 'exercise' and 'adherence' here are used in conjunction to the terms used within the reviews. Exercise, is relating to supervised and structured exercise which is the exercise intervention used in the research studies included in the reviews. Whereas, adherence is defined as "the degree of attendance or completion of prescribed exercise sessions" (Kampshoff et al., 2014, p. 2). The purpose of the considered systematic reviews overviewed in this section is to summarise the findings from existing quantitative research (mainly randomised controlled trials), which examined predictors and 25

determinants of exercise intervention adherence and maintenance. The reason for including and discussing systematic reviews which focus on factors influencing exercise adherence, is to provide a broad overview of the existing literature which focuses on exercise and PA behaviour in people affected by cancer. The findings from these reviews will underpin a critical discussion regarding quantitative research findings, in relation to whether they can be applied and used to understand this phenomenon. Further, the need for qualitative methods will be highlighted, with a specific focus on phenomenology in order to gain a deeper understanding and insight into the lived experiences of PA.

Findings from the systematic reviews (Husebø, Dyrstad, Søreide, & Bru, 2013; Kampshoff et al., 2014; Ormel et al., 2018) concluded that one's PA history before cancer diagnosis is an important factor, which influences PA behaviour during and after treatment. All three of the reviews report that PA/exercise history is a "strong predictor" of adherence and maintenance to exercise interventions. Husebø et al. (2013), specifically examined behavioural and motivational predictors of exercise intervention adherence, they stated that exercise stage of change, intention and perceived behavioural control were statistically significant predictors of exercise intervention adherence. Husebø et al. (2013) suggested that, those that those who were active before diagnosis, are more likely to have a positive attitude towards PA and therefore more likely to maintain PA. Additionally, exercise was described as a habitual behaviour for those who were regularly active for a prolonged period before diagnosis (Husebø et al., 2013), thus highlighting that exercise is a habit to those who were regularly active. Further suggesting that, they are more likely to maintain or adhere to exercise during and after treatment, compared to those who were not previously active before their diagnosis. However, Husebø et al. (2013) highlights contrasting findings amongst studies and they reported that, having a cancer diagnosis may lead to people changing specific behaviours such as increasing their PA levels. This highlights the importance of the need to explore individual lived experiences and meanings of PA to obtain more understanding of what may influence one's PA levels and why, at a deeper level. Rather than just identifying possible factors which may influence PA.

Ormel et al. (2018) reported, other factors which were identified as possible factors which influence exercise intervention adherence and maintenance such as: cancer stages and treatment, motivation, self-efficacy, support, location of the exercise intervention and feedback from the exercise instructors. Ormel et al. (2018) discusses how there are a variety of factors which influence adherence to exercise such as: side effects of treatments, self-efficacy, social support and physical fitness etc. and these are dependent upon different factors such as stages of cancer, type of cancer and treatments. Therefore, highlighting, that PA behaviour amongst people affected by cancer is a complex phenomenon and to attempt to understand this phenomenon, I argue the need for a deeper exploration of individual's experiences and personal meaning of IPA, to gain a deeper understanding of this. Furthermore, Kampshoff et al. (2014) disagrees with the findings from Ormel et al. (2018) and Huesbø et al. (2013), as they state that there was insufficient evidence of an association between exercise adherence and factors, for example; self-efficacy, perceived behavioural control, stage of change, cancer type, physical fitness and location of the exercise intervention. Kampshoff et al. (2014) reported that the inconsistency 26

of findings across the studies included in the review was the main reason for the insufficient evidence of these factors. Kampshoff et al. (2014) used a best-evidence synthesis to rate the quality/evidence of the findings from the included studies and to draw conclusions from them. Therefore, they determined factors as either strong, moderate or insufficient evidence based on whether these factors where at least 75% consistent across the studies included in the review (Kampshoff et al., 2014). As Ormel et al. (2018) stated, this method of synthesis is not appropriate as there are a variety of characteristics with regards to individual studies and the heterogeneity of the study sample, for example the exercise intervention and sample demographics. Again, this emphasises the complexity of this phenomenon and highlights problems with regard to the methods used within systematic reviews which are typically linked to trial designs and their focus on efficacy outcomes rather than understanding processes. It is possible that certain factors will be disregarded or excluded, if they do not consistently appear across the studies included in the review, despite being reported as an influencing factor by some studies. This highlights the objective nature of the reviews and primary aim to simply identify factors which influence PA behaviour amongst this population, rather than attempting to understand the meaning of these factors on a subjective level (Weed, 2005). From an interpretivist position, the concept of generalisability is another concern; as generalisability is one of the main purposes of quantitative research. However, as an interpretivist and due to the complexity of the phenomenon, I believe that simply identifying a general pattern amongst the findings and across the studies means that certain issues are not explored. For example, why a specific intervention might or might not work for an individual. In addition to this, it could be suggested that the understanding of how the specific factors identified, specifically impact or influence PA adherence and maintenance is limited.

## 2.2.1 A discussion of the findings between quantitative systematic reviews and mixed methods reviews, which investigate factors which influence cancer survivors PA behaviour.

The reviews discussed above included quantitative studies only, although this is considered to be gold standard research; it is important to review findings from experiential research from multiple perspectives, to provider a deeper understanding of experiences of PA and the meaning of these experiences amongst cancer survivors (Popay, Rogers, & Williams, 1998). Therefore, below I will discuss reviews which included qualitative studies exploring cancer survivors' experiences of barriers to and motivators of PA. I will provide a discussion of the findings between the systematic reviews which are discussed above and the findings from qualitative research.

Clifford et al. (2018) reviewed, qualitative, quantitative and mixed methods research which examined the barriers, facilitators and preferences for exercise amongst cancer survivors, who had completed treatment. The studies included in the review involved both cancer survivors' experiences of participating in an exercise intervention and cancer survivors' experiences of self-initiated PA (no exercise intervention). This contrasts with the systematic reviews discussed above. Clifford et al (2018), acknowledged that across both quantitative and qualitative studies the barriers and facilitators were

consistent, and the most commonly reported barriers to exercise were: treatments related side effects, lack of time and fatigue. Lack of knowledge and information from health care professionals, regarding the intensity and type of exercise were also reported as significant barriers to initiating and maintaining exercise. This finding is supported by Ormel et al. (2018), they identified a similar finding which stated that personalised feedback from the exercise professionals, who facilitated the exercise interventions motivated patients and influenced their adherence to the exercise programme. Although the studies included in both of the reviews differed, with regards to their context and objectives such as: the studies including in Ormel et al's (2018) systematic review examined exercise intervention adherence, whereas those in Clifford et al.'s (2018) review examined barriers and facilitators of self-initiated PA, the importance of health care professionals and gaining knowledge to initiate safe exercise are highlighted within both reviews. The emergence of this finding within both of the reviews despite the different contexts of the included studies, further emphasises the importance of receiving information with regards to exercise from health care professionals and the knowledge gained to initiate or maintain safe PA within this population. However, additional research is needed to obtain more knowledge and understanding more specifically of; how does receiving information influences PA behaviour, what types of information is needed and when is it best to give PA advice/information. Again, this highlights the need for more qualitative based studies to explore this in more depth.

Similar findings emerged from two reviews, which synthesise findings from studies which identified influencing factors such as: barriers and motivators of PA within breast cancer survivors (Browall, Mijwel, Rundqvist, & Wengström, 2018) and lung cancer survivors (Granger et al., 2017). The importance of exercise advice received from health care professionals is highlighted within other reviews which focus on a specific cancer type. Other factors were identified as influential factors across both reviews, for example: physical limitations/side effects of cancer and treatment, low motivation, social benefits, perceived health benefits and physical improvements, and structured exercise led by a skilled instructor. Therefore, implying that influential factors affecting PA adherence and participation are similar amongst different cancer types.

### 2.2.2 Qualitative research studies exploring cancer survivors' experiences of barriers and facilitators to self-reported physical activity

A descriptive study exploring cancer survivors' experiences of barriers and facilitators to self-reported PA (Cummins et al., 2017), conducted 24 individual semi-structured interviews with individuals following a cancer diagnosis. The cancer type and time since diagnosis varied amongst the participants, the majority of the participants were diagnosed with breast cancer (8), were 1-2 years or >3-4 years post diagnosis and the mean age was 58. Five themes were identified: you're on your own, dis-ease, becoming acclimatised, the importance of others and the meanings people ascribe to PA. Participants talked about feeling abandoned and isolated following the completion of their treatments, and reported how the lack of information and advice from health care professionals hindered them to return to 'normal' daily activities. In particular, PA advice was sparse and those who recalled receiving advice

described it as 'generic'. Consequences of cancer and treatment such as fatigue and physical limitations were highlighted as a hindrance to PA. Many of the participants appeared to feel conscious about their altered bodies in a sense of physical abilities and appearance; this led to feelings of embarrassment and uncertainty about their physical capabilities. Others mentioned how they have adapted their everyday activities around their side effects of cancer treatments and physical abilities. Physical changes and lack of specific PA advice from health care professionals, led to feelings of fear and uncertainty about what is safe and effective and acted as a barrier to participation in PA, therefore the importance of others to offer guidance and support was acknowledged. Benefits of PA such as: aiding recovery from cancer and treatment, regaining physical abilities to return to normal and to prevent the risk of recurrence were acknowledged as motivators to PA. The findings from Cummins et al. (2017), offered a different perspective from the previous studies discussed above, as they explored the lived experiences of barriers and facilitators of self-reported PA, rather than factors which influenced exercise intervention adherence. Additionally, the methodological approach utilised by Cummins et al. (2017) aims to describe the barriers and facilitators identified and the meanings of PA. This helps to further understand how these factors identified interact with and impact upon one's PA behaviour during and after cancer treatment.

Findings from Smith et al. (2017), reflected those of Cummins et al. (2017) suggesting that information from health care professionals, side effects of treatment, health benefits of PA such as aiding recovery from cancer and reducing the risk of recurrence, social support and structure exercise were all important factors which influence cancer survivors' participation in PA. Again, the majority of participants in the study (L. Smith et al., 2017) were diagnosed with breast cancer, were <5 years post diagnosis, and the mean age was 58. Despite both of these studies (Cummins et al., 2017; L. Smith et al., 2017) exploring cancer survivors' experience of self-initiated PA, as opposed to exploring the experiences of participation in an exercise intervention, their findings highlight similar findings to Ormel et al. (2018).

## 2.3 Qualitative research exploring breast cancer survivors' experiences of physical activity

Firstly, I will discuss the existing reviews which included studies exploring women's experiences of PA after breast cancer diagnosis. I will then discuss a number of individual studies from the reviews, to provide a richer discussion of the current literature with regards to: the methods used, participant characteristics and the criticality of the studies. Additionally, this will provide further justification for the methodological approach used in this thesis.

According to Midtgaard et al. (2015), the meta-synthesis of qualitative research which they conducted, was the first review "to draw together qualitative research on the experiences of cancer survivors participating in exercise-based rehabilitation" (Midtgaard et al., 2015). Their review included 19 studies which included: mixed cancer types, different stages during treatment and different exercise 29

interventions. However, they reported that the majority of the participants were women and the interventions were mostly group based. Three themes were identified from across the included studies: Emergence of continuity, which is described as the exercise intervention provided the cancer survivors with a purpose and something to look forward to; the second theme is preservation of normality, this includes the physical and social benefits of participating in an exercise intervention; the third theme is reclaiming the body, is describes as physical recovery and enhanced performance due to participation in exercise, having a professional instructor and exercising with other cancer survivors increased their confidence and motivation to exercise. It is important to note the similarity of findings between this review and other systematic reviews as discussed above, and therefore, demonstrating the most influential factors of participation in exercise interventions and self-initiated PA. Accordingly, it is equally important to note how the exploration of the experiences of participation in exercise interventions, provides more opportunity to understand the meaning of these experiences.

Similarly, an integrative review conducted by Browall et al. (2018), included 17 qualitative studies exploring PA experiences of women with breast cancer, during or after adjuvant treatment, including supervised and unsupervised physical activities (Browall et al., 2018). Thematic analysis was used to analyse the data, in pairs the authors developed codes, these were then discussed together by the pairs, and the codes were grouped to develop themes. The themes identified are: benefits from PA during treatment, benefits from PA activity after treatment, facilitators and barriers to participating in PA. When comparing the reported findings between those who participating in a supervised exercise intervention and those in an unsupervised intervention; all reported increased wellbeing and improved health as benefits of PA. Whereas, those in the supervised exercise interventions reported other benefits of PA such as: having a skilled instructor, exercise with women who have similar experiences, feeling 'normal' and having control over cancer. Additionally, there are some similarities and differences amongst the reported barriers between the groups such as; treatment related side effects, lack of support from friends and family, lack of information from health care professionals and time/other responsibilities were reported in both groups. Changes in physical appearance and the desire to participate in PA within a cancer specific supervised environment were expressed by those who participated in unsupervised exercise. The slight variation of the reported barriers and facilitators amongst the two groups, allows for a deeper understanding of the experiences of PA participation within different PA environments. These findings from Browall et al. (2018), reflect those from a similar review (Livsey & Lewis, 2017), which was limited to breast cancer survivors post treatment and their experiences of participating in a supervised exercise intervention (see Appendix 1). Although, there are differences in the participant sample and PA context, findings appeared to be very similar for example, the four themes identified most prominently across the studies were: control, transitioning phase, social support and safe environment. Participating in an exercise intervention led to: feeling in control over their health and physical wellbeing, side effects of treatment and their chances of cancer recurrence; the opportunity to exercise provided them with a focus away from breast cancer; the transitioning phase involved 'moving forwards' from cancer and their treatment and regaining 'normality', through rediscovering their sense of self and confidence; having the opportunity to share similar experiences 30

and understandings with other women who have had breast cancer was acknowledged as a facilitator of adherence to the exercise intervention and exercising in a breast cancer specific environment, which is supervised by a professional, led to feeling safe and comfortable. The importance of engaging in PA activity within a group based, cancer specific setting, with supervision of a professional; appears to be a very important facilitator. This has been acknowledged across other studies, with particular value for female cancer survivors (Emslie et al., 2007; McDonough, 2011). It is important to acknowledge the subjective nature of interpretation, and as a result the interpretations of previous study findings will differ amongst individual researchers and therefore across different reviews exploring qualitative literature. As a result of this, the findings and themes identified across the literature reviews may differ (Popay et al., 1998).

I will now discuss individual qualitative studies which specifically explore breast cancer survivors' experiences of self-initiated PA (no intervention involved). For the purpose of this thesis, I will focus on studies which involve breast cancer survivors who have completed hospital based adjuvant treatment. This is to narrowly explore the literature within this field, to provide a discussion with regards to the methods used within the studies and justify the rationale for the thesis research.

A qualitative study conducted in Canada (Brunet, Taran, Burke, & Sabiston, 2013), explored breast cancer survivors' perceptions of factors which influence their ability to maintain self-initiated PA. Nine women who identified themselves as 'physically active' participated in the study, the majority of the women had completed primary treatment within five years of the study and the mean age was 55 years. Semi-structured interviews were conducted with them women and thematic analysis was used to analyse the data. Two main themes were identified: perceived barriers and perceived motivators. The participant's described experiencing physical limitations, pain and fatigue, as a consequence of their treatment and they explained how these factors disrupted their PA routine. A lack of motivation and confidence in their physical abilities since being diagnosed had also interfered with their physical activities. Whereas, other factors labelled as 'environmental and organisational' factors were identified such as: time, access to facilities, weather, safety issues and lack of knowledge/information. These were described as difficulties when trying to maintain physical activities, uncertainty of what is safe and effective for them since being diagnosed with breast cancer was acknowledged. Maintaining health, managing weight and improving physical fitness were all mentioned as physical motivators to PA. Additionally, experiencing enjoyment and the importance and habit of being physically active motivated the participants to maintain their participation in physical activities. Being physically active provided opportunities such as experiencing social support, feeling good about themselves and maintaining routine, these were acknowledged as additional contributors. It is noteworthy that the barriers identified by these participants are similar to those in other studies, who have taken part in an exercise intervention, highlighting the common influences of PA participation and maintenance amongst breast cancer survivors. The research study provides an alternative perspective in comparison to those discussed above, as the women did not participate in an exercise or health intervention. However, there are some limitations to the study as acknowledged by the researchers and myself. For example, Brunet et al. (2013), reported the women defining themselves as 'physically active' as a limitation to the study and acknowledged that involving women who have varying levels of PA, would have allowed for a greater exploration of factors which affect PA levels from different perspectives. Additionally, the interview guide focused solely on questions regarding motivators and preventative factors, this could be implied as a limitation to the study, as the themes identified almost reflect the topics raised in the interview. Therefore, it could be argued that the data gathered was influenced by the researchers' agenda and did not capture the whole experience, or explore in depth the experiences of PA amongst these women.

A study using a phenomenographic approach explored women's' experiences of PA after treatment for breast cancer (Larsson, Jonsson, Olsson, Gard, & Johansson, 2008). Twelve women aged 31-65 and had completed surgery between 6-24 months, participated in semi- structured individual interviews. Topics surrounding background information about cancer treatment, PA behaviour before and after treatment, how the treatment influenced PA levels, information from health care professionals and how the information influenced PA were explored in the interviews. Larsson et al. (2008), utilised Dahlgren and Fahlsberg's 7 step phenomenographic procedure to analyse the data, the researchers provided information of these steps and how they were followed within the study. Four themes were identified: compliance to instructions and need for support, struggle to get back to normal and fear of negative side-effects, a wish to stay normal and not allow limitations and getting control of the situation with new strategies. The researcher's acknowledged that physical limitations as a result of breast cancer treatment caused disruption with returning to 'normal' activities, due to the women not receiving specific information from health care professionals with regards to implementing PA after treatment, and therefore leading the women to being fearful of causing further problems. The incentives to remaining active include regaining 'normality' and trying to control their health and well-being. Again, commonalities in the challenges breast cancer survivors' face when trying to implement PA after treatment is highlighted here. Although the researcher's provided some details of the steps taken to analyse the data, no information was provided with regards to methods used to ensuring the quality of the research or researcher's reflections of potential study limitations. Therefore, knowledge of the researchers' influence on the data collected and analysed is lacking, thus making it difficult to fully understand the women's experiences of PA within this study. With reference to the phenomenographic approach used, research reflections and acknowledgements of their position as a researcher is vital.

As we can see above, explorative research on cancer survivors' experiences of PA are sparse, specifically experiences of self-initiated PA. Additionally, none of the studies used interpretative phenomenological analysis as a method to collect and analyse the data. This method is valuable in health sciences research to explore individual meanings of these experiences and to gain a deeper understanding of how they impact and interact with one's PA behaviour. Therefore, more research is needed to gain a deeper understanding of the meaning and experiences of PA amongst cancer survivors. This knowledge may help future research and PA implementation, furthermore justifying the rationale for my thesis.

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## 2.4 Health care professionals' perspectives of giving physical activity advice to cancer survivors

As we can see from the literature above, one of the most commonly reported barriers to PA participation is the lack of specific information and guidance from health care professionals. Despite having a desire to increase their PA levels, cancer survivors' fail to implement this, due to a lack of knowledge and confidence of how to implement more PA into their lives, after a cancer diagnosis and treatment (Sander, Wilson, Izzo, Mountford, & Hayes, 2012; Smith-Turchyn, Richardson, Tozer, McNeely, & Thabane, 2016). This demonstrates the instrumental effect of health care professionals, to encourage and guide cancer survivors how to initiate PA safely and effectively. However, previous research findings indicate that many health care professionals fail to discuss or promote PA with cancer survivors (Daley, Bowden, Rea, Billingham, & Carmicheal, 2008; Fisher, Williams, Beeken, & Wardle, 2015). A UK study conducted by Daley et al. (2008), found that only 44% of breast cancer professionals recalled giving PA advice to patients. A postal questionnaire was sent out to medical and clinical oncologists and surgeons (clinicians) who were registered with the Cancer Research UK Clinical Trials Unit database. The questionnaire included questions which asked; clinicians to report and provide information about whether they routinely discuss and give PA advice during consultations with breast cancer patients, asked them to indicate who they thought would be the most appropriate to deliver PA advice to cancer patients. Within the questionnaire there was an open comment section to add specific details of the PA advice they have gave and additional questions were also included to identify their; weekly moderate PA levels, age, gender, and medical speciality. A similar study found that only 37% of oncologists reported providing PA advice in the past 3 months (Hardcastle et al., 2018). Oncologists and oncology healthcare providers were recruited from seven different oncology societies across the world, the oncology membership organisations sent out an online questionnaire to their members. The questionnaire included questions regard to their: experiences of PA, concerns, confidence and current practice with promoting PA to patients. Hardcastle et al. (2018) reported that perceived behavioural control and their personal PA levels were positively associated with their PA promotion behaviour. Additionally, they reported that PA behaviour was positively associated with social norms, attitudes and confidence to promote PA to patients. Therefore, suggesting that one's PA behaviour influences their feelings of control and confidence to promote PA. Further, Hardcastle et al. (2018) concluded that the oncologists PA behaviour strongly influenced their attitudes towards PA, with regards to whether they perceive it as part of their role and those who were more active, were more likely to promote PA.

In recognition of these issues, growing research focuses on the perspectives and beliefs of health care professionals, with regards to promoting PA to cancer survivors. Clinicians and oncologists lack of PA knowledge, have been reported as a barrier to promoting and discussing PA with patients (Fong, Faulkner, Jones, & Sabiston, 2018; Nadler et al., 2017; Smith-Turchyn et al., 2016). The oncologists within Fong et al. (2018) and Smith-Turchyn et al, (2016) discussed how they felt inadequately prepared to promote safe and effective PA to patients and therefore, they did not actively promote PA.

Furthermore, it is suggested that those who have a lack of PA knowledge, do not perceive PA as a high priority with their role, in relation to other responsibilities such as discussing treatment information (Fong et al., 2018; Smith-Turchyn et al., 2016). Other barriers towards PA promotion amongst health care professional involved in the cancer treatment pathway have been reported such as; limited time with patients (Cantwell et al., 2018; Hardcastle et al., 2018; Keogh, Olsen, Climstein, Sargeant, & Jones, 2017; Nadler et al., 2017; Smith-Turchyn et al., 2016; Spellman, Craike, & Livingston, 2013) and lack of resources (Cantwell et al., 2018; Hardcastle et al., 2018; Smith-Turchyn et al., 2016; Spellman, Craike, and Livingston, 2013).

Health care professionals' perceived facilitators to promoting PA with cancer patients has also been examined across a range of disciplines and research studies. Existing literature have identified the desire for health care professionals to receive more resources such as handouts and specific training/education in relation to PA, to facilitate effective PA promotion to cancer patients (Cantwell et al., 2018; Fong et al., 2018; Nadler et al., 2017; Smith-Turchyn et al., 2016). Other facilitators were identified across the studies, such as: having a qualified exercise professional as part of the clinical team (Cantwell et al., 2018; Nadler et al., 2017; Smith-Turchyn et al., 2016), improving access to information and facilities (Cantwell et al., 2018; Smith-Turchyn et al., 2016). It appeared that the desire for extra resources and facilities to facilitate effective PA promotion amongst health care professionals would increase their confidence and intention to promote PA.

In addition to this, there are some inconsistency amongst the findings across some studies with regards to the health care professionals' attitudes and perspectives of promoting PA. The study conducted by Spellman et al. (2013) shown that the 32.3% of the clinicians neither agreed or disagreed that discussing PA was part of their role, whereas the study by Hardcastle et al. (2018) 69.9% of the oncologists believed it was part of their role. This difference could be due to the different sample characteristics included in the studies; there were in total 31 clinicians in Spellman et al.'s study (2013), with the majority being male (22), radiation oncologists (11) and aged between 30-40 years (14); whereas, the study by Hardcastle et al. (2018) included 123 oncologists, 57 participants were male and 60 were female, 36 participants were aged 36-45 and 46-55 years of age and 67 were medical oncologists. As a result of the different sample characteristics and the subjective nature of self-report questionnaires, the attitudes of the respondents may be different and therefore may cause a difference in the study findings. Interestingly, despite the differences in attitudes towards their role in promoting PA the majority of respondents from both studies, reported feeling confident to discuss and/or promote PA (Hardcastle et al., 2018; Spellman et al., 2013). Despite the oncologists reporting that they feel confident to give PA advice and those who prescribed advice, findings shown that 60% of the advice given did not match the guidelines (Hardcastle et al., 2018) furthermore highlighting the complexity of PA promotion.

Although, the literature examining the barriers and facilitators of promoting PA from the perspectives of health care professionals is beneficial to gain some understanding, relating to the issues and challenges

faced. Again, the literature relied heavily on quantitative methods and therefore, limits the opportunity to explore in depth the understanding and meaning of prescribing PA amongst health care professionals. More specifically, other research methods are needed to obtain a deeper understanding of how the barriers and facilitators identified, impact and interact with health care professionals' PA promotion behaviour. It is important to note here that within the studies discussed above, two of the studies (Fong et al., 2018; Smith-Turchyn et al., 2016), utilised qualitative methods to examine factors affecting PA promotion from the perspectives from health care professionals. These studies offer more insight and knowledge into the meanings of PA promotion, in relation to exploring in more detail the barriers and facilitators of promoting PA, in comparison with quantitative studies which focus on just identifying factors and measuring the effectiveness of these. However, the studies conducted by Fong et al. (2018) and Smith-Turchyn et al. (2016) only provided descriptions of the factors which influenced PA promotion amongst the health care professionals involved in the studies. Future research is needed, which utilises interpretive phenomenological methods to interpret the meaning of these factors, to enhance the understanding of how they impact PA promotion amongst health care professionals.

#### 2.5 Thesis rationale

Following the review of existing literature, the studies discussed above suggest that a) people who are affected by cancer experience a magnitude of factors which influence their PA levels, either positively or negatively; and b) there is uncertainty in relation to health care professionals' roles and PA promotion behaviour. In addition to this, the review highlights the limited number of qualitative studies utilising interpretative phenomenological methods to explore lived experiences or the meanings of these experiences. More specifically, there are a limited number of studies which use these methods to a) explore breast cancer survivors' lived experiences of PA and b) to explore breast cancer nurses' perspectives and experiences of promoting PA.

Research studies utilising interpretative phenomenological methods, are needed to obtain a deeper understanding of this phenomena and to gain a unique insight into the experiences and meanings they hold (Smith, Flowers & Larkin, 2009). Further, I argue that studies utilising interpretative phenomenological methods are important and valuable in health research, as they go beyond just simply describing experiences and providing objective accounts of a phenomenon. (Brocki & Wearden, 2014). It allows an exploration of the processes which may influence behaviours such as PA and PA promotion, rather than examining outcomes and efficacy of interventions for example. Therefore, I propose to utilise an interpretative phenomenological approach throughout this thesis.

Additionally, to my knowledge there is no study which utilises a phenomenological approach to explore both; breast cancer survivors' experiences of PA, and breast care nurses' perspectives and experiences of promoting PA to breast cancer survivors. Exploring the perspectives and experiences of breast care nurses and combining these with the breast cancer survivors' experience of PA, offers a unique perspective and insight into understanding this phenomenon from a holistic lens. This will contribute to 35

the existing literature and knowledge within this field and hopefully influence future research and PA promotion amongst health care professionals.

In the following chapter, I will discuss the different phenomenological methods and provide a deeper justification for utilising an interpretative phenomenological approach, to obtaining a deeper understanding of this phenomenon.

# 3. Research methodology

There are a variety of methodological approaches that can be used to inform the research design and methods chosen; which in turn guides the way we come to answer the research question (Willig, 2008). There is a wide variation of qualitative research approaches such as; ethnography, phenomenology, thematic analysis and more (Ritchie, Lewis, McNaughton Nicholls & Ormston, 2013). However, the methodological approach chosen for this research is phenomenology, in this chapter, I will describe my own epistemological and ontological assumptions and I will discuss how my philosophical assumptions informed the choice and development of the methodology used for this research. I will then describe some phenomenological approaches and I will provide a justification for using an interpretive phenomenological approach.

# **3.1 Introduction**

According to Creswell, (2012), research methodologies are based on philosophical assumptions, these involve ideas and beliefs which inform and guide the research process. They are characterised by ontological, epistemological and methodological assumptions (Egon G. Guba, 1990). Epistemology is defined as the theory of knowledge, it raises questions of what can be known and what counts as knowledge (Creswell, 2012; King & Horrocks, 2010). Ontology refers to the nature of reality, 'the claims or assumptions that a particular approach to social enquiry makes about the nature of social reality' (Blaikie, 2007, p. 13). Methodology refers to the process of research, the methods chosen are outlined and justified in relation to the philosophical assumptions embedded (Creswell, Hanson, Clark Plano, & Morales, 2007). Different researchers hold different beliefs about the nature of reality and knowledge, thus leading to different approaches to research; they are often referred to as the positivist and interpretivist paradigms, these generally (but not always) underpin quantitative and qualitative research respectively (Petty, Thomson, & Stew, 2012). Accordingly, paradigms can determine how the research should be conducted; in relation to the research approach, design and methods used, these are based on the researcher's philosophical assumptions (Collis & Hussey, 2009).

#### 3.1.1 Research paradigms

The positivist approach to research is commonly used within the natural and social sciences, and is often referred to as the 'scientific approach' (Walsh & Wigens, 2003). Positivists tend to adopt an objectivist epistemological view; this assumes that the nature of reality is objective and exists independently (Egon G Guba & Lincoln, 1994). This approach aims to discover 'scientific truths' and is concerned with testing relationships between controlled variables, to identify 'cause and effect' relationships (Walsh & Wigens, 2003). Thus positivist researchers remain detached from the object of research (subject) to avoid biases and rely on quantitative methods to measure and explore the causes and effects, of an objective single reality (Carson, Gilmore, Perry, & Gronhaug, 2001).

The interpretivist paradigm rejects that there is a single objective reality and they believe that multiple realities exist. Consequently, knowledge is conceptualised as a social construction of multiple realities and is based on individual perspectives (Ponterotto, 2005). Thus, interpretivists value subjectivity and attempt to develop a subjective understanding of individual's experiences and perspectives, with the aim to interpret meanings rather than predict cause and affect relationships (Rubin, Babbie, Babbie, & Pa-pi, 2001). Therefore, interpretivist researchers and the subjects of the research are interactively linked; the researcher remains open to new knowledge and allows the subjects to help with the development of this new knowledge throughout the research study (Egon G Guba & Lincoln, 1994, p. 111) This approach relies on qualitative methods and focusses on interaction and language of human beings, to discover, understand and make sense of individual perspectives and experiences (Holloway & Wheeler, 2010). However, within this paradigm there are other positions which are disguised, in particular distinctions between ontology realism and relativism (King & Brooks, 2016).

# 3.2 Epistemological and ontological assumptions

As mentioned previously, the purpose of this research is to explore breast cancer survivors' experiences of PA and their meanings of the experience, alongside the breast cancer nurses' experiences and perspectives of promoting PA to see if this might influence how breast cancer survivors' experience PA. My role and experience as a cancer exercise specialist instructor, and the focus of my research have both led me to become situated within an interpretivist position. Throughout my undergraduate study, I became familiar with research occurring within the positivist research paradigm, which was concerned with objectively measuring the positive effects of PA in breast cancer survivors. However, I am concerned about people's experiences and how they make sense of their experience; in particular, my experience working alongside breast cancer survivors as an exercise instructor led me to question, what does PA mean to these people? I believe that their individual experience and meaning of PA is important for gaining an understanding about their world from multiple perspectives. Therefore, the positivist view of experience is not helpful, for my research aims and interests which are concerned with the first person experiences; rather than imposing theoretical ideas and measurements which are driven by the researcher.

Additionally, my experience and position as an exercise instructor influences my ontological and epistemological beliefs; I believe that my social experiences with breast cancer survivors and the information I have gained, influence my knowledge and meanings of the world, or more specifically my knowledge of breast cancer survivors and PA. I deliver regular exercise classes for women who have had breast cancer; during these classes', conversations regarding their experiences of treatment side effects, meetings with health care professionals and their experiences of PA often came up. These conversations developed my interests and understanding into the similarities and differences between the women's experiences of certain aspects (just mentioned). Therefore, my epistemological and ontological assumptions underpin the methodology chosen for this research study, which is phenomenology; this is because of my concerns with lived experience, understanding the individual's 38

meaning of their experience and my belief that knowledge is socially constructed, which my position and experience as an exercise instructor leads to my assumptions.

# 3.3 Phenomenology

Phenomenology is concerned with exploring lived experiences and attempts to understand the meaning of this experience to the individual. There are a variety of approaches and techniques within phenomenology and have developed from its roots in philosophy (Laverty, 2003). Consequently, phenomenological psychology is often known as an 'umbrella term', rather than a single position because of the variety of approaches and ways in which it is utilised (Brooks, 2015; Langdridge, 2007). Below I will attempt to describe and discuss the main approaches to phenomenology.

#### 3.3.1 Phenomenological philosophy

Phenomenology was established in the early 20th Century, Edmund Husserl (1859-1938) is often credited as the founder of phenomenology (Langdridge, 2007). Descriptive (transcendental) phenomenology was developed by Husserl; he was concerned with identifying essential components of lived experiences and aimed to describe the meanings of the essential components, as they appeared to the person's consciousness (Lopez & Willis, 2004; Spinelli, 2005). This is referred to as the lifeworld, and is a fundamental concept of phenomenology (Brooks, 2015). Husserl believes that the meaning we make of the world is based upon the interrelationship between our consciousness and the world; he labelled this 'intentionality' (Spinelli, 2005). He argues that humans are always conscious of something, in which there is always an object for this consciousness; the object is often, though not always, a material thing such as a table and the *object* can be perceived by the *subject* which is a human being (Langdridge, 2007). Husserl suggested that intentionality is a made up of two 'correlational poles', which are labelled noema and noesis (Ihde, 1986, p. 43). These terms refer to the different aspects of experience; noema refers to what is being experienced, this is the object which we focus upon. Noesis is how we (subject) experience the object. For example, in this research study PA and promoting PA is the noema, PA is the object of the participants' experience. On the other hand, the noesis is how they experience PA and promoting PA and their meaning which they have constructed towards the experience (interpretation).

As mentioned previously, Husserl's goal is to precisely describe the essence and meanings of the lived experience, as they appear to the person's consciousness. He assumes that the researcher must adopt a *transcendental phenomenological attitude*, to describe the experience of consciousness as it appears (Giorgi, 2007). *Epochē* and *phenomenological reduction* are methods developed from Husserl to adopt a *transcendental phenomenological attitude*, which attempts to escape from the *natural attitude*. The *natural attitude* is our conventional shared understandings or beliefs adopted from science (Valle, Halling, & Valle, 1989). *Epochē* is sometimes referred to as bracketing and it means the researcher must attempt to set aside his or her assumptions and personal biases about the phenomena being

explored (Giorgi, 2007; Langdridge, 2007). Phenomenological reduction refers to describing all details of the conscious experience of the phenomena as it appears to the person, excluding pre-existing knowledge or assumptions of the phenomena and without trying to explain the experience (Spinelli, 2005). Therefore, Husserl and other transcendental phenomenologists believe that it is possible to achieve a 'god's eye view', in which a person can view intentionality from the outside (Ihde, 1986; Langdridge, 2007).

#### 3.3.2 Existential turn

Although existential phenomenologists follow Husserl's work and the notion of intentionality, they critiqued the notion of achieving a transcendental attitude and questioned the possibility of completely bracketing of our natural attitude (Langdridge, 2007). This is referred to as the existential turn; existentialists do not believe it is possible to detach ourselves from the way we see the world and the phenomenon under investigation. Unlike Husserl and transcendental phenomenologists who focus on the essence of the lifeworld, existential phenomenologists generally focus on existence (Spinelli, 2005, p. 103). Martin Heidegger was one of the first phenomenologists who critiqued Husserl's notion of adopting the transcendental attitude; Heidegger believed that we as human beings are "inseparable" from our world. He and other existential phenomenologists highlight the interrelationship of the individual with others and their world; Heidegger refers to this as "being-in-the-world" (Valle et al., 1989, p. 7). Heidegger's focus was to understand the meanings of human existence, through interpretation not just description; fundamental factors such as language and history and cultural aspects are therefore important to understand experiences of the world (Brooks, 2015). He argued that investigating human existence and the meanings of existence requires interpretation, which is based upon previous assumptions (Heidegger, 2010). Therefore, the researcher must recognise and expose their involvement with the investigation of existence; this is referred to as reflexivity which is introduced in the hermeneutic circle, this I will talk about later on in this chapter (Brooks, 2015).

The work from Heidegger inspired other existential phenomenologists such as Sartre, de Beauvoir and Merleau-Ponty (Langdridge, 2007). Although they were concerned with understanding existence, unlike Heidegger, they focused on theorising existence. Existential phenomenology is extensive; I do not have the scope to discuss it in depth within this thesis. However, Merleau-Ponty is considered to be the most influential in phenomenological psychology (Brooks, 2015; Langdridge, 2007); this may be largely due to his emphasis on *embodiment*. Merleau-Ponty argues that human beings are connected to the world, therefore, our meanings of the world are based upon our perceptions; he refers this to *embodied consciousness*. He claims that our body connects us to the world and is a vehicle which guides us to how we understand the world, this is labelled as a body-subject (Finlay, 2006). Therefore, he rejects the notion of the possibility of taking a "God's eye view", however, he also remains committed to the notion of phenomenological reduction (Langdridge, 2007, p. 36).

#### 3.3.3 Hermeneutic turn

Hermeneutic philosophers claim that understanding experiences involves methods exploring people's narratives of their experiences and employing methods of interpretation, rather than simply describing experience. Gadamer and Ricoeur followed Heidegger's later work, which focused on the position of interpretation which leads us to our understanding of the world (Todres & Wheeler, 2001). Like Heidegger, Gadamer believes that language is central to understanding, especially conversation (Langdridge, 2007). He believes that conversation enables our understanding of a phenomenon to be revealed and through conversation we attempt to create a mutual understanding of the experience with others. However, Gadamer develops hermeneutic ideas further when he says that our understanding is shaped by our prejudgements, which are dependent upon our history; he suggested that we should focus on our preunderstandings to open up meaning (Todres & Wheeler, 2001). Therefore, he claims that out understanding of other's experiences, is influenced by our prejudgements and pre understandings this is labelled as "our own situatedness" or *horizon* (Frie, 2010, p. 87). Gadamer suggests that these *horizons* can both limit and enable our understandings; however, they are overlapping and developing continuously. He believed that the *fusion of horizons* enables us to gain mutual understandings (Langdridge, 2007).

Like Gadamer, Ricouer acknowledges that language and interpretation of language are key elements for understanding to emerge. However, Ricouer developed interpretation and the concept *hermeneutics of suspicion*; this involves an attempt to find hidden meaning (Langdridge, 2007), he claims that both modes of interpretation: empathy and suspicion are essential to understanding.

Interpretation is described as a circular process, which involves moving from parts of the experience, to the whole experience and this is a back and forth process; this is labelled as the hermeneutic circle (Mackey, 2005). Preunderstandings are made explicit; these are considered as partial understandings of the phenomena and the reconsidered to enable new insights to emerge (the whole).

In summary, hermeneutic philosophers believe that interpretation is an essential component of understanding. They claim that our interpretations are based upon historical experiences; this is referred to as situatedness; in which, they reject Husserl's notion of adopting a transcendental attitude and the possibility of setting aside historical experiences and preunderstandings of the phenomena. Hermeneutics adds reflexivity, turning us to question our preunderstandings and previous experiences and self-reflect on how these may influence our interpretations and understandings of the phenomena under investigation (Laverty, 2003).

#### 3.3.4 Phenomenology as a research method

In this chapter, I have explored and discussed some of the philosophical assumptions which form the basis of phenomenology. I will now consider how these assumptions are applied to different phenomenological research methods. Although there are different approaches to phenomenological 41

research, the main aim of any approach is to explore the lived experience of a specific phenomenon which is being investigated; with an attempt to 'return to the things themselves' (Langridge, 2007). How the researcher attempts to 'return to the things themselves' is dependent upon the approach they adopt. As mentioned there are a variety of approaches to phenomenological research, the approach adopted by the researcher is dependent upon the research question. Each approach has distinct philosophical underpinnings, methods of data collection, methods of analysis and ways to present the research findings.

Descriptive phenomenology is the most strongly informed by Husserl's original work, developed by Giorgi in the 1970's at Duquesne University (Giorgi, 1985). This method is also referred to as the Husserlian approach, as it follows Husserl's philosophical approach. The main focus of this method is to identify the essence of experience, through *epochē* and *phenomenological reduction*. Participant descriptions of their experience of the phenomena are collected via methods including written descriptions and interviews. The Sheffield School has recently developed the descriptive approach, following Giorgi; including more focus on existentialism into the analytical process (Langdridge, 2007). Certain aspects of the existential factors of the lifeworld are used to analyse descriptions of lived experiences; this is distinctive, as the analytical process involves examining the data to remove things which are not essential to the phenomenon, rather than thematically describing experiences. There are other descriptive approaches such as Colazzi's method (Colaizzi, 1978), which involves a seven step process to analysis, and Moustakas' heuristic method (Moustakas, 1994).

Hermeneutic and interpretative phenomenological methods reject the notion and engagement with *epochē*; their concern with interpretation. Interpretative phenomenological analysis (IPA), is the most commonly used method in the UK; it was developed by Johnathon Smith at Birkbeck College, in the 1990's (Finlay, 2009). The central focus is interpretation, with less emphasis on description. This method involves thematically analysing data, which focuses on the lived experiences of the phenomena.

Another method of hermeneutic phenomenology is proposed by Max van Manen (Van Manen, 1990) this approach is flexible and he suggests that it should be specific to the sample and phenomenon being investigated. He proposes the use of reflecting on essential themes of the lived experience to investigate and analyse the experience; he moves from parts of the experience to the whole.

### 3.4 Interpretive approaches utilised within this thesis

An interpretive phenomenological approach was chosen as the most suitable method for the thesis as a whole. This was dependent upon my research interests, overarching research question and my dual role as an exercise instructor and researcher. I do not believe that it is possible to adopt a transcendental attitude or achieve *epochē*, partly due to my experiences as a cancer rehabilitation exercise instructor and my relationship with the breast cancer survivors (participants from Phase One of this thesis). I believe that my experiences and relationships with the participants, partly contributed to my pre-

understandings of their experiences and meanings of PA; however, exploring their experiences enabled me to gain a deeper understanding, with a unique insight of the meanings of PA. Additionally, I agree with the argument that understanding is based upon historical and social contexts, which derive from past experiences. This perception could relate to my understanding of the participant's experience of PA and how the participant's make sense of their own experience of PA. Therefore, as a researcher, I had to expose my pre-understandings, presumptions and previous experiences and reflect upon how these might influence the research process, through reflection; rather than attempt to set these aside and completely bracket them. As discussed there are a variety of research methods within phenomenology, which are specifically suited to the research question. This enables flexibility of choice and enables the researcher to utilise different methods to collect, analyse and present the research; which involve two different sample groups and distinct aims for each phase. Therefore, I have utilised two different phenomenological data analysis methods for each phase of the research, I will explore these in more detail below.

# 3.4.1 The utilisation of interpretative phenomenological analysis (IPA) for Phase One

For this phase, I have chosen to use Smith's IPA, to gain understanding of breast cancer survivors' individual experiences of PA. This method aims to explore personal lived experiences; Smith recognises that exploring meaning of the experiences is an interpretative endeavour (J. A. Smith, 2017). Thus, IPA involves a 'double hermeneutic' position; in which the participant interprets their experience of the phenomenon, whilst the researcher attempts to make sense of the participants' account of their experience (J. Smith & Osborn, 2003). According to Pietkiewicz and Smith (2014), the 'double hermeneutic' process involved in IPA makes the analysis richer. Another essential component of IPA is idiography (Pietkiewicz & Smith, 2014). This involves detailed examination of individual's lived experiences and perceptions of the phenomenon; the participant's descriptions of their experience are analysed case by case, before developing general statements of the phenomenon. I believe that the idiographic aspect of IPA is very well suited to this study as I believe that each individual experience is essential and provides different perspectives on the phenomenon and therefore, they should be made visible. It could be possible that my relationship with the participants prior to conducting this research study, illuminated the importance of each individual's experiences and influenced my personal views. IPA provides a 'step by step' framework to guide the analysis process, however this framework is flexible and can be modified and adapted when appropriate, to suit the needs and experience of the researcher and the objectives of the research study (Larkin, Watts, & Clifton, 2006). This is particularly useful as a novice researcher, as I had never analysed research or used IPA previously to conducting this research. The framework provides guidance throughout the analytical process and allows the research to modify the steps if needed to assist the analytical process.

As discussed in the literature review, qualitative research adopting phenomenological methods to understand breast cancer survivor's lived experiences of PA is sparse. I believe that phenomenological research, in particular IPA, is a valuable approach which provides a deeper understanding and therefore, knowledge of individual lived experiences within the health sciences (Finlay, 2009; J. A. Smith, 2017). Therefore, adopting IPA to gain a better understanding of how breast cancer survivors' experience PA and understand their meanings of PA is crucial; furthermore, the unique insights and understandings which may contribute to improved health practice and inform future research.

#### 3.4.2 The utilisation of template analysis (TA) for Phase Two

For this phase, I have chosen to utilise TA, this is an alternative method to IPA (Langdridge, 2007). Template analysis (TA), developed by Nigel King (King, 2004), focuses on producing a thematic analysis of experience, which enables the researcher to explore significant aspects and meanings of experience. This method involves a template, which is involves *a priori* themes, which are identified before collecting the data. This is referred to as the initial template, which is applied to a subset of transcripts and modified if necessary. This template is then applied to the remainder of the transcripts and revisions are made, this leads to the development of the final template.

This method was chosen as the most appropriate for Phase Two of this thesis, this is because of the time constraints and the specific aims of this phase. Unlike Phase One, it is not my main focus to gain an in depth understanding of each individual's experiences; however, it is my focus to gain insight into the breast cancer nurses' experiences and perspectives of promoting PA and giving PA advice to breast cancer survivors. TA is not underpinned by a fixed philosophical or theoretical position and is therefore, a flexible approach which can be utilised within different methodological and philosophical positions (King & Brooks, 2016). Thus it is an appropriate method to use within phenomenology. In addition, TA has been utilised within a number of health care research studies (Goldschmidt, Schmidt, Krasnik, Christensen, & Groenvold, 2006; Rodriguez & King, 2009). TA is acknowledged as a flexible and useful method of data analysis; the utilisation of a priori guides the analysis process, while still allowing new and unanticipated themes to emerge (King & Brooks, 2016, p. 11). Again, as mentioned previously as a novice researcher I have not utilised this method previously, therefore, the flexible framework is useful as it provides guidance throughout the analytical process. A key feature of TA is the flexibility of hierarchical coding; this explicitly encourages coding at varying levels and depths; to allow the researcher to focus on themes which are of particular relevance to the research aims (Brooks, McCluskey, Turley, & King, 2015).

Both of these methods acknowledge the importance of engaging in self-reflection, to expose any presumptions, pre-understandings and experiences, to illuminate how these might influence the different phases of the research process throughout this thesis. I have kept an audit trail throughout the research process, to reflect upon my experiences and illuminate how my pre-understanding and

experiences. I have documented these reflections of particular aspects of the research process in chapters four, six, seven, nine and ten.

# 3.5 Chapter summary

In this chapter I have highlighted and discussed the different philosophical underpinnings and development of phenomenology. I have explored some of the different phenomenological research methods; having considered the different methods to explore breast cancer survivors' lived experiences of PA and breast cancer nurses' perspectives and experiences of promoting PA, I have chosen to use phenomenology as the methodological approach. I have chosen to utilise both IPA and TA separately to structure the data analysis of Phase One and Phase Two of my research. In the following, chapter I will discuss how IPA was applied in Phase One of this thesis.

# 4. Phase One – Method: Breast cancer survivors

The overall approach is experiential which is informed by phenomenology. The approach used for Phase One of the research study is interpretative phenomenological analysis (IPA), this was chosen as the most suited methodology, to understand the phenomena under investigation which is; the lived experiences of PA amongst breast cancer survivors. This chapter presents the method for Phase One of the research, see chapter seven for the method of Phase Two.

# 4.1 Research aim and objectives

The overarching aim for Phase One is: An exploration of breast cancer survivors' lived experiences of PA.

The objectives of Phase One of the research study are:

- 1. To explore various aspects of breast cancer survivors' experiences of PA
- 2. To individually interview breast cancer survivors who have attended a specialised exercise class

### 4.2 Sample and recruitment

Ten breast cancer survivors were recruited, after giving informed consent to participate in the current research study. Below I will give an explanation and discussion about the sampling method chosen and the recruitment procedure.

#### 4.2.1 Sampling method

The participants were selected based on their lived experiences of the phenomena under study, so that they can share their insights (Smith, Flowers, & Larkin, 2009). This method is known as purposeful sampling, and was chosen to ensure that rich information can be collected from specific individuals who share knowledge and experiences of the phenomena under investigation (Palinkas et al., 2015). Palinkas et al. (2015) explains that there are multiple purposeful sampling strategies, which are employed to achieve different goals and purposes of research. For the purpose of this research, I applied the use of both convenience and homogeneity strategy. Convenience strategy is described as selecting participants who are "easily accessible to the researcher" and homogeneity is used to focus on similarities within a particular group of individuals (Palinkas et al., 2015). The participants were selected through convenience, as I already had access to a group of women who shared a particular experience, which was specific to the research phenomena. According to Smith et al. (2009), a homogenous sample is an important aspect to consider when constructing an IPA study and recruiting participants. The extent of homogeneity met within a research study depends on the philosophical

underpinnings of the research (Smith et al, 2009). Sample homogeneity can be established based on a variety of factors (Robinson, 2014). The specific types of sample homogeneity I have considered are; demographic, geographical and life history. The sample share commonalities amongst these factors of homogeneity as they are; females (demographic), from the same location (geographical) and share a past experience of breast cancer and participate in an exercise class (life history).

#### 4.2.2 Recruitment procedure

The participants were recruited from an exercise class which I deliver at the University. I informally mentioned my interest in the area for potential PhD research topic during an exercise class and they showed an interest. Once ethical approval was gained from the University (Appendix 2), I formally informed the potential participants about the research study and left the information sheet and consent forms (Appendix 3, Appendix 4) for the study on a desk in the room where the exercise class is held. This enabled the women to voluntarily take a form if they were willing to participate in the research study. The information sheet included: a description of participant involvement, stated their right to withdraw from the study at any point, and promised protection of their anonymity and confidentiality.

In total, ten women agreed to take part in the research study and were interviewed. The participants characteristics are provided below in Table 4-1. For the purpose of protecting the participants' identity, specific information is not included in the table, such as their age, ethnicity, year diagnosed and year completed hospital treatments. Therefore, the averages of specific characteristics have been calculated to provide an overview of the participants' characteristics. All of the women with the exception of one were White British and the average age of the participants was  $65.8 \pm 8.2$ y. The average time since diagnosis was  $2.8 \pm 0.7$ (years) and the average time since completing hospital based treatments was  $2.6 \pm 0.9$ y (years). The variation between the participants' time since diagnosis, time since completing hospital based treatments and the stage of breast cancer may affect the homogeneity of the research study, it would have been desirable for the time frame since completing treatment to be the same across the sample, to allow for a closer comparison of the participant's experiences. However, due to the practicalities and time constraints involved, it would have been difficult to recruit such a homogeneous sample for this research study.

The date, time and location for the interviews were arranged with the potential participants. All interviews were conducted at the University, before the interview proceeded the participants signed a consent form (Appendix 3), to agree to participate in the research and state their understanding of the research procedures. I highlighted their involvement procedures, their right to withdraw at any stage before, within and after the interview and sensitivity issues and access to available support if needed. It is important to make a note that all participants were made aware that, if they decided to withdraw from the study at any point, this would not affect their involvement in the exercise classes.

# **Table 4-1 Participants' characteristics**

Pseudonym	Breast cancer stage	Lumpectomy	Mastectomy	Chemotherapy	Radiotherapy	Reconstruction	Hormone therapy
Valerie	II	N	Y	Y	N	Y	Y
Pauline	I	Y	N	N	Y	N	Y
Maggie	111	N	Y	Y	Y	N	Y
Mabel	DNK	Y	N	N	Y	N	Y
Shirley	1	Y	N	N	Y	N	Y
Bev		Y	N	N	Y	N	Y
Julie	DNK	Y	N	N	Y	N	Y
Joanna	1	Y	N	N	Y	N	Y
Marian	1	Y	N	N	Y	N	Y
Amanda		N	Y	Y	Y	N	Y

Abbreviations: DNK-do not know, N-no, Y-yes.

Within IPA there is no specific rule regarding the sample size for a research study, however, larger sample sizes are deemed as "inappropriate" (Pietkiewicz & Smith, 2014) and guidelines suggest a sample size of 3-16 participants for IPA research studies (Robinson, 2014). Therefore, sample sizes vary amongst IPA studies, and are dependent on a variety of factors, for example the aims of the research study (Brocki & Wearden, 2014). For this study, ten participants conducted interviews, this sample size is deemed as appropriate as it is within the guidelines.

### 4.2.3 Inclusion Criteria

Women who had completed primary surgery, chemotherapy and/or radiotherapy for breast cancer, were able to speak English and were 18+ years of age were invited to participate in the research study.

Those who met the following criteria were excluded from the research study:

-Women who are still undergoing surgery or hospital based treatments

-Women who cannot speak English

# 4.3 Participant profiles

In this section I am going to provide a brief biography of each participant and their background. It is important to note that, each participant has been assigned a pseudonym to protect their confidentiality and maintain anonymity.

#### 4.3.1 Valerie

Valerie received a mastectomy, chemotherapy, a reconstruction and hormone therapy. Valerie highlights her interactions with the NHS professionals as problematic and challenging and therefore, decided to be treated privately. She describes herself as always being active and leading a healthy lifestyle. Valerie engages in regular physical activities such as; walking, Zumba and fitness classes.

#### 4.3.2 Pauline

Pauline received a lumpectomy, radiotherapy and hormone therapy. Pauline describes her diagnosis as life changing, since her diagnosis she has changed her lifestyle to become healthier and increase her physical fitness. She now participates in regular physical activities such as; Pilates, fitness classes and walking. She highlights reasons for increasing her PA levels as; preventing breast cancer recurrence, maintaining a healthy weight and improving her overall health.

#### 4.3.3 Maggie

Maggie received a mastectomy, chemotherapy, radiotherapy and hormone therapy. Maggie highlights her treatments as being restrictive, as they prevented her from doing usual activities, and she describes completing her treatments as a sense of freedom. Social support from others who have shared similar experiences, increasing physical fitness and health to fight illness, reverse treatment related side effects, improve confidence and knowledgeable exercise instructor were all acknowledged as reasons which influenced her participation in the exercise class. She now only participates in the exercise classes held at the university.

#### 4.3.4 Mabel

Mabel received a lumpectomy, radiotherapy and hormone therapy. Mabel shows her appreciation and gratification for the support she received from the health care professionals. She describes herself as lazy before her diagnosis and has changed her lifestyle since being diagnosed, to improve her physical and mental health. Other reasons for increasing her PA levels are: preventing chances of recurrence, reversing the effects of aging, improved mood, having a knowledgeable exercise instructor and shared social support with others who have similar experiences. Mary participates in the exercise class and walking.

#### 4.3.5 Shirley

Shirley received a lumpectomy, radiotherapy and hormone therapy. Shirley reports feeling abandoned from the health care professionals since completing her hospital based treatments and suggests a desire for more follow up care. Due to a lack of communication between health care professionals, there appears to be some confusion with regards to the completion date of her hormone therapy and results from a bone scan, resulting in feelings of worry and concern for her future health. Before her diagnosis Shirley regularly walked with her husband, since attending the moving Forwards course she now regularly attends the exercise class. The reasons she provides for increasing her PA levels and attending the class are: to give something back to research, improve health, shared social support with others who have similar experiences, and having a knowledgeable exercise instructor.

#### 4.3.6 Bev

Bev received a lumpectomy, radiotherapy and hormone therapy. Bev reports also feeling abandoned from the health care professionals once completing hospital based treatments. She reflects upon her previous experience as a health care professional and she reports expecting follow up care. She describes her PA levels as higher since completing treatment, to "prolong a healthy life", improve psychological well-being and mood, and prevent chances of cancer recurrence. Bev participates in physical activities such as: walking, gardening and attends the exercise class at the university.

#### 4.3.7 Julie

Julie received a lumpectomy, radiotherapy and hormone therapy. Julie participates in PA to improve her health and well-being; she appears to focus on the physical benefits of PA when describing her reasons for participating in PA, despite previously stating how she is not a "fan" of PA. There appears to be internal conflict between her personal beliefs and perceptions towards PA and her expectations of the benefits and experiences of PA. During the time Julie was diagnosed, her husband was diagnosed with terminal cancer also; she became a carer for her husband, while undergoing treatments for breast cancer. Throughout the interview, she often stated how it was difficult for her to reflect upon her experiences during the time she was diagnosed and receiving treatments because her main focus was caring for her husband; which almost distracted her from thinking about how she felt during this time. She discusses how PA was an activity which she did alongside her husband before they were diagnosed with cancer, she implies that it was something which they shared with one another. Thus once her husband had passed away, her focus and motivation to participate in PA disappeared. However, she claims that the specific focus of the exercise class held at the University and her perceived benefits of attending the exercise class, motivates her to attend regularly.

#### 4.3.8 Joanna

Joanna received a lumpectomy, radiotherapy and hormone therapy. Joanna describes PA as a distraction from her thoughts and worries. Before her diagnosis she participated in gardening and walking, whereas now she also participates in the exercise class at the University. She explains that feeling good and preventing the risk of cancer recurrence are reasons for increasing her PA levels since her diagnosis.

#### 4.3.9 Marian

Marian received a lumpectomy, radiotherapy and hormone therapy. Marian states that she has always led an active lifestyle; however, she reports that since being diagnosed she now participates in more activities such as the exercise class at the University. She explains the reasons why being active is important to her such as: maintaining physical fitness and abilities, physical appearance, preventing/control over the risk of cancer recurrence, enjoyment, social benefits, and improving health and mental well-being. She explicitly states that she would be "depressed" if she was not able to participate in regular physical activities.

#### 4.3.10 Amanda

Amanda received a mastectomy, chemotherapy, radiotherapy and hormone therapy. Amanda describes how she expected more follow up care from the health care professions once she had completed hospital based treatments. She reflects upon her previous diagnosis and compares the care and support from health care professionals. She describes how she has never been particularly active throughout her life but due to aging factors such as arthritis, her PA levels have decreased. However, she now participates in the exercise class when possible to alleviate the problems associated with aging. Socialising with other women, who have had similar experiences and improving physical abilities were described as reasons for participating in the exercise class.

#### 4.4 Data collection procedure

Individual semi-structured interviews were chosen as the most appropriate data collection method, to explore in depth participants' experiences of the phenomena under investigation (J. Smith & Osborn, 2003). Although, there are other methods of data collection used within IPA studies such as focus 51

groups, written personal accounts via diaries and letters etc. (Pietkiewicz & Smith, 2014), this method is commonly used within IPA studies, as it provides flexibility, allowing the participant to direct the interview as they wish and talk about their personal experience in their own words (Smith, 2017).

An interview guide was developed (Appendix 5) based on the review of literature and discussions between the supervisory team. The guide consisted of various topics relevant to the phenomena, covering their history and experiences of engaging in PA, whether and how their cancer treatment affected their engagement in PA and whether or not the received any type of PA advice from health care professionals, alongside their feelings and perceptions around their breast cancer diagnosis and PA. I was also interested in how, if at all, their experience of receiving PA advice from health care professionals affected their engagement in PA and their perceptions of this. The guide involved open ended questions to aid the direction of the interview and open the topic of conversations without leading a response from the participant. Lists of suggested probes were included as a tool for myself as the researcher if needed, for further elaboration and deeper questioning to gain a deeper understanding of their experience. The guide was used flexibly to open up the discussion of specific aspects of their experience, unlike a structured interview which is conducted following a specific sequence of questions (Biggerstaff & Thompson, 2008). The sequence and format of the questions could differ in response to the participant's answers, allowing them to lead the discussion freely.

#### 4.4.1 Interview setting

As discussed previously, the relationship between the interviewer and interviewee is vital to allow for a deeper exploration and understanding of their experiences. The rapport established prior to the interview procedure instils a sense of comfort for the participant and shared understanding of the research aims, which is believed to be essential for disclosure of sensitive topics and therefore, gaining access into the lived world of their experiences (Willig, 2008). According to King and Horrocks (2010), the physical environment with regards to where the interview will be conducted is important, to ensure that both the interviewer and interviewee felt comfortable and risks of disruption are reduced. Therefore, risk assessment forms were completed with the option for conducting interviews on the University grounds and/or within the participants' homes, this gave the participants the option of where they wanted the interview to be conducted. The interview date, time and location were all agreed and arranged between the researcher and each participant.

#### 4.4.2 Interview process

All of the interviews were conducted within the University, between May-July 2016, the average duration of the interviews were 40 minutes. Before the interview, I usually had an informal conversation with each participant to settle myself and participant. I found this particularly helpful when starting the interview, as I felt that the conversation flowed, rather than starting the interview abruptly. I began the interview with an explanation of the research purpose and interview procedure, each participant then gave oral consent to participate in the interview and for it to be recorded. The participants' diagnosis 52

and treatment background was explored first, to explore their experiences as a whole and to open up the discussion.

During the interview, I paid particular attention to the participant's body language and expressions when describing their experience. It was important to observe their body language due to the sensitive nature of the topic, their body language and responses to specific questions could reflect how the participant feels towards the topics being explored. If I sensed that a participant was becoming distressed I comforted them and asked if they wanted to pause the interview or move onto a different topic. Additionally, I made a note of this on my interview guide sheet; I used these notes during the analysis process to reflect on the interview and make sense of the participant's understanding of their experience and understand what it means to them.

After each interview I recorded my personal reflections, with regards to how I felt it had gone, areas of interest which arose through the conversations and my impressions of how the participant responded to the questions and interview. This allowed me to change or improve my interview skills if necessary to enhance the data collection process, additionally, the reflections were considered during analysis to aid my understanding and interpretations of the participants' accounts of their experiences.

# 4.5 Managing the data

All interviews were transcribed verbatim by myself, using express scribe software and then exported onto individual Microsoft Word documents. Transcribing the interviews, myself allowed me to become familiar with each of the participants' personal accounts of their experience, which helped with the analysis process. Although the transcription process was fairly straightforward, I was faced with some minor challenges when including punctuation and grammar, whilst trying to capture some of the participants' dialects and ways of speaking. To ensure this, I typed the participant's original spoken words and to clarify meaning I enclosed words in brackets. I attempted to complete an individual transcript the day after each interview, whilst the experience was fresh in my mind and I was able to reflect upon important moments during the interviews such as body language. This helped to ensure the accuracy of the transcripts and maintain the individuality of each interview, with the participant and interview context at the forefront of my mind during the transcription process. My initial plan of transcribing each interview almost straight away differed depending on other work related and PhD responsibilities during this time. In total it took four months to transcribe all the interviews. Conventions were used when transcribing the interviews, to identify specific features of the conversation such as, pauses were characterised as '[pause]', I also identify non-verbal features such as gestures and body movements '[points at arm]', emotions '[laughs]', '[upset]' etc. These identifiers help the reader to capture the context and meaning of the conversation between the participant and researcher during the interview (Bailey, 2008).

# 4.6 Data analysis

Although there is no set approach prescribed for conducting IPA, I used a framework proposed by Smith, Flowers & Larkin to help guide me through the analytical process (Smith, Flowers, & Larkin, 2009). Smith et al. (2009) advise researchers who are conducting IPA for the first time, to engage 'closely' with the steps suggested within the framework, to help make the process more manageable. This framework involves a step by step guide, to facilitate the researcher through the organisation and development of the analysis. It is important to note here that, this guide is flexible and can be adapted when appropriate for the researcher and objectives of the research (Pietkiewicz & Smith, 2014).

The steps followed are as shown below:

- Step 1- "Looking for themes": Initial analysis of the first transcript, notes developed into emergent themes
- Step 2- "Connecting themes": Clustering emergent themes to develop emerging superordinate themes
- Step 3- Ideographic write up of themes: Superordinate themes written up ideographically, with identifying information to help find themes within the transcript.
- Step 4- "Continuing analysis across all cases": Stages 1-3 repeated, with focus on "convergences" and "divergences" across the data.
- Step 5- "Developing a master table of themes": Table of superordinate themes constructed.
- Step 6- "Write up": The transformation of themes into a written narrative account, using verbatim extracts to support the themes.

# 4.6.1. Step 1- "Looking for themes"

I read the first transcript a number of times and took initial notes, which I wrote in the left-hand margin. The initial notes were comments made upon interesting features within the transcript about what the participant said or how they reacted. Re-reading the transcript helped me identify connections between what the participant said throughout the transcript and the new ideas and notes which emerged. This process allowed me to see the picture as a whole, as I became familiar with the participant's experience and transcript as a whole. I transformed the initial notes from the analysis into phrases which are described as "emergent themes". An example of this process can be seen in Appendix 6

# 4.6.2. Step 2- "Connecting themes"

For each transcript, I listed the emergent themes in chronological order and identified connections between the themes. I clustered the themes together based on their connections with each other, I

developed a new name for the themes which represents the cluster and made it identifiable, this called a "superordinate theme". I listed and placed the clusters under each superordinate theme within the table. I compared the superordinate themes alongside the transcript, to ensure that they matched the language the participant used to describe their experience. I used quotes from the transcript to identify where the theme can be found within the transcript and to ensure that there is rich evidence to support the theme. If themes did not have sufficient data within the transcript, they were excluded from the list.

#### 4.6.3. Step 3- Idiographic write up of themes

To increase my knowledge and skills with IPA, it was appropriate to write up an ideographic account of the transcript. This was to develop my critical awareness of the transcript as a whole and to explore my understanding of the participant's account. I particularly struggled with developing a superordinate theme title which captured the experience described by the participant. Therefore, I thought it was appropriate to write up the emergent themes in chronological order, including quotes from the transcript to evidence my analysis. This captured the participant's account as a whole, however, in talking I found that not all of the themes had particular relevance to the research phenomena being explored. See Appendix 7 for an example of the idiographic write up.

#### 4.6.4. Step 4- "Continuing analysis across all cases"

Once I had completed steps 1-3, I then continued the analysis with a new transcript. The analysis and themes identified from the previous transcript were put aside and did not aid the analysis for the subsequent transcript. I followed this approach to ensure that each transcript was treated as a completely new case, and therefore, was analysed ideographically.

#### 4.6.5. Step 5- "Developing a master table of themes"

Once each transcript had been analysed, I then looked for convergence and divergence across the transcripts. With critical input from my supervisory team, I explored the superordinate themes across the transcripts and created a visual table of these themes, see Appendix 8. The themes were then categorised and prioritised based on their richness of quotes which highlighted the themes and the relevance of the theme to the research phenomena being explored. This process aided the development of the "master table of themes".

#### 4.6.6. Step 6- "Write up"

The final step involved transforming the master table of themes into a written account, outlining the participant's experiences. The themes are explored and explained, quotes from the transcripts are used

to illustrate the themes and my interpretation of the meaning of these are transparent throughout. This stage of analysis is provided in chapter five.

I adapted stage three of this guide in particular; the original stage involved developing a table of superordinate themes, whereas I thought it was best to write up an idiographic narrative account of each participant's case. As a researcher new to IPA, this was chosen as an appropriate method for this stage rather than producing a table of themes, to develop my skills of undertaking IPA and to ensure a deeper understanding of each individual's experience as a whole. When I had completed stages one to three of the analysis for each transcript, I would send it to my supervisors for them to consider my findings and discuss their interpretation of analysis. This helped me during the analysis process, especially during the first transcripts as I found it difficult to immerse myself within the data whilst adopting an IPA attitude when analysing the transcripts and writing up an idiographic account. Additionally, this provided the opportunity for my supervisors to challenge my interpretations, to gain an insight into the development of the themes and to ensure that they were not developed as a result of my preconceptions. This is one method employed to ensure that the findings are credible (Thomas & Magilvy, 2011). I had difficulties trying to capture the voices of the participant's, when deciding a theme title; as a result, theme titles were replaced and/or edited through the analytical process. The development of themes and the analytical process were recorded and saved to provide evidence of the development of the final themes, see Appendix 7.

Throughout the analytical process, I kept a reflective diary of my thoughts, feelings and preconceived ideas of the data. This enabled me to understand my personal interpretations of the data and reflect upon my decisions during the analytical process. Additionally, it helped me to explain and justify my reasoning for the development of themes, which in turn, strengthens the credibility of the research findings (Thomas & Magilvy, 2011).

#### 4.7 Quality of the research study

There are ongoing debates about ensuring and evaluating the quality of qualitative research, due to the diversity of methodologies, and their associated methods and procedures (Willig, 2008). As a result of the diversity within qualitative research methods, there is a lack of universally agreed criteria or methods of evaluation set in place, thus enhancing the vulnerability of qualitative research against critique of the validity and quality (King & Horrocks, 2010; Yardley, 2000). Despite the ongoing debates around which methods are most appropriate to assess the quality of qualitative research, it is "imperative and unavoidable" to evaluate the quality of research, in order to demonstrate that the research is 'valid' (Yardley, 2000, p.219). However, whichever criteria are used should attend to the specific research paradigms whilst providing flexibility, allowing for the criteria to be applied across different qualitative methods (Tracy, 2010). I will use the eight-point quality conceptualisation by Tracy (2010), to help me produce good qualitative research. The conceptualisation is flexible and can be used across a variety

of qualitative research paradigms, for researchers with different skills and goals. Therefore, this seems most appropriate for myself as a researcher and the current research.

#### The eight markers are:

**Worthy topic**: Tracy states that good research is interesting, significant, relevant and timely. The current research covers a very interesting topic, which explores the lived experiences of a phenomenon, which is personal and significant for those who are involved. Additionally, the research might be useful to inform future health care practice and research, this highlights the significance of the research and its application to the wider field. Other aims of the research are to provide a unique insight into the phenomenon, to gain a deeper understanding, therefore providing interesting research.

**Rich rigour**: Rigour involves consideration of the data collection and analysis procedures. A deep description of the sample, data collection and analysis procedures is provided, to ensure that the reader can understand the processes involved. I have provided a thorough description and explanation of the themes developed throughout the analysis, to ensure that they are appropriate.

**Sincerity**: This relates to transparency and authenticity of the research. This can be achieved through reflexivity; throughout the research process. I have noted my personal feelings, preconceived ideas, beliefs and knowledge and how these may impact the research. To achieve transparency, I have used an audit trail which documents stages of the research journey and explanations for the decisions made throughout, such as the sample chosen, setting for interviews, analysis method and procedures etc.

**Credibility**: This relates to the trustworthiness and plausibility of the research. This can be achieved through providing detailed accounts and descriptions of how the findings have emerged. Again, this is achieved through my audit trail to document my reflexivity throughout the research process.

**Resonance**: This relates to the impact and value of the research. According to Tracy, aesthetic merit and generalisation both lead to resonance or impact. Aesthetic merit is described as "the text is presented in a beautiful and evocative way". The data and findings are written in a language with reflects the voices of the participants and intertwines with the research methodology, which is interpretative phenomenological analysis.

**Significant contribution**: This is the significance of the research study. The research aims to influence future research and policies within the field therefore, it would be heuristically significant. The research also aims to provide a deeper understanding of experiences of the phenomena, therefore, the knowledge gained from the research would provide practical significance and influence future research and PA provision within healthcare.

**Ethical**: includes factors such as; procedural which involves ethical actions dictated by larger organisations and ethical review boards to protect the participants and the researcher. For this research

I have gained ethical approval by The University of Huddersfield's school research ethic panel and HRA approval. Relational ethics- the relationship between the researcher and participants is respectful, caring and connectedness. I have a personal relationship with the participants and share a connectedness with them. Finally, exiting ethics involves ethical practices beyond data collection stages, such as considerations of how the data will be displayed. I have avoided using any information that leads to identifying the participants and the language I have used within the write up of the findings, reflects the language used by the participants to describe their account of the experience.

**Meaningful coherence:** does the research study accomplish what it sets out to? To achieve meaningful coherence, the research design, data collection and analysis methods are appropriate for the theoretical framework and research goals. Another, is to ensure that the research study interconnects for example, the findings attend to the research questions.

# 4.8 Ethical considerations

Ethical approval was submitted and gained from the University of Huddersfield, School Research Ethics Panel. The process of obtaining informed consent from the participants is provided in more detail earlier on in this chapter.

#### 4.8.1. Informed consent

All participants who agreed to participate in the study provided informed consent. Before the participants gave informed consent, they were provided with written information about the study, the research procedures, their involvement in the study, and their rights to withdraw (Appendix 3).

# 4.8.2. Confidentiality and anonymity

The University of Huddersfield's Data Protection policy 1998, and the Data Protection Act were followed, to ensure the confidentiality of personal data. All participants were advised that within the research and dissemination of results, they will remain anonymous by allocating pseudonyms and omitting any information which could lead to them being identified. The personal information collected throughout the study was not shared with anyone else or other participants of the study. Paper copies with personal, identifiable information of participants such as contact details, consent forms and interview transcripts were stored and locked securely in a personal University office desk drawer. The recordings of the interviews were deleted as soon as they were downloaded onto the encrypted memory stick, all research data is stored on a personal memory stick, which is encrypted and kept secure.

#### 4.8.3. Protection and safety of the participant

It is the responsibility of the researcher to ensure that the participant is protected from harm during the study. The participants were reminded of their right to terminate the interview or withdraw from the study

at any point. Due to the sensitive nature of the research topic and exploration of their thoughts, feelings and experiences, there is a risk of participants becoming upset and possibly experience distress during the interview. Following the advice from my supervisors' procedures were put into place, in case of any upset or distress caused by the interview questions. For example, I would support the participant and ask them if they would like to take a few minutes break from the interview to compose themselves, and/or if they would like to proceed to the next topic. If distress continued, then I would ask them if they would like to terminate the interview. I had relevant contact details of support groups/organisations such as; Macmillan and Breast Cancer Care, if additional support was needed. However, these were not required.

#### 4.8.4. Safety of the researcher

The main supervisor was informed of the times and dates for each interview, additionally a school technician was aware of this information, to allocate room availability and access. I was given information of the University's support services, in case I encountered any distress of difficulties throughout the interviews and research study. However, I have not needed to access this support. Any issues that have arose throughout the study have been discussed with my supervisory team.

#### 4.9 Reflexivity

Prior to conducting the research, I already knew the participants as I instruct an exercise class on a weekly basis at the University, for women undergoing and who have completed hospital based cancer treatments. I began assisting with the delivery of the exercise class for my personal experience, as I became a newly qualified exercise cancer rehabilitation specialist instructor at the time. Through my experience of assisting the classes and participating in regular conversations about PA with the women, my interests in their experiences and reasons why they participate in PA, more specifically the exercise class had developed. Therefore, when I was presented with the opportunity to undertake this PhD, from the very beginning the women in the exercise class declared an interest in the research study and their willingness to participate if needed. Fortunately, this facilitated the recruitment, as they were very enthusiastic about participating in the study and agreed to participate almost instantly.

As a qualitative researcher, and with particular acknowledgment to my relationship with the participants prior to conducting the research study, it is important to recognise my central role as the researcher and the influences I have on the selection, collection and interpretation of the research data (Finlay, 2002a). Within IPA, the researcher aims to gain access to the participant's world and collects first person accounts of their experience of a phenomena, to understand the personal meanings of this experience to the participants. The researcher actively engages with the participants and the data throughout the research process; therefore, 'bracketing' or separating oneself from the research process is impossible (Larkin et al., 2006). A connection is developed between the participant and researcher and the researcher must be aware and open to "intertwining" one's body with the participants, to develop a true

understanding of their experience (Finlay, 2005). The notion of "intertwining bodies" is a reflexive process of understanding, which involves the researcher becoming "embodied" within the language and interaction between themselves and the participant to understand the experiences of the participant. Alongside that, the researcher is reflective of their own experiences and perceptions when coming to understand the experiences of the participants, Finlay (2005, p.271), defines this relationship between the researcher and participant as "embodied intersubjectivity".

The acknowledgement and reflection upon one's relationship and involvement with the participants and the research data, should be documented throughout the research process and made transparent to the readers, to ensure the trustworthiness of the study (Berger, 2015; Finlay, 2002a, 2002b; Savvides, Al-Youssef, Colin, & Garrido, 2014). This process is known as reflexivity, it is used widely within qualitative research to highlight the researcher's subjectivity, and in turn enhancing the rigour of the research (Bradbury-Jones, 2007; Shaw, 2016). More specifically, the importance of engaging in reflexivity in health care research has been acknowledged, due to the central role of the researcher and the dynamic relationship between the researcher and participants (Biggerstaff & Thompson, 2008; Burns, Fenwick, Schmied, & Sheehan, 2012). According to Finlay (2002a), the understanding of reflexivity can vary depending on the aims, functions of its use, and methodological position of the researcher, for example reflexivity can be understood as a tool to explore one's personal accounts as a researcher and how these influence the data being produced.

Throughout the research process, I have recorded my reflections of embodiment throughout the research process and my feelings towards these, within a reflexive diary. An example of reflexivity which I have documented, is my thoughts and feelings before, during and after conducting the interviews. I reflected upon how my thoughts and feelings may have influenced my ability to conduct the interviews and therefore, influence the data being collected. More specifically, I highlighted my intertwined roles of researcher and exercise instructor and the relationship between myself and the participants, with relation to the research process. I acknowledged and reflected up the advantages and challenges faced, as my role as a researcher having a relationship with the breast cancer survivor participants. As discussed above, knowing the participants facilitated the recruitment process and pre gained trust was established prior to collecting data. However, to some extent, the participant's expectations of my prior knowledge and understanding of their experiences, sometimes affects the detail the participant provides when reliving their experience or describing the meaning of that experience. Therefore, posing the question of whether my relationship with the participants influenced the data being collected.

There have been discussions and debates about the positions of the researcher, in terms of both the insider/outsider status and how the status of the researcher may influence the research and produce potential advantages or challenges (Burns et al., 2012; Hayfield & Huxley, 2015). According to Hayfield and Huxley (2015), the insider/outsider status is determined by how the researcher 'fits' amongst the group of participants, an 'insider' is located within the group or as a 'member', whereas an 'outsider' is not a member of the group. The status of the researcher is also dependent on the characteristics and

commonalities that the researcher shares with the participants, such as; gender, age, or shared lived experience (Dwyer & Buckle, 2009; Gair, 2012). It has been argued that having an 'insider' status is advantageous and produces benefits, including ease of access to and recruitment of the participants and building trust and rapport with participants is easier (Burns et al., 2012; Dwyer & Buckle, 2009). Therefore, this can increase the opportunity to obtain rich and authentic accounts, due to sharing knowledge and or similar experience with the participants and therefore leading to enhanced understanding (Gair, 2012; Hayfield & Huxley, 2015). However, many challenges of being an 'insider researcher' have been identified for example, the participants may assume that the researcher will already know and understand their experience and therefore fail to provide full explanations and details of their experience (Dwyer & Buckle, 2009). Additionally, the position of an 'insider researcher' may be problematic during data analysis and dissemination of the findings, as the researcher may struggle to set aside their personal experiences and beliefs and therefore affecting numerous stages of the research process (Finefter-Rosenbluh, 2017). Whereas, an 'outsider researcher' may approach the data openly and therefore, analyse and present the data reflecting the experiences of the participants (Hayfield & Huxley, 2015). Dwyer and Buckle (2009), develop the idea of researchers being "in between" and argue against the notion of being an 'insider' or an 'outsider' researcher. However, this idea of "in-betweeners" is challenged by Ryan (2015). Ryan argues against the use of the 'insider' and 'outsider' status' and highlights the dynamics of the researcher relationship and position to the participants, with the use of dance as a metaphor to describe the 'shifting positionalities' (2015). This concept of 'shifting positionalities' and rejecting the notion of a 'static' researcher position, is supported by other researchers (Savvides et al., 2014; Soni-Sinha, 2008; Weiner-Levy & Abu Rabia Queder, 2012).

In consideration to this idea of a dynamic researcher relationship, I believe that my relationship with the breast cancer survivors and role as an exercise instructor intertwined during the research process, and thus causing a shift in the dynamics of the relationship with participants. Upon reflection, I came to realise that my relationship with the breast cancer survivors enabled them to open up and give personal accounts of their experiences, and for some, they felt comfortable and safe to show their emotions. This facilitated the data collection process, as I in turn, felt comfortable to delve in deeper and ask personal guestions of their experiences, which allowed me to gain unique insight into the individual meanings of the participant's experience. In reflection of this, I viewed myself as an 'insider', I felt a sense belonging to the participants because of this relationship I had with them. However, this relationship with participants was complex, and shifted amongst different conversations throughout the interviews and with different participants. Sometime I felt as an 'outsider', I recognised that due to the context of the interview, some of the participants felt nervous during the interactions, they seen me as a 'researcher', as though there was a power divide between us and I noticed how this made me feel uncomfortable during those interactions. For example, I noticed that those who felt nervous, were concerned about answering the questions correctly for the purposes of my research and therefore, their responses to questions seemed to be hesitant and their narratives of their experience sometimes seemed to be vague. Additionally, my role as an exercise instructor and having prior relationships with the participants 61

and partly knowing their experiences of breast cancer and PA, led me to believe that I was a 'partial insider'. However, since reflecting upon the interactions throughout the interviews, it became more evident how little I knew about each participant on an individual and personal level. The personal interactions during the interviews allowed the participants to open up and reflect upon their experience, some of the participants found this difficult, as they admitted to never reflecting upon their breast cancer experience and discussing this with others before. I found listening to other's feelings and experiences of breast cancer very difficult at times, this sometimes affected my ability to interview as I felt it was inappropriate to delve deeper into their experiences, which was upsetting them. Additionally, my status shifted towards being an 'outsider' as I became to realise that I have never had such personal and insightful conversations with the participants prior to their interviews and so, trying to understand what the experience meant to them was sometimes difficult, as I have not shared the same experience. Reflecting on this, allowed me to challenge my understanding and interpretations of the participants' experiences and question whether or not they are influenced by my pre conceptions, which have been developed through my roles as an exercise professional and researcher.

Engaging in reflexivity throughout the research process, allowed me to become aware of my position as a researcher and understand how my position is not a fixed position, it is dynamic and moves fluidly in relation to the different contexts throughout the research process. This enabled me to understand and interpret how my position with the participants and the data influenced the research process.

#### 4.10 Summary

This chapter focuses on the methods and research design utilised based on IPA approach. The aims of IPA are to explore in detail the participant's lived experiences of a particular phenomenon and what that experiences means to them (J. A. Smith & Osborn, 2015). IPA was chosen as the most appropriate method to highlight breast cancer survivors' lived experiences of PA. As mentioned earlier in this chapter, my dual role as the researcher and exercise instructor may influence the process of data collection and analysis procedures however; this will be disclosed through reflexivity throughout the research process. It is important to note that my interpretations may be different to others and therefore, I will follow the guidelines discussed in this chapter, to evaluate the quality of my research. Within this chapter, I demonstrated my reasoning for why I have chosen specific methods, with regards to the research aims, context and my philosophical position as a researcher.

# 5. Phase One - Findings

In this chapter I will explore the breast cancer survivors' experiences PA and illuminate the meanings of their experiences. I will present my interpretation of this phenomenon, utilising interpretative phenomenological analysis. I will organise the chapter based on the structure of the themes within the final template which was developed, this is seen in Table 5-1.

# Table 5-1 Phase One: Breast cancer survivors' findings

Overarching themes	Themes	Subthemes			
Losing and regaining	Lost sense of	Being physically restricted			
control of the body	control	Lost sense of self and identity conflict			
	Regaining control	Adopted a healthier lifestyle to prevent cancer			
		recurrence and maintain optimum health			
		Using PA as a tool to regain and improve physical abilities			
Experiences and	Experiences of	Feelings of abandonment and lack of support			
perceptions of support	support from professionals	Appreciation and acknowledgement of support			
		Experience of PA advice from health care			
		professionals			
	Support from significant others	Importance of support from friends and family			
The meaning of PA	"l've always been	Focus on health and fitness			
	active".	Participation for enjoyment			
	"I didn't do anything	Exercising to prevent chances of breast cancer			
	before coming to	recurrence			
	the class"				
The importance of	Sense of social	Shared experiences and understanding			
being with "other	camaraderie and				
people who were in the	belonging	Safe environment			
same boat"					

# 5.1 Losing and regaining control of the body

This theme was captured across a number of the participants' accounts, as they delved into how their cancer diagnosis and treatment affected their everyday lives. This theme looks at how the participants felt they had lost their sense of control, as a result of their cancer diagnosis and treatment and how they felt they had regained control. This theme involves the two subthemes; *Lost sense of control* and *Regaining control*.

# 5.1.1 Lost sense of control

This subtheme focuses on how the participants' highlighted a lost sense of control, as a result of their cancer diagnosis and treatment. This subtheme consists of two themes: Being physically restricted and lost sense of self/identity conflict. It was apparent for some of the participants; the side effects of their treatments had prohibited them from doing certain daily living activities. Whereas, for others their treatment regime was seen as a burden, as they reported feeling restricted, which again prohibited them from doing usual daily activities. Therefore, control over their bodies' physical abilities and over one's life had felt lost, as though cancer was in control during this time in their lives.

# 5.1.2 Being physically restricted

Many of the participants reported doing less activity during and initially straight after their treatment, some of the participants particularly highlighted, how they felt this had impacted on them.

For several of the participants, the side effects of surgery had restricted their physical movements causing a disruption to their everyday lives:

**Valerie:** The only thing I was doing was walking [pause] I couldn't do anything else, I couldn't do Zumba, I couldn't move my arms [pause] erm [pause] I didn't do Zumba forrr 10 months! I got, I got back to it after 10 months.

**Pauline:** It did frustrate me not being able to use my arms. Well you couldn't do simple things like, I know this sounds silly but cleaning the toilet because you're not supposed to do long swooping movements so you couldn't do any of this [movements] any cleaning or anything like that so I just sat and it drived [drove] me nuts.

As shown above, restrictions to their range of movement as a consequence of surgery proved to be frustrating for Valerie and Pauline. The pitch and repetition of the word "couldn't" accentuates the feeling of frustration caused by the lack of physical movement they had. The visualisation of them being a prisoner to their own bodies is created here, as the desire to be physically able to do "simple" tasks is apparent, unfortunately this is not possible. The disruption caused from being physically restricted

appears to be a burden for them both, this is highlighted when the lists the activities they couldn't do during this time. It seems reasonable to suggest the participants felt a lost sense of control over their movements and their lives as a whole.

For Maggie, the controlled treatment regime and the physical attachment to her treatment had not only restricted her from physically undertaking certain activities but also, restricted her whole life whilst undergoing treatment. She describes how the treatment had become the focus of everyday life, creating the sense that she was confined to the treatment regime and lost her sense of self as a consequence of the disruption caused by the ongoing treatment:

**Maggie:** I seemed to of been under a controlled regime [treatment] for so long that ermm we couldn't, ermm for any length of time because ermm I had to keep going back for the for the flushing out [clearing the catheter], which had to be done every week.

**Maggie:** The district nurse used to have to come ermm everyday between a certain time, for 5-7 days.

The sense of being a prisoner to her treatment is suggested here, as she reports being confined to a *"controlled regime"*. The language Maggie uses within these extracts, suggest how her everyday life was focused around her treatment schedules, and almost put on hold until she had completed her treatment. For example, the repetition of *"every"* within these extract emphasises how often she received treatment and how it had restricted her everyday life. Note how she uses the first person plural *"we couldn't"*, here she is referring to herself and her husband, further emphasising how it had affected her and her husband.

Maggie also discusses other forms of treatment which she had, such as a "PORT" attached to her chest, this is a device used to deliver chemotherapy, which consists of catheters inserted into the chest or upper arm (Madabhavi et al., 2017). She describes how this caused disruption:

**Maggie:** It was awkward for when you, when you had your clothes on and bathing because [pause] ermmm you could either have them just hanging loose, which I was a little bit wary of because I thought they may get pulled or tugged [pause] errmm so I liked to to have mine [catheter] sort of ermm coiled up and then they [breast care nurses] put plasters across it to keep it [pause] err sealed on your chest er but they they're [catheter] not actually water tight, so you [have] to be careful while bathing.

This extract suggests that the physical complications caused by the catheter are somewhat of an annoyance for her. This is implied through her description of her concerns about the catheters and extra care for ensuring that they do not get *"pulled or tugged"*. Again, this maintenance and caring for the catheter causes disruption and restrictions against undertaking tasks such as bathing, which she would 65

usually do without any effort before her treatment. Additionally, there is a sense of internal conflict towards her treatment here, as she seems disgruntled and controlled almost by the restrictive treatment procedures and regime. However, on the other hand, as a result of the treatment being attached to her, she seems to form an attachment with the catheter, in a literal and metaphorical sense. She takes ownership and control over the catheter: "*I liked to to have mine*", the use of possessive pronoun *"mine*" and verb *"liked*", implies a sense of attachment and satisfaction. Perhaps she felt a sense of control and attachment here, as she was in control of the catheter which was attached to her own body, rather than the chemotherapy invading her body from an external source.

Whereas for Julie, it appears that her hormonal treatment has caused issues which have affected her physical movement:

**Julie:** When I come to the class, I have awful joint pain in my legs and I put that down to the [pause] medication I take for the breast cancer. I've discussed it with the doctor and that is really and I can sort of track it back to when I started taking it, that err you know? I just have this joint problem [pause] quite painful you know at times.

She discusses how the pain caused restricts how far she can walk and other physical movements. The language used to describe the pain, suggests that it is severe, which causes major disruption and therefore impacting her levels of PA. However, she doesn't appear to be entirely sure that her pain is caused by her hormonal treatment.

# 5.1.3 Lost sense of self and identity conflict

Another form of loss of control is seen within the extracts from the participants who experienced changes in their body image and appearance. A few of the participants expressed how changes in their appearance as a consequence of treatment have impacted them, creating a lost sense of self:

**Maggie:** I think the worst bit about the chemotherapy was the hair loss [pause] in fact I think that was [laughs] the worst bit of the lot [pause]. Well what [pause] devastated I think the word is, you know, you know? It can happen [hair loss], you're always like to think it might not happen [pause] ermm and and unfortunately erm mine wasn't gradual err I'd wash my hair and I did what I shouldn't of done. I rolled it and put it in the towel, I didn't comb it out straight away, when I'd took the towel off, the hair came away with it, most of it. Which is, is quite a shock [pause] erm it's ermm it's coming to terms with the fact that [pause] this isn't [pause] ermm it made my view to me ermm I didn't think I was the same person, it was like coming to terms and getting to know a new person.

Her language here imitates a sense of identity conflict, as she describes herself as *"a new person*" and says *"I didn't think I was the same person"*. For Maggie, when she lost her hair, she appears to lose her 66

sense of identity alongside it. The repetition of *"coming to terms"* implies that she is trying to accept her new image and therefore her *"new"* identity. The notion created of losing her hair almost instantly, compared to gradual hair loss, heightens the trauma of the experience. The disrupted speech within this extract almost reflects the trauma she felt, as they signify hesitance and struggle when reliving this particular experience.

The idea of a becoming a *"new person"* is highlighted further within the following extract:

**Maggie:** I knew the day that I went for the operation I was me, the old me and I knew when I came round the day after, I would be a different me because my body would be different. And it's it's erm it takes, or it took me quite a long time to come to terms and accept the new me [pause] because the body image is affected because I'd not had a reconstruction, so I am lob sided, I am you know [pause] I am only half of what I was.

Maggie's description of herself creates the picture of rebirth, as she describes herself going into the operation as *"the old me"* and awakening from the operation as *"the new me"*. This suggests confusion and difficulty with accepting her new sense of self. Furthermore, the term *"lob sided"* and claiming that she is *"only half of what I was"*, emphasises the conflict she felt because of the changes in her appearance. It appears that she associated her breasts with her identity; therefore, when she had a breast removed, she perceived herself differently and describes herself as a different person. Highlighting the idea of being trapped in her *"new"* body, and therefore feeling a lost sense of self.

Whereas, for Amanda, her concerns focused on how her husband would perceive her to look without *"two boobs",* rather than how she felt about herself:

**Amanda:** So then like it wasn't, that I was worried about what I were going to look like. It's just, it's like [at the] back of your mind. You're thinking "will they [husband] think I'm funny?" Or "will they [husband] want somebody, who's got two boobs?".

Amanda makes it very clear that she did not worry about herself but she worried about how her husband would respond to how she would look after receiving a mastectomy. She appears to question her appearance through the thoughts of others, this is suggested when she mimics her thoughts. The adjective *"funny"* suggests that she may see herself as 'abnormal', as a result of the mastectomy, implying a sense of self identity conflict, which she avoids to admit. Like Maggie, Amanda appears to associate her breasts with her identity and perhaps as a definition of her femininity, as she feels *"funny"* without them, suggesting that she is different.

Despite Pauline not having a mastectomy, she discusses how she feared the possibility of needed a mastectomy:

**Pauline:** And as a woman, breast cancer you think, "mmm are we gonna' have to take my breast off" and again both sides thinking "am I gonna' end up with nothing" [laughing] which is daunting and I mean OK. If they have to take them, then they have to take them but as a woman it's [pause] not easy.

The language she uses imitates the idea of the breasts being associated with identity and femininity. The repetition of *"as a woman"* reflects the sense of femininity which is associated to breasts here and so emphasising the detrimental effects of a mastectomy to self-identity.

# 5.2 Regaining control

Many of the women explicitly stated that they had adopted a healthier lifestyle, such as eating healthier and increasing their participation in PA, to either regain their health and physical abilities or to improve them. Some of the women discuss their thoughts and beliefs about breast cancer being linked to their lifestyle choices such as diet and PA. It was acknowledged that to regain a sense of control, some of the women have changed their lifestyle since being diagnosed to prevent cancer recurrence and maintain optimal health. This theme is split into two: adopting a healthier lifestyle to prevent cancer recurrence and maintain optimum health and using PA as a tool to regain and improve physical abilities.

# 5.2.1 Adopting a healthier lifestyle to prevent cancer recurrence and maintain optimum health

There appears to be a sense of internal drive to attempt to control their chances of cancer recurrence through adopting healthier lifestyles.

Joanna in particular questions if her lifestyle had perhaps caused her diagnosis:

**Joanna:** I think just realising you should be, there's so many things about on television and everywhere that says you know, you should be exercising at least I don't know is it 15 minutes a day or 20 minutes a day?

LE:150 minutes a week so yeah

Joanna: Yeah and you think I'm not, then you think perhaps I wouldn't of got breast cancer if I had.

There is a sense of self blame here, as Joanna is questioning herself about whether she is to blame for her diagnosis because she was not participating in the recommended amounts of PA. It appears that she has acquired information about the benefits of PA and cancer risk, since being diagnosed and perhaps this provides her with an answer as to why she got cancer. It could be possible that she has increased her PA levels since being diagnosed to prevent cancer recurrence. Joanna continues to discuss how she forced herself to do more PA because she believes that it prevents *"cancer coming back"*:

**Joanna:** I used to find it really uncomfortable erm but aft now I realise that exercise is good [pause] for preventing cancer coming back and just you feel better. So although I think, I don't want to do this exercise bike today, I can't be bothered

LE: Yeah

**Joanna:** But then if you force yourself to do it, you're ok then afterwards. You think "yeah I've done that's good" and you feel better.

The notion of PA acting as another form of treatment to prevent cancer recurrence is created here. Additionally, the term *"force"*, almost suggests that she does not exercise for her own enjoyment but she does it to simply prevent *"cancer coming back"*. The repetition of *"you feel better"* within the extracts above, could suggest two things. One being that she feels better once exercised because it makes her feel energetic and happier. The other being that she feels better because she is doing something which she believes may prevent her chances of recurrence and therefore it may offer a peace of mind.

Pauline implies a similar sense of guilt and reasoning for her breast cancer diagnosis:

**Pauline:** Well [pause] being on the other side of cancer now, I realised that I should of been doing more PA [pause] and I want to do it, to stop it coming back because of the weight and PA affects it coming back [pause] so I'm doing everything I can to stop that and because I enjoy PA now. I mean it's the biggest part of my week now, going to the classes and things. It's changed my life for the better and it's doing me health more good as well.

Note how the language she uses within this extract, suggests a sense of realisation and self-blame with regards to the cause of her cancer diagnosis: *"being on the other side of cancer now, I realised"*. She paints the picture of her life before her diagnosis, which did not involve much PA or perhaps weight management, however she has changed her lifestyle since being diagnosed, after realising that it affects her chances of cancer recurrence. Again, imitating the notion of PA acting as another form of treatment for breast cancer and recurrence prevention. However, unlike Joanna, Pauline now enjoys PA and makes it a priority within her weekly schedule. It could be possible that her feelings of enjoyment are instilled by a sense of control over her chances of reoccurrence and contribution to her improved health.

Maggie discusses how she has increased her PA levels since being diagnosed, to increase her fitness and health, to ultimately prevent illness and diseases:

**Maggie:** I would say it's more now [pause] than before I was diagnosed [pause] yeahh and some of that and some of it is psychological knowing the fact that erm all being under the err the impression that that ermm to err keep [pause] illness and disease at at bay you need to have a fit body and a good immune errr system. Which of course when you've had this and an treatment err your immune system ermm gets fairly [pause] battered about. Ermm like I say, I have the thyroid problem which affects my immune system anyway. So I feel that I perhaps need it more because ermm that's impeding my immunity and I want to keep my body fit, to counteract whatever that that the thyroid takes away from ma [pause] my erm ability to fight.

Although Maggie does not explicitly refer to directly preventing cancer recurrence within this extract, she does refer to increasing her PA to increase her chances of preventing or alleviating illnesses and diseases. This highlights the idea of using PA as a mechanism to defend herself form illness and disease and therefore feeling in control.

Mabel also explains how she has changed her lifestyle since being diagnosed. The notion of self-blame and looking for a cause of the cancer diagnosis is continued below:

**Mabel:** Yeah I just want to keep it at bay by eating the right foods and stuff like that, cos [because] they say "eat healthy and it should keep it away" doesn't it? and exercise keeps it away, so they said.

Note how she uses the third-person plural pronoun when talking about how eating healthy and exercising possibly helps prevent cancer recurrence. This suggests that she wants to highlight that she has acquired this information from others, rather than it being her own opinion. It could be possible that she wants to portray herself as a good patient, as she is stating that she is doing the things which she has been advised to, in order to prevent recurrence. Again, changing lifestyle choices after cancer diagnosis to prevent recurrence is seen within this extract, it is almost as though being diagnosed with breast cancer has made them conscious of their health and how to lead a healthier lifestyle. Additionally, it could be possible that the participants are looking for something to blame for their cancer diagnosis and with the fear of recurrence looming over them; they are actively taking control of their health and future, through adopting healthier lifestyles to prevent their chances of recurrence.

On the other hand, leading a healthy lifestyle and being physically active has always been an important part of Marian's life:

**Marian:** Probably because I want to keep as fit as possible cos' I think that, you know? Keeping your body fit it [is] good for anything, not only just for cancer you know? It's really good. I've always been very [pause] into healthy [pause] eating and looking after myself. So I suppose, yeah so I suppose, having [a] diagnosis has made me even [pause] make sure you know? Even more so.

Although leading a healthy lifestyle has always been important for Marian, having a diagnosis appears to have increased her desire to increase her fitness and health further. Further highlighting the notion that through having a cancer diagnosis and treatments, this increases awareness and consciousness of the importance of their health.

# 5.2.2 Using PA as a tool to regain and improve physical abilities

Several of the participants discussed the physical effects of their treatment and how this had impacted upon every day activities and therefore caused disruption in their lives during this time. Some of the participants adopted PA as a tool to regain control over their physical movement and fitness, which they had lost as a result of their treatments.

Valerie talks about what types of PA she did after her diagnosis and treatment, and how she believed that they helped her to improve her physical abilities:

**Valerie:** I walked and I had a set of exercises for my arm anyway following my operations and I did them religiously. Three times a day and sometimes we'd hear the cords snapping, some of them was stretching across the table [imitates a snapping noise] and you'd hear it snap and doing behind [shows movement] putting my arm down my back and then tryna' [trying to] just raise them up above my head. Which was, that took months to be able to do that, so I believe it helped a lot.

The language which Valerie uses here is very descriptive to emphasise the traumatic experience of cording, which was a side effect of her surgery. The visual movements and images created within this passage highlighted the experience which she encountered and the difficulties she faced when moving her arms. Note how she describes her routine of the arm exercises and refers to this as *"religiously"*, to highlight how often she did the exercises and how important she felt they were towards her recovery.

Maggie also discusses how she thinks that exercising has helped her to regain her full movement in her arm:

**Maggie:** I now have full movement in that arm [points at left arm] and I can only put it down to the fact that erm, I've exercised every week. Sometimes twice a week erm, in in the gym [exercise class] and I think, I think the weights have helped with that?

The language within this extract creates the sense of uncertainty, as she suggests that exercising and using weights as helped regain her physical movement back in her arms. On the other hand, the repetition of *"I think"* implies that she may be second guessing her predictions and beliefs here. It could be possible that she truly believes that exercising has increased her physical abilities but she is also aware that other factors may have helped such as time since her operation.

# 5.3 Experiences and perceptions of support

All of the participants discuss the support they experienced during the time of diagnosis and treatment. The level of support the participants felt they had received, from health care professionals differed amongst the participants. This theme is split into two subthemes: experiences of support from professionals and support from significant others.

# 5.4 Experiences of support from professionals

Several of the participants discussed how they thought the breast care nurses were unsympathetic and felt abandoned once they had completed hospital based treatments. Whereas, others appreciated the support they had received from their breast care nurses throughout their diagnosis and treatments.

### 5.4.1 Feelings of abandonment and lack of support

Unfortunately, Valerie had a very traumatic and unfortunate experience with the national health care professionals from the initial point, when she went to the doctors for a check up on a lump which she had found. However, when she was diagnosed Valerie discussed how she felt unsupported by the breast care nurse:

Valerie: Then she said to me ermm, (mimics breast care nurse) "have you got life insurance?" [pause] and I said "am I dying?" [increased pitch]. Haven't you know, this is the cancer diagnosis, I said "am I dying?" [increases pitch], she said, she didn't answer me. I said "am I gonna' be here for my next birthday", so and she said (mimics breast care nurse) "well when's your birthday?" So I burst out crying and I said "well it can only be within the next 12 months, am I DYING?" [pause] ermm and she didn't answer me and my husband was absolutely livid at that point.

As we can see here, Valerie plays out her experience when she was diagnosed and mimics the questions the breast care nurse was asking. This is to highlight the insensitiveness of the situation which she experienced and how she felt unsupported by the breast care nurse. It is important to note how her pitch increased within this extract to emphasise her surprise and anger with the lack of sympathy from the breast care nurse.

Several other participants discussed how they felt unsupported and abandoned almost, once they had completed their hospital based treatments:

**Bev:** You see I was, I trained as a nurse, many many moons ago and I suppose, I just expected it to be a clinic led after care. And so I was quite surprised when I was supposed to manage it myself and if you know, you do get something that's strange you panic. Especially when you

don't think it's appropriate to drop in the local hospital and say "look I've got a sore boob or I think I've got a lump" or whatever it is.

**Bev:** I would have felt better, you know, I'd of felt that there was somebody other than me, supporting me.

As we can see, Bev expected and wanted more after care support from the health care professionals to prevent underlying worry. There is a sense of reliance from health care professionals to offer advice on health concerns and in turn provide support to prevent worries. The notion of abandonment is highlighted within the second extract, as she appears to feel alone and entirely responsible for reaching out for external support.

Shirley also describes how the only support she received after completing her treatments, was from the exercise professionals:

**Shirley:** Ye I mean suppose in a way, it, it was the only support we got you know? I don't hear anything from the breast care nurses or anything. I mean it's up to me, if I had any worries, I know where to go.

The idea of being abandoned from health care professionals is created here again, as Shirley highlights being responsible to reach out for support if she needed it. The language and tone of voice used when she is explaining that she did not get any other support, than from the exercise professionals, creates the sense of Shirley feeling let down and almost disappointed.

The idea of abandonment is emphasised even further in the next extract from Amanda:

**Amanda:** I just feel as if once they give me that pack of pills [hormonal tablets], it was goodbye end of [pause] because there's been nothing you know? Nothing whatsoever since then.

Amanda creates the image of being pushed aside and uncared for once she was given her hormonal treatment. Again, there is a sense that Amanda expected more support and after care from the health care professionals and because she had not heard anything, disappointment is heightened and implied within this extract. Amanda continues to explain how she would have felt better, if she had a check-up with a health care professional once a month:

**Amanda:** As I say erm, it's just little things. What if you, if you had one appointment after [pause] you've had your operation and they just look at you and say (mimics health care professional) "right everything's fine, it's going on as it is". But that's it, that's all you need is, just you keep [pause] just, just at back [back of your head] your thinking is everything as it should be you know?

Again, the reliance on advice from health care professionals after their recovery is highlighted here. It appears as though the expert opinion from health care professionals would provide a peace of mind for some patients. Additionally, if the breast care nurses contacted the patients or arrange a check-up to discuss any health concerns after their treatments, it would prevent feelings of abandonment for some as they would feel supported.

### 5.4.2 Appreciation and acknowledgment of support

Some of the participants discussed their appreciation for the support they had received from the health care professionals throughout their breast cancer journey. Others acknowledge and show gratitude for the support they had received from the exercise professionals and compare this to the non-existent or lack of support, from the health care professionals after their treatment.

Valerie highlighted the support and care she received from the private health care professionals throughout her interview. She appeared to indirectly compare the support and experiences of care between the national health care service (NHS) professionals and the private health care professionals:

Valerie: I felt the[y] saved my life.

LE: Yeah going private?

**Valerie:** Absolutely, they move so quickly erm, they're very professional. Erm, my main breast nurse down there, she's absolutely wonderful. She's there at the end of the phone, any time I do need her and I have rung her occasionally.

As we can see, she is very grateful for everything the private health care professionals have done for her. The language she uses in the first sentence emphasises the gratitude she felt and this could be interpreted in two ways. One being that this is hyperbole to describe her feelings towards the private health care professionals. Or the other, being that she truly believes that they saved her life, as they treated her and eliminated the breast cancer. It could be possible that she is not only referring to them saving her from cancer but from the NHS also. Additionally, the adjectives used to describe their services are all positive, which further emphasises her gratitude and recognition for their support.

Despite Mabel explaining that she didn't like the doctor who initially screened her because *"he was so abrupt"*, she discusses how she had felt supported by other breast care nurses:

**Mabel:** The Macmillan nurse she was fantastic you know. So when he [the doctor] went out, she, she you know? She said [mimics nurse] "I'll tell you everything he's said now because you might take it in a bit better". And I did, you know. She was lovely.

It appears as though Mabel perhaps felt more comfortable with the breast care nurse delivering the advice to her. This could be due to the abrupt attitude of the doctor or perhaps she felt the breast care nurse was more sympathetic and understanding because of her role as a breast care nurse and as a female. Again, Mabel uses positive adjectives to describe the personality of the nurse and emphases her appreciation of the support she felt. Mabel continues to show her appreciation towards the health care professionals and creates the image of her relying on this support and comfort provided by the nurses, almost as though she adopts the role of a child longing the comfort of their parents:

**Mabel:** I went to see Dr.Whitmore [pause] yes Whitmore? Yeah, and she was absolutely brilliant with me. She calmed me down and she explained it all, sat in the bed next to me. She did a little diagram of me bust and told me where the lump was [pause] She says "it's only a small one, don't be worrying about it". She says erm "we'll sort you out, you know and we'll do everything we can and what we'll do, we'll cut around further round the lump. So you get all the cancer, plus part of the skin around it" and she was lovely. If I hadn't had her, I don't know what I'd of done [begins to cry]

The picture she creates of being a childlike figure here, is implied through the description of the nurse sitting next to her, in her bed, providing comfort and support. Furthermore, in the last sentence, she emphasises her gratitude for the support by suggesting without Dr. Whitmore's help, she wouldn't have managed or even been here today. This highlights the notion of how important the sympathy and support from the health care professionals is to the patients throughout all aspects of their breast cancer journey.

However, unlike others, Julie appeared to almost refuse relying on others for support when caring for her husband and undergoing treatment for breast cancer. Although, she did acknowledge the opportunities for additional support:

**Julie:** The whole Macmillan support system were there if and when I needed to call on them, which I didn't. I mean they were there right at the very end, when I really needed, I needed help. I couldn't deal with it anymore [pause] erm and the hospice people but apart from that no. I never sort of called on any help, you know? I just wanted to deal with it as best as I could myself

There is strong sense of control here and willingness to cope by herself. She almost refuses the help from others until the very end of her husband's life. It could be possible that Julie wanted to stay strong for her husband and be responsible for his care.

Others, appreciate the support they had received from the exercise professional. Shirley describes the support from the exercise professional as:

**Shirley:** I mean suppose in a way it, it was the only support we got you know I don't hear anything from the breast care nurses or anything

As discussed previously, Shirley felt abandoned by the health care professionals and therefore, the support from the exercise professionals may be the only support she experienced or acknowledges after completing her treatments. Additionally, Valerie expresses her feelings towards the support providing by the exercise professional below:

Valerie: I just felt like that was the first time anybody had actually spent any time explaining anything to me and going through things, saying [mimics exercise professional] "that's too much or that's too little". [mimics herself] "am I doing too much here?" and to be walked through the exercises, and talked through and demonstrated and somebody watching you do them and saying [mimics exercise professional] "yeah that's ok" [pause] does that make sense? And when we started the weights, he started off on smaller weight and we [other women in the exercise class] know you are monitoring us.

Again, Valerie describes the support and guidance from the exercise professional as the only support she had received with regards to after care. The reliance of guidance and physical demonstrations to help with their understanding of the physical aspects of recovery are highlighted within this extract. It appears that Valerie was unsure of how to do certain exercises given to her by another professional and therefore, she was worried that she would cause further problems with her physical movement.

The sense of appreciation and reliance on the guidance and support from the exercise professional is further highlighted within the next extract:

**Maggie:** I like the, you know? The fact that we were being monitored for it err, to start with, like in the pod. Err, it makes you feel as though somebody is taking some er, perhaps a greater interest in what's, what's happening to you and errmm, and gives you that little bit of motivation to be [pause] better.

It could be possible that Maggie is implying that the health care professionals did not take an interest in her recovery or how she felt after she completed her treatments. Or on the other hand, she is just appreciating the supervision and guidance from the exercise professional, as this makes her feel cared for. Again, highlighting the importance of support from others.

### 5.4.3 Experience of PA advice from health care professionals

When asked about what types of information and advice they received about PA, most of the women reported receiving exercise leaflets from health care professionals. However, specific exercise advice was not given until they attended the Moving Forward course, which covered a talk specifically on PA.

Marian appears to have a stoical acceptance towards the lack of personal advice given by the health care professionals:

**Marian:** Erm, err, I think you're given the sort of leaflets after hospital [pause] then you've got a breast cancer nurse that's sort of keeps in touch for the first few days. Yeah you get a leaflet which tells you exactly what to do for your arms and what to do, on what days, how quick to you know, so you knew how much to do.

The language used creates the image of a somewhat distant relationship with the breast care nurse, which filters into a non-existent relationship. Additionally, the contraction of the second person pronoun *"you've"*, creates the sense of impersonal contact and distance between her and the breast care nurse also. However, unlike others, Marian does not explicitly state the lack of personal support from the breast care nurse as a problem, this could reflect her stoical acceptance of this. Marian acknowledges the importance and usefulness of the exercise leaflet given to her:

**Marian:** It, the basic one [leaflet] after operation, I really needed that one cos' I wouldn't have known [pause] how much, how far to take it you know what I mean?

The leaflet provided Marian with guidance on what exercise to do. Again, it appears as though she was uncertain of this, due to her physical limitations prior to her treatments. It could be possible that she was worried about causing further physical problems as a result of doing something incorrectly.

Pauline describes what information she received from the health care professionals and what information she had attained herself:

**Pauline:** OK well they give you a big folder when you are first diagnosed, tell you all about side effects and all this. There was a little bit about you need to get up, once you have had your operation and feel like it, just do a bit more of activity, just to get your muscles working more than anything and there was a bit about diet and everything. And then when I was in St James' having my radiotherapy, there were lots of leaflets there about how cancer affects you and I think there was one called PA after cancer [pause] but they didn't specifically give it to you, it was just available.

Pauline describes how the information with regards to PA after cancer, was not personally given to her. Again, there is a sense of the advice being impersonal, as she discusses how a folder of information was given to her. Creating the image of this folder being given to all patients, as a standard procedure, however, there is no personal advice given from the health care professionals to help the patients. Pauline further explains that she still follows the arm exercises which were included on a leaflet, which she was given after radiotherapy. Therefore, suggesting that although the information about exercise is received in an impersonal manner, they are important and useful for those who are willing to do exercises to assist with their recovery.

Whereas, for Valerie, a physiotherapist gave her an exercise routine and physically shown her how to do them:

Valerie: I did and to be honest [pause] erm with hindsight it was pretty poor [pause] When I was in hospital a physio came in [pause] and it was straight after my mastectomy. She says "I've got a set of exercises, I'm gonna' leave you a sheet for a set of exercises, this is what you need to do" ermm [mimics the physiotherapist] "starting tomorrow, you need to walk your hands up the wall" and she, she did that, she was in 5 minutes and left.

As we can see from the language which she uses, Valerie was not very happy with the delivery of this information. Perhaps Valerie expected more support and guidance of how to do the exercises on the sheet from the exercise professional, or again, she may have wanted the delivery of the information to be more personalised. This reflects her previous comments about the exercise professional being the only person who had helped her with exercises etc. Therefore, further highlighting the importance of guidance and instruction from a professional, to help them understand how to conduct the exercise appropriately.

Others stated that they did not get any advice from the health care professionals with regards to PA:

**Mabel:** Well they never actually mentioned anything until there's, you know? That course came up the Moving Forward one.

Julie: No, nothing until I went to the, you know Brier court thing? [Moving Forward course]

Joanna: No I don't think so, [I] can't remember any no. Only at the Moving Forward course.

**Shirley:** Well just in the moving forward course. Somebody came who was before Keith started on it, it was somebody else that did it.

As we can see, the only information on PA, that the women can recall receiving is from the Moving Forward talk. This is a course which includes talks from professionals, covering different topics for breast cancer patients and exercise is one of the talks covered.

# 5.5 Support from significant others

The majority of the women discussed the support from their friends and family during the time of diagnosis and treatment. The level of support received from significant others were implied as a coping

mechanism for some during such an unfortunate time in their lives. Others discuss how their partners encouraged them and motivated them to exercise.

### 5.5.1 Importance of support from family and friends

For many of the women their husband's or friends came with them, to provide support during their initial screening or results from their screening. This was acknowledged as a coping mechanism for the participants.

**Bev:** So my husband was with me through all of this which was great, erm I certainly didn't mind him being there.

Valerie: I attended the breast clinic erm my husband attended with me.

**Shirley:** We went back and my husband was with me and they came in and said [mimics health care professional] "unfortunately yes it is breast cancer butt it is soo soo small you wouldn't of found it yourself".

**Pauline:** My husband didn't know I was having that, he just thought I was gone for an ultrasound and he was sat there and I went like this [hand action suggesting to go towards her], cos I didn't want to cry in front of all those people.

When the participants were asked to describe their experience of being diagnosed, most of them mentioned their husband's engagement during this time. This could be implied in two ways, one being that they wanted to show their appreciation for their husband's support and therefore, bring attention to them. The other being that they were simply just setting the scene and describing their experience, which involved their husbands being there for them during this time. However, it is important to note their acknowledgement of their husband's support and how it may be seen as a coping mechanism for them.

Whereas, for Mabel, her friends supported her and went with her to receive her test results:

Mabel: So I went with my friends again and they were brilliant

She continues to discuss how they were "good" for her and how she needed "good friends at times like that". Again, suggesting the need for support from significant others during such an unfortunate time to help cope. She then continues to discuss how her husband and daughter provided support for her, however, she appears to contrast the types of support they offered:

**Mabel:** Yeah me husband [laughs] when I were in Bradford, when I got diagnosed, I rang him and I said erm "I've got cancer" and he were driving and he pulled in and he was roaring like a baby and I wasn't and he was [laughs]

**Mabel:** And me daughter, she was the positive one and I got into Brighouse, went for a coffee and me daughter, she was there and she put her arms out [laughs] and that was it tears.

Note how she describes her husband as a "baby" and her daughter as the "positive one". Creating the image of her husband and daughter switching the roles of father and daughter, as her husband signifies a baby and her daughter was portrayed as the adult in the situation. It is indicated that Mabel relied on the support from her loved ones and acknowledgement of their feelings, to perhaps feel cared for and loved. Additionally, it is important to note that despite the laughter within these extracts, Mabel found it very difficult to relive her experience and often became upset when talking about her experience. Therefore, the laughter is indicated as a mask to cover up her true emotions or on the other hand, to help manage them during the interview, as it is difficult for her to talk about.

Valerie repeatedly mentions the support and help she received from her husband throughout her interview. She creates the sense of togetherness throughout her breast cancer journey, as she portrays the image of her husband sharing the experience with her, through the language she uses throughout:

**Valerie:** Yeah, so we got called in at 5 O'clock and when we went in there, there was the consultant was sat down and there was two nurses there and to be honest I didn't think anything of that. We went in and sat down and she just said immediately [mimics health care professional] "I'm sorry to say you have breast cancer" and my mouth just dropped and I remember looking at me husband gaping.

The repetitive use of *"we"*, when describing her experience, highlights the sense of togetherness. She rarely uses the first person singular pronoun when describing her experiences. This could perhaps signify that she does not like talking about herself or perhaps that she wants to highlight the support her husband offered her during this unfortunate time.

Many of the women discuss a different type of support provided from their husband's, in regards to PA. For some, their husbands provided motivation and encouragement to be active and often the participants were active with their husbands. This sense of togetherness and moral support when participating in PA appeared to be important to the participants, particularly for those who did not appear to enjoy PA.

Julie describes how her husband provided a focus and reason for her to do PA:

**Julie:** I mean I've never been a gym bunny or anything like that and I'm not, I'm not a fan of PA you know? I don't get anything from it, I've never done a lot, so Greg was really my focus to do it. You know [we] used to get up every morning, going to that was the first thing we did, going to the gym and then so once he wasn't there to motivate me [pause] I, I find it difficult to motivate myself you know?

The gym was an activity which Julie and her husband did together, her repetitive use of *"we"*, creates the sense of togetherness. Through participating with her husband, this provided Julie with a *"focus"* and motivation to go and therefore implied as support from her husband.

Joanna also, portrays her husband as a motivator to encourage her to be more active. She expresses her lack of motivation to stay active at home or outside the exercise class:

**Joanna:** The guilt is, "I should be doing this and I'm not" and then Daniel would say to me "are you doing your bike"? [Laughs] I go "no I don't want to" [laughs]

Although Joanna is aware of the health benefits of being physically active and feels guilty, she appears to find it difficult to motivate herself to do more activity outside of the exercise class. Similar to Julie, her husband supports her by encouraging her to do more activity and perhaps motivate her more. Her laughs here, resemble the actions of a naughty child as her laughs indicate guilt and disobedience. Similarly, Joanna describes how she was very apprehensive about attending the Moving Forward Course and her husband encouraged her to eventually go:

**Joanna:** Yeah, I didn't want to go on it at all. Ermm but Daniel my husband said "oh you must go, you must go" [pause] ermm I, I really had to force myself to go and err and I did and I'm glad I did really.

Again, Joanna seems reluctant to do something and with the support and encouragement from her husband, she *"forced"* herself to attend the course. Although, despite being apprehensive at first, she changes her language and pitch when describing how she feels about attending the course. Furthermore, suggesting that without her husband's encouragement, she might not have attended the course.

# 5.6 The meaning of PA

The meanings of PA differ amongst some of the participants and often reflect their previous PA behaviour. For some of the participants' PA has always been an important part of their lives and so, they use positive language when describing their thoughts and feelings towards it. There is a sense that

for these participants, PA provides a sense of 'normality' as it was something which they engaged in regularly throughout their lives. Whereas, others indicated that their PA levels were either low or non-existent before their diagnosis; the notion of increasing their PA levels since completing their treatments implies how they are using PA as a tool to control their health and risk of cancer recurrence. The idea of their diagnosis being a symbolic awakening is implied throughout as the women discuss how they have become aware of the importance of their health and fitness, since being diagnosed. This theme is split into two subthemes: "*I've always been active*" and "*I didn't do anything before coming to the class*". These themes highlight the differences amongst the women and their meanings of PA.

#### 5.6.1 "I've always been active"

For some of the participants, it appears that their meaning of PA relates to a sense of 'normality'; from the extracts below we can see how they describe PA in relation to their lifestyles:

Marian: Well it's just my lifestyle I suppose really, it's just a part of my lifestyle.

**Valerie:** It's always been important to me to exercise, erm we quite [pause] as my son's call us a "fit fam" [laughs] we're a fit fam. My sons both attend the gym, we've always eaten healthily.

**Shirley:** I mean I've always, we've always been active in [pause] in that we've always gone walking long walks.

Note how Marian repeats the statement of PA being "a part of my lifestyle" to emphasise the importance of being active, this creates the image of PA being a focus of her life. The repetition of the singular possessive pronoun "my", signifies that PA is personal to her and it is something which she does for herself. Whereas, Valerie and Shirley use "we", "us" and "we've", which accentuate the idea that PA is something which they do with others such as their partners and families. Therefore, PA possibly provides them with a sense of togetherness, with those who they engage in PA with. Furthermore, Valerie highlights PA as an important factor not only for herself but for her family also, suggesting that PA has played a vital role throughout their lives as a family. The different descriptions of their meanings towards PA could reflect their reasons for and experiences of engaging in PA; for example, Marian often describes her perceptions of the benefits of PA in relation to herself, whereas, the other participants discuss the involvement of significant others when engaging in PA. Therefore, suggesting that for some the social aspect of engaging in PA with others may be important and influence their experiences of PA. It is important to note how the participants repeatedly use "always", when describing their PA behaviour, implying that PA is their 'normality'; it is something which they have engaged in for a long period of time.

### 5.6.2 Focus on health and fitness

Participating in PA appears to provide some of the participants with a sense of control; this is evident in their accounts, when describing their experiences and perceptions of the benefits of engaging in PA:

Valerie: I think exercise is really really important! Not only does it make me feel better physically [pause] in myself, I always feel like after I've exercised, I always feel like I've got more energy. I think it's it does you good psychologically too, ermm I feel better about myself, I feel [pause] I don't know? I feel happier when I'm exercising [pause] does that make sense?

**Marian:** Ohh lots [pause] social, erm feeling good, it makes you feel good. Err, just well-being really, it just keeps you [pause] it's just my thing [laughs]

**Shirley:** Well just as a means of keeping healthy, trying to keep me weight down which is not isn't working.

Valerie is much more expressive within her response to the question, which emphasises the meaning of PA to her; she provides a list of the different benefits she experiences from engaging in regular PA. There is a sense of feeling good repeated throughout her extract above, this is also evident in Marian's extract when she is also discussing her experience and meanings towards PA. This can be implied as they *"feel good"* because they are actively taking control of improving their health and well-being, or they *"feel good"* and happier because they are doing something which they enjoy. Additionally, Shirley also discusses her perceptions towards PA in relation to improving her health and well-being; however, she implies that she does not experience the benefits, which she describes unlike Valerie and Marian. It could be possible that Shirley is just simply being modest here, or she might participate in PA with the hope that her weight will decrease. I did not probe this further, so I can only interpret the meaning of this extract.

### 5.6.3 Participation for enjoyment

When asked what types of PA do they participate in, Marian and Valerie both discuss the different exercise classes which they do:

**Marian:** I do a lot of dance type exercise, like I do erm, I do, I take part in a dance show twice a year. It's just like an adult dance class that we do like; I do rehearsals for that every week. I do Pilates er, I do another dance, well it's [an] aerobic class.

**Valerie:** I'm not really a gym person I'm more of ermm, aerobics, I like to throw myself up and down a little bit. I like to do Zumba and I find it wonderful, it's a great laugh [pause] you know?

and we do toning afterwards and that's a great laugh too but it's a just for one way to get to keep fit.

It appears that they both like to do group based exercise classes, rather than individual based PA. Again, this could highlight the importance of togetherness and social support when participating in PA. Note how Valerie explicitly states that she is *"not a gym person"*, possibly suggesting that she doesn't particularly enjoy individual based PA. The language Valerie uses when describing Zumba is very positive and focuses on the social aspects, as she repeats *"it's a great laugh"*, again accentuating the enjoyment which she receives from participating in PA with others.

When I probed Marian further about what she meant about *"social"*, when I asked her why she participates in PA, she responded:

**Marian:** Meeting new people, erm er like-minded people I suppose, cos' they've sort of, you tend to have the same interests you know?

Marian repeats the idea of being with other people who enjoy similar things to her, such as exercising and keeping fit. This implies that the social aspect of exercising within a group is important to Marian and *"meeting new people"* provides her with a greater incentive to be active, other than improving her health and fitness.

Whereas, for Shirley the only group based exercise class which she participates in is the exercise class for breast cancer survivors:

**Shirley:** Well er,, say we were keen walkers so sort of twice, three times a week we'd be out walking. I, I don't drive so if I'm going for the bus it's a twenty minute walk to the bus, alright? Going to the bus is downhill coming back from the bus is up hill, you know? Ermm, the walking we still do but no, we don't walk as far because of me husband's health now. But I do try to do bits on my own at times but I suppose and then coming here [exercise class]

Walking is the only PA which Shirley has done, however, she emphasises the amount by describing her husband and herself as *"keen walkers"*. Suggesting that they walked regularly, she further emphasises how much walking she does by describing the distance from her house to the bus stop. It could be possible that she wants to portray herself as an active person by describing how much walking she does because of my role as an exercise instructor. The sense of PA being a shared activity with her husband is further accentuated here, as she discusses how her husband's health impacts on her PA levels.

When Valerie and Marian are not participating in exercise classes, they would do other types of PA such as walking. The language used to describe walking differs between the two:

**Marian:** Friday, Saturday and Sunday, I would do, I don't do any classes but then I would do me normal things like walking dog, perhaps go on a bike ride or [pause]

**Valerie:** Yeah and the walking we do like to walk [pause] erm and get and you're out in the fresh air so that makes you feel better too. [We] Take a packed lunch go for the day, you know and I just feel free [pause] you know? It's that sense of you know, when you're out in the country side and you can breathe and it's just that, that open spaaace and it's like [deep inhale] breatheeee

As we can see, Marian describes walking as her "normal things", suggesting that perhaps the exercise classes offer more enjoyment and purpose for her. Whereas, she may see walking as something which can be done anywhere at any time therefore, it is simply just "normal" and something which she does on her own, therefore she is not very enthusiastic about it. On the other hand, Valerie's language is very positive and enthusiastic, which contrasts from Marian's. The image created here, is openness and freedom as though she has been trapped inside. The notion of being trapped could be symbolic for Valerie being held prisoner by her cancer and trapped by the worries which she has, and so being in the country side enables her to almost escape her fears, as she embraces the scenery and life itself. The statement "you can breathe" highlights life and being alive, again, reflecting the notion of escaping cancer and perhaps death. Additionally, the sense of escapism captured here, provides Valerie with a sense of enjoyment.

### 5.6.4 "I didn't do anything before coming to the class"

Most of the women reported how their PA levels have changed since being diagnosed with breast cancer and attending the Moving Forward course. Implying that their diagnosis was a symbolic awakening, as it provided them with the realisation of how important their health and fitness is. As discussed previously, for many of them women PA is interpreted as a tool which is used to improve their health and ultimately prevent their chances of cancer recurrence.

Amanda describes what types of PA she did before her diagnosis:

**Amanda:** Well before the diagnosis erm [pause] I just like basically [pause] well you did like, you know? We used to walk but not you know, we'd like say maybe walk to town or walk erm onto the like, like a shopping centre further on you know? We'd walk on there erm and basically that was about the only exercise I did do, other than like you know? Your house work, which is exercise.

Amanda's language within this extract emphasises the lack of PA she did before her diagnosis. It is almost as though she doesn't want to over estimate how much activity she did and therefore downplays

or over emphasise how little she did do, this is suggested with the use of language such as "I just basically", "but not you know" and "that was about the only exercise I did".

Similarly, for Bev walking was the main activity used to describe her activity before her diagnosis:

**Bev:** Well they are higher because I've deliberately worked at getting them higher [pause] so like erm we used to go for a walk whenever we fancied but it might be once a week, once a fortnight something like that.

Bev creates the sense of once being uninterested in being physically active and implies that it was something which she did rarely with her husband. However, since being diagnosed she has made it her priority to do more PA, reflecting the notion of her diagnosis waking her up to the realisation of the importance of PA.

Pauline also discusses walking as the only activity which she did before her diagnosis:

**Pauline:** Well I didn't go to any exercise classes or anything like that, but I had started doing long walks because where I live. It's all hills [pause] so it's good, you know?

However, as we can see her language is much more enthusiastic and positive towards walking as an activity. She recognises walking as a respectable type of exercise, compared to Amanda and Bev who both appear to disregard walking as respectable. It could be possible that because the women now attend an exercise class which specifically targets different aspects of the body and fitness, they are comparing walking to the class and therefore disregard their previous PA levels.

Meanwhile, Mabel states that she didn't do any PA before her diagnosis and is critical of herself and PA:

**Mabel:** I didn't do any exercise beforehand. Now I do a lot more, yeah. It's helped me an awful lot because I never did exercise. I were very lazy, so this to me, I'm improving all the time. I feel so much healthy, I feel that and you've been marvellous with us, you know? Honestly, you have, you know? And we look forward to coming you know? So that's good because one time, I would of said "exercise forget it, no chance".

Mabel appears to be very negative towards herself and PA before her diagnosis, saying that she was *"very lazy"*. The repletion of not participating in PA and explicitly stating her thoughts towards exercise *"exercise forget it, no chance"*, suggests that she perhaps didn't enjoy doing it. Whereas, since being diagnosed, her attitude and behaviour changes towards herself and PA and this is reflected within the language she uses; *"I'm improving all the time"* and *"we look forward to coming"*. Again, this highlights the notion of her diagnosis awakening her to the realisation of the importance of PA and her enjoyment

for it. Note how she uses the first person plural pronouns when expressing her thoughts of the exercise class. This creates the image of her speaking on behalf of the other women who attend and therefore a sense of social camaraderie.

Interestingly, when I asked Julie to describe her PA levels since being diagnosed, she reports them as being *"a lot less"* and is critical of herself for this:

**LE:** Are there any other reasons for that then, other than your husband not being there to motivate you?

**Julie:** No, well just no, just being lazy I suppose, always thinking of other things to do, [mimics her thoughts] "I'm not going to" [pause] that's why I do like coming to this class because there is a focus, you know to come. Whereas, just to go to the gym on my own I think "oh I'm not going there today, I'm going to do so and so instead". I mean, I do, I do garden, and I do walk most days but I don't do anything really physical.

Similar to Mabel, Julie describes herself as *"lazy"*, when discussing why she believes her PA levels have decreased. There is a sense that Julie avoids going to the gym because it was once something which she did with her husband and going alone may be too emotional for her. On the other hand, her husband used to be her focus for doing PA and without him she has no focus or motivation to go to the gym and therefore, as she mentions the exercise class has a focus which provides her with a motivation to go. Similar to other women, the language which she uses to describe her PA levels implies that she is disinterested almost in PA and as a result she doesn't participate in much.

#### 5.6.5 Exercising to prevent chances of breast cancer recurrence.

As we can see, most of the women have increased their PA levels since being diagnosed. This highlights the notion of their diagnosis as a symbolic awakening, which made them realise the importance of their health and how PA can help improve this and perhaps prevent the risk of cancer recurrence. Therefore, motivating them to become active or for some, increase their activity levels.

When I asked what PA means to them or why do they participate in PA, the majority of the women discuss how they have realised the importance of being active, since they have been diagnosed. The main focus is to maintain or improve their fitness and health, in particular to reduce their chances of recurrence.

For Pauline, not only has she realised that PA is important to maintain her weight and reduce the risk of recurrence but she has realised that she enjoys PA:

**Pauline:** Well [pause] being on the other side of cancer now, I realised that I should of been doing more PA [pause] and I want to do it. To stop it coming back because of the weight and PA affects it coming back [pause] so I'm doing everything I can to stop that and because I enjoy PA now. I mean it's the biggest part of my week now, going to the classes and things. It's changed my life for the better and it's doing me health more good as well.

Her language appears to be very defensive within the extract, the repetition of stopping the cancer coming back emphasises Pauline's strong desire to control her chances of recurrence. PA is implied as a symbol for a defensive weapon, which is used to fight off the cancer and stop it from intruding her body again. Her language changes from being defensive, to enthusiastic when she is describing why she participates in more PA. This reflects her change in topic about the reasons why she does PA, rather than it providing a defensive mechanism against cancer she discusses how she enjoys PA.

Other women, also suggest that PA can be used to improve health and prevent cancer and illness coming back and ultimately prolong their lives:

Joanna: Yeah because you do everything to try and make it not come back.

**Maggie:** I do realise that erm and I can understand and see the logic in the fact that, to fight off illness of any kind your body needs to be in a fairly fit state.

**Bev:** I'm not motivated normally to do a lot of exercise, but I am strongly motivated if I think it's going to prolong my healthy life.

Within these extracts the focus of improving their health to prevent cancer is highlighted. Implying that the overall goal of a prolonged *"healthy life"*, provides them with a greater incentive to participate in PA. The term "fight off" which Maggie uses, reflects Pauline's use of words and idea of PA acting as a defensive weapon, as she creates the image of being at battle against cancer and she is trying to *"fight"* it.

Whereas, others link PA to improving health and well-being or managing physical problems, rather than specifically using it as a tool to prevent cancer recurrence:

**Mable:** Just something clicked and and said "right you've got to get healthy now", you know? "You've got to do your exercise and keep going" and you know? "cos' [because] you ache

everywhere". I used to have arthritis in my knees and they were really bad and it's improving a lot since I started me exercise, which is good isn't it?

**Amanda:** I don't really know how, what it [pause] other than erm it's getting you out and about and it's making you, that maybe you don't ache as much. Well like with me, with my hips if I sit [pause] if I sat all day long, then I really would be [pause] have problems. So I've got to do some exercise, if it's just walking down [the] garden or round [the] house. The good thing is that we've got stairs at home and they're quite steep.

The theme of PA helping manage aching and improve physical movement is highlighted across Mabel and Amanda's extracts above. However, the language and hesitant speech creates the sense that they are doubtful about the benefits of PA. For example, Mabel suggests that she is waiting for my response or agreement to her statement when she says *"which is good isn't it?"*, although this could simply be a rhetorical question, her tone of voice implies that she was expecting a response. Whereas, Amanda seems uncertain how to answer the question, when asked what PA means to her. Again, there is a sense that she is trying to think of an answer which she believes would be the right answer, which I want to hear. The speech disfluency within her sentences act as hesitance, as she pauses whilst she is thinking of what to say.

### 5.7 The importance of being with "other people in the same boat"

This theme highlights the need for a sense of belonging and how important this is to the participants. Many of the women show their appreciation for having the opportunity to meet others who have similar experiences, either through the Moving Forward course or the exercise class. There were different factors which were acknowledged as prominent features through "being with other people in the same boat" and these are the subthemes: *Sense of social camaraderie and belonging, shared experiences and understanding* and *Safe and comfortable environment*.

#### 5.7.1 Sense of social camaraderie and belonging

Although many of the participants were supported by significant others during their breast cancer journey, some reported feeling lonely and isolated throughout their experience:

**Maggie:** think you find yourself [pause] if they say "it's the loneliest time of your life", it is. Because unless you are surrounded or can be with people who are, or have had the same experience [pause] no matter how hard somebody else tries, I don't, er they don't understand.

**Valerie:** All my links were in London. So my breast care nurse was in London, I felt really isolated as it was. You know because most people that come here [exercise class] know each

other from the hospital, they're having chemo, they tend to get to know each other. I was having chemo with people that were travelling from far in and Londoners and various other people.

The desire to be in the company with other women, who have had similar experiences, is illuminated within these extracts. The language used creates the image of a journey which they have travelled alone, with a need for the sense of belonging and to feel understood by others who have the same experiences. This is implied particularly through Maggie's statement *"they don't understand"*, her tone of voice is somewhat sharp and implies that she felt slightly despondent. The repetition of the feeling lonely highlights the need for shared experiences and support, *"it's the loneliest time of your life"* and *"I felt really isolated"*.

The importance of being around other women who have had breast cancer is highlighted below:

**Valerie:** So I just remember it was just nice to be around other women [pause] erm, that were in the same boat as me.

The expression *"in the same boat as me"* creates the visualisation of people undergoing the same situation. In this instance, Valerie is referring to other women who have had cancer and she can relate to them and share her experiences. There is also a sense of belonging, which she was longing for throughout her journey, as reported above. The adjective *"nice"* suggests that she felt content in that moment, being in the company of other breast cancer survivors.

### 5.7.2 Shared experiences and understanding

Having the opportunity to share their experiences and support others in the exercise class, appears to be important to many of the women.

Pauline implies that the shared understanding and social aspects of the exercise class, provide her with a reason to continue her participation:

**Pauline:** Other than health reasons, no [pause] and it's nice to share it with other people who have been through the cancer experience.

The idea of sharing her experience with others, accentuates the importance of a sense of belonging. Although it is not completely clear what she is relating to when she says *"it's nice to share it"*, this could be implied in two ways. One, being that she enjoys sharing her experiences of breast cancer with others, through general conversations within the class. The other being that she enjoys exercising with other women who have survived cancer and exercising could be symbolic for survival or recovery, which she is sharing with them. Like Pauline, Maggie also suggests that exercising with other breast cancer survivors, motivated her to join the exercise class:

**Maggie:** I probably wouldn't of bothered doing it you know? I might of perhaps, eventually gone back to the exercise class, that I went to once a week but erm [pause] That would then be with people who had not had my experience and I find they both, that they both go together well. Because we all do talk to each other about, you know? Odd things that erm, that crop up and one of us could say "oh I've got so and so" or "I've got a pain here, oh I've got that". I'm glad you know and it sort of erm, it's a mind easer.

Her appreciation for exercising with other breast cancer survivors and having the opportunity to share their experiences is highlighted when she says *"they both go together well"*. The idea of exercising to improve her health, whilst listening to others experiences of problems, which she may have, accentuates the sense of *"feeling better"* which was discussed previously. There is a sense of normality when she states *"it's a mind easer"*, creating the image of her realising that her experiences are perhaps normal and nothing to worry about, as she can relate to the experiences of others.

For Mabel, providing the support to other women in the exercise class appears to be important to her:

**Mabel:** Like, if Maggie [is] going for a certain thing at the hospital, she'll tell me about it or you know? And it's someone to confide in. If she's a bit worried or Amanda or any of them. If they are worried about something, we talk to each other and help each other. So if we didn't have the class, we wouldn't be able to do that would we?

The idea of the exercise class providing an opportunity for breast cancer survivors to support each other is emphasised within this extract. The language Mabel uses creates the image of a supportive network established amongst the group, as she repeatedly uses *"we"*, again creating the sense of belonging.

Interestingly, Shirley compares her experience to others in the class and is critical of herself:

**Shirley:** Because I'm doing different sort of exercises to just walking and then the company of the people there we've all been thro[through] [pause] I feel a bit of a fraud in a way. I feel that everybody else has, that their cancer was much more serious than mine. But it's still nice to come and listen to their experiences, which every now and then we do sort of things get mentioned.

Despite showing her appreciation for exercising with other breast cancer survivors and sharing their experiences amongst the group, Shirley appears to feel like an imposter. This is implied through the language she uses to describe her feelings; *"I feel a bit of a fraud"* and *"their cancer was much more serious than mine"*. Feelings of self-conflict is apparent here, as she stops mid-sentence and corrects

herself to describe the differences between her cancer experience and others. Additionally, the language she uses shows conflict, as she describes feeling like an imposter, which creates the assumption of an unpleasant feeling and she then continues with *"it's still nice to come"*.

#### 5.7.3 Safe environment

For others, the main reason which attracted them to the class was because it was specifically targeted for breast cancer survivors. This was acknowledged as an important factor for some of the women, as they felt the exercises would be specific and safe for their recovery.

Julie describes the reasons why she attends the exercise class below:

Julie: I'm not, there int' [isn't] the social side to it because we only come, I mean we talk when we are here don't we but I mean there's no sort of social aspect to it [pause] cos' that's why a lot of people go to gyms and things don't they? But that's, that's not me, ermm so no not really. I just come to just try and you know, be as active as I can and I just think that the exercise that we do in this group are specific to, to the problems we've had, we've all had the same problem so.

Julie appears to disagree with other women, as she reports that there is no *"social side"*. Therefore, emphasising the importance of the specificity of the content within the exercise class, rather than the social environment. The idea of feeling safe is created here, as she states that the exercises are specific, implying that they are safe and beneficial for the recovery of breast cancer survivors.

Pauline accentuates the idea of feeling safe because of the specificity of the exercises:

**Julie:** I mean I could of gone to join a gym or something but because it was targeted at people with, who'd had breast cancer. [Mimics her thoughts] "it'll be, they won't be trying to do something that you shouldn't do" because I could have gone to a gym and started lifting all sorts of things but you're not supposed to do that.

Pauline creates the sense of being afraid to cause physical damage after her breast cancer treatments and so she avoided joining a gym. The specificity of the exercises involved and the purpose of the class was implied as an important factor, which attracted her to the exercise class. Additionally, the importance of the exercise instructor being knowledgeable of breast cancer is highlighted here as she says *"they won't be trying to do something that you shouldn't do". "They"* is implied as the exercise instructor, therefore, she is suggesting that she wouldn't be asked to do any exercises, which would perhaps cause an injury.

# 5.8 Chapter Summary

This chapter highlights the prominent features which influence the breast cancer survivors' experiences of PA for ten participants. The participants spoke about how their treatments had affected physically and emotionally. This was seen in a sense of *losing control*, they then discussed how they *regained control* through adopting PA and other health behaviours. The participants explored their experiences of support from health care professionals, exercise professionals and significant others, and they reflected upon how the level of support received affected them. The importance of receiving support from different networks was acknowledged as important, to help cope throughout their breast cancer journey. The meaning of PA was explored amongst the participants, PA was recognised as a tool to improve health and fitness and prevent the risk of cancer recurrence. Finally, the participants acknowledged the benefits of being with other women who have similar experiences, in particular in an exercise setting. This created the sense of belonging and a safe environment.

# 6. Phase One - Discussion of the findings

In this chapter I will reflect upon my experience of utilising IPA throughout the analysis stage of Phase One of my research study. I will then discuss the themes separately, in relation to findings from existing research to explore similarities and differences amongst the findings. Finally, I will discuss the strengths and limitations of Phase One of the research.

# 6.1 Discussion of the themes

I will explore the themes which emerged from analysing the data and discuss the similarities and differences of findings from existing literature, with the findings from my research.

### 6.1.1 Losing and regaining control of the body

This theme describes how the participants associate themselves with their body, with regards to feeling in control or losing control. It appeared that having breast cancer and receiving treatment for breast cancer resulted in physical changes of the body. Physical changes were either changed body image and/or limitations to physical abilities, these changes were a result of breast cancer treatments. Most of the participants described experiencing physical limitations after their treatments, which disturbed everyday activities and PA, leading to disruptions of the sense of self. Whereas, some experienced changes to their physical appearance as a result of treatments, these changes appeared to cause a sense of identity conflict. As a result of experiencing physical changes, it seems that the participants lost a sense of self and normalcy.

Previous literature has found that changes to the body's physical abilities and body image, altered some women's perceptions of themselves as they viewed themselves differently or as a 'new person' (Brunet, Sabiston, & Burke, 2013; Brunet, Taran, et al., 2013; Sander et al., 2012; Tighe, Molassiotis, Morris, & Richardson, 2011; Trusson, Pilnick, & Roy, 2016). The women's awareness of their changed bodies has been described as 'embodied knowledge', this may cause the women to relate to the world in different ways (Benner & Benner, 1994; Pedersen, Groenkjaer, Falkmer, Mark, & Delmar, 2016). For example, before the treatment and disruption caused to physical abilities, individuals undertake daily activities without reflecting on their bodies or actions, Benner & Benner (1994), describe this as being 'at home in the world'. But when they experience a bodily change which affects their physical abilities and therefore, daily activities, the individual becomes aware of their body and actions and reflects upon this (Benner & Benner, 1994, p. 219). This is known as embodied knowledge. Some of the participants within my study reflect upon changes to their physical abilities and compare this to their body and its abilities before diagnosis and treatment. This will be discussed in more detail and in relation to existing literature below.

#### 6.1.1.1 Lost sense of control

I found that a sense of losing control was associated with the side effects and symptoms of their breast cancer treatment. For many of the participants in the study, physical limitations as a result of their treatment had caused disruptions to their everyday lives and restricted them from returning to 'normal' physical activities, which they did before their diagnosis. This was implied as a lost sense of self, as the disruption of everyday life, led them to reflect and make meaning of their being in the world, in relation to physical manifestations. Findings from other studies identified physical limitations such as fatigue, pain, stiffness, and decreased physical fitness and strength, as barriers to PA for breast cancer survivors (Balneaves et al., 2014; Brunet, Taran, et al., 2013; Hefferon, Murphy, McLeod, Mutrie, & Campbell, 2013; Larsson et al., 2008; Whitehead & Lavelle, 2009). A quote used within Brunet et al. (2013) study, provides an example of their everyday lives being disrupted by the physical limitations caused by breast cancer treatment, as the individual focuses on the reflection of how the body responds to opening a door, because of the pain and weakness of the body. Similarly, some of the participants within my study, describe the difficulties they face when doing "simple things", such as housework chores. This supports findings from Brunet et al. (2013) and highlights the idea of 'embodied knowledge', as the participants are aware of how their bodies have changed due to physical disruptions and they reflect on how this disruption affects everyday activities such as cleaning.

Additionally, physical limitations relating to the ageing process such as joint pain and stiffness are identified as a physical barrier in Hefferon et al.'s (2013) and Whitehead & Lavelle's (2009) findings. Participants in Heffron et al.'s (2013) study associated the physical limitations with treatments and ageing, they appeared to be confused with which caused the issues and described both ageing and the side effects of the treatments as the cause. It could be possible that aging was a dominant theme in Hefferon et al.'s (2013) and Whitehead & Lavelle's (2009) studies, as most of the participants were over 50 (Hefferon et al., 2013) and all participants were described as "older", aged 59-86 in Whitehead & Lavelle's (2009) study. Therefore, the participants may experience more physical limitations relating to ageing and focus on this within the interviews and focus groups. Although, the studies mentioned above illuminate the challenges that breast cancer survivors face after receiving treatment and are in line with the findings from my study; they do not provide a deep exploration of the participants' meanings regarding the physical implications of the cancer treatment and how this affected their participation in PA and perceptions of self.

In my findings, another sense of losing control was identified through the participants' descriptions of changes to their body, in relation to their physical appearance. Through my interpretation, this was labelled as identity conflict, as it appeared that for some of the participants, their appearance implicated their identity and perceptions of self. It seemed that for those who experienced physical changes to their appearance, they challenged their identities and viewed oneself differently from their 'normal' or former self. Similarly, some of the participants who did not receive such treatments and therefore, did

not experience changes to their body image, described how they worried about the possibility of needing surgery and how it would affect the way they would look and feel. The threat and experiences of an altered physical appearance, led to reflections of their embodied experience with the world, as they challenge their identities. Changes to the body as a result of illness and treatments is described as an "unhomelike experience" (Svenaeus, 2000), which causes one to question and reflect upon their being in the world and sense of control over their body.

Findings from existing literature are in line with those from my study, as it is suggested that experiences of bodily changes, in relation to physical appearance and body image has caused women to reflect on their relationship with the world, in terms of how they identify themselves (Brunet, Sabiston, et al., 2013; Tighe et al., 2011; Trusson et al., 2016). An example of this from my study, is Maggie's experiences of changes to her physical appearance, caused by chemotherapy and surgery. She describes herself as a "new person" and a "new me", suggesting that her sense of self had changed as she began to challenge her identity and relationship with the world. This highlights the importance of appearance for Maggie, and how it implicated her self-perception and self-identity, this is reflected within the findings of Trusson et al.'s (2016) study. Some of the women discussed how their experiences of bodily changes with relation to having a mastectomy, affected their perceptions of self and disrupted their relationships with partners, and therefore to an extent disrupted their lives (Trusson et al., 2016). Although, Maggie does not discuss her perceptions of how others might respond to her bodily changes and how these affected her relationship with her husband, Amanda revealed her concerns about how her husband would react to her changed body. The focus on body image and altered appearance was only highlighted within Maggie and Amanda's interviews, whereas disruptions to physical abilities were more prominent across most of the participants' interviews.

However, it is important to note that changes to physical appearance was not a dominant theme throughout my research, unlike other existing research. Whereas, the focus on changes to the body with regards to physical limitations, is much more dominant across the participants' experiences within my study. It could be possible that because I have recruited the participants through their involvement in an exercise class, this causes them to focus on their bodies' physical abilities and the meaning of their body and its relationship to the world.

#### 6.1.1.2 Regaining control

Most of the participants who suggested a lost sense of control, as a result of the treatment and changes to their body, described ways in which they have adopted a healthier lifestyle to improve their health and physical abilities. This was interpreted as the participants' desire to regain control and cope with the physical changes. Perceived physical benefits of PA such as improving health and fitness, improving physical abilities, managing weight and assisting recovery from cancer treatments, have previously been reported as facilitators of PA amongst breast cancer survivors (Browall et al., 2018; Brunet, Taran,

et al., 2013; Midtgaard et al., 2015; Wurz, St-Aubin, & Brunet, 2015). Using PA as a tool to regain control over their sense of self, was a dominant theme throughout my findings, this was displayed in different ways amongst the participants. One was using PA to retain one's sense of existing 'normality'. The other, was using PA to create a new sense of self.

For some, using PA as a tool to retain a sense of existing 'normality', was evident. For example, it appeared that for those who engaged in regular PA as a 'normal' part of their lives before their diagnosis; PA provided them with a sense of control to regain their physical fitness and strength, to return to preexisting physical activities and PA levels. This was particularly evident within Marian and Valerie's personal accounts of their meanings and experiences of PA. They both highlighted the importance of PA and described their relationship with PA, in a sense of PA being a central part of their life. Therefore, using PA as a tool to improve physical abilities and return to pre-existing PA levels, which was once disrupted as a result of the physical limitations caused by the treatment, led to a sense of control over their sense of self and being in the world. Similar findings are found within existing literature, which explores breast cancer survivors' experiences of participating in an exercise intervention. Luoma et al. (2014), found that the women expressed the desire to return to 'normal' and regain the identity of being a healthy woman again. Similarly, Bulmer et al. (2012), reported that the participants had a "strong internal drive" to move on from cancer, participation in the exercise programme was acknowledged as an important factor which helped this transition. Some of the participants in Brunet et al. (2013) study, reported feeling a sense of "empowerment" and "control" over their body. Again, findings are similar in an exploratory study (Wurz et al., 2015), participants reported that participation in a group based programme enhanced feelings of normality over their lives and feeling in control. These findings are in line with the findings and interpretations of the present study, which demonstrate individual meanings of PA as a tool to retaining a sense of 'normality' or returning to their pre-existing identity or perceptions of self.

Some participants within my study, use PA alongside other lifestyle behaviours, to create a new sense of self. Some of the participants discuss their previous PA and lifestyle behaviours and compare how they have adopted their lifestyle since being diagnosed. Using PA to change their previous lifestyle and control their overall health and well-being is a dominant focus amongst the participants within my study. The majority of the participants believe that they are controlling their risk of breast cancer recurrence through adopting a healthier lifestyle and increasing their PA levels. Some of the participants explicitly stated that they have adopted a healthier lifestyle since being diagnosed, to increase their health and fitness; which in turn they believed if they were fitter and healthier that they would improve their chances of fighting off cancer if it returned and other illnesses. Others indicated how they had acknowledged the importance of their health and fitness, with relation to reducing their chances of becoming ill or fighting a disease. This again captures the notion of embodied knowledge, as it is perceived that being diagnosed with cancer has made them reflect and become aware of the importance of their bodies, in relation to being fit and healthy. Therefore, upon reflecting on the importance of their health, the

participants have re-evaluated the importance of their lifestyle and changed activities such as increasing their PA levels and eating more healthily. This is perceived as the participants taking control over their health and cancer outcomes. These findings have been reflected in other studies which explored breast cancer survivors' experiences and perceptions of PA (Brunet, Taran, et al., 2013; Bulmer, Howell, Ackerman, & Fedric, 2012; Luoma et al., 2014; Midtgaard et al., 2015). These findings highlight the experiences and meanings of PA for these individuals and indicate the sense of regaining control, through participating in PA.

Findings from Brunet et al. (2013), however, are slightly different, as the importance of the body and health appeared to be focused on body image and appearance. For example, the women had a desire to adopt a healthier lifestyle to maintain their weight and physical appearance. Some described the importance of looking good on the outside, to help them feel good about themselves. It could be possible that the focus on the importance of body image and appearance is central within Brunet et al.'s (2013) study because of the purpose, which was to explore women's experiences with their bodies following breast cancer treatment. Additionally, the majority of the participants in Brunet et al.'s (2013) study had undergone chemotherapy (8 out of 11) and 5 were described as overweight. Whereas in my study, only 3 out of the 10 participants had undergone chemotherapy and measurements of their weight status was not taken. Therefore, it could be possible that the focus on body image and appearance was central in Brunet et al.'s (2013) study because of the sample characteristics and possible experiences of changes to their appearance, as a result of chemotherapy.

### 6.1.2 Experiences and perceptions of support

This theme captures the participants' descriptions of their experiences and perceptions of the support they received from health care professionals and significant others. This theme as a whole somewhat overlaps with other themes, which explore the participants' experiences of support from diagnosis to the date of the interview and within different contexts, such as; 'abandonment' and 'appreciation of support' from health care professionals, and 'importance of support from significant others' regarding coping with the diagnosis and treatment. However, for the purpose of the discussion, I will only discuss the subthemes 'PA advice from health care professionals' and 'support from significant others', in relation to the PA context. The reasoning for this is to focus on parts of the participants' experiences of PA, as I believe that these subthemes are particularly important parts of the participants' experiences of PA as a whole.

#### 6.1.2.1 PA advice from health care professionals

Many of those who reported receiving PA advice from health care professionals, indicated that the advice and information was given out as part of routine care and that it was not personal or specific to them as an individual. There was a sense of disappointment for some, whereas others appeared unconcerned when reporting this. Valerie received personal physiotherapy treatment; however, she 98

described the instructions she received from the physiotherapist as "pretty poor". Others stated that they did not receive any information, with regards to PA until they attended the Moving Forward Programme, which covered a topic specifically on exercise and PA. Some of the women indicated how they felt unsure of what types of PA were safe and effective after their treatments, they perceived this to be due to the lack of guidance and information provided by health care professionals. A lack of information and knowledge of what types and how much PA is safe, after breast cancer treatments are commonly reported as barriers to PA participation (Browall et al., 2018; Larsson et al., 2008). This illuminates the importance of support and advice from health care professionals, in relation to PA and how this may influence the breast cancer survivors' experiences and attitudes towards PA. The importance of receiving specific information and guidance is highlighted within the literature which explores breast cancer survivors' experiences of participating in an exercise programme. Amongst the literature, the support and guidance received from a skilled and knowledgeable exercise instructor is acknowledged as being important (Browall et al., 2018; Bulmer et al., 2012; Luoma et al., 2014). Bulmer et al (2012), reported that the relationships with the exercise instructors were "highly valued" and they instilled a sense of safety and confidence, which encouraged the participants to adhere to the exercise programme. Similarly, the importance of having a skilled instructor was acknowledged in Luoma et al.'s (2014) study, as the participants described feeling safe and trusting the exercises involved in the programme. This particular theme was demonstrated within Maggie and Valerie's descriptions of the exercise class; Maggie felt motivated during the exercise class because she was being monitored and supervised by the exercise instructor. Valerie also appreciates the presence and guidance from the exercise instructor, as she implies how she felt safe when exercising because she was being supervised by a professional. The supervision from the exercise instructor was also recognised as meaningful to some of the other participants, as some of them described the supervision from the instructor as a source of social support. Shirley in particular, states that it was the only support she received from any professionals since completing her treatments. Maggie also felt that the instructor was interested in her well-being and physical health, implying other professionals were not. The findings from existing literature and my study, all highlight the importance of support from professionals, to guide the participants and prevent them from being fearful of engaging in PA.

#### 6.1.2.2 Support from significant others

It was apparent that those who did not enjoy PA, needed more encouragement and support to motivate them to participate in regular PA. For example, some of the participants reported how their husbands provided support and encouragement to participate in PA. Some explicitly stated that without the encouragement from significant others, they wouldn't participate in as much. However, it was perceived that these participants, who struggled to motivate themselves to be more active, did not participate in regular PA before their diagnosis because they do not enjoy it. This is apparent for Julie, as she states "I've never been a gym bunny or anything like that and I'm not, I'm not a fan of PA you know? I don't get anything from it, I've never done a lot, so Greg [husband] was really my focus to do it".

Brunet et al. (2013), found that social support was a contributing factor for continued engagement in PA, a woman in the study reported "My husband, he encourages me when I work-out. He compliments me, and it makes me feel good and keeps me going." However, this was only evident within one participant's account. Interestingly, findings from Emslie et al.'s (2007) and Sander et al.'s (2012), differed from the findings of the current study and Brunet et al. (2013), as they show that significant others such as family and friends, were described as a barrier to PA. Some of the women reported that their partner's and family members were concerned that the exercise class was "too much" for them, and revealed how this caused conflict (Emslie et al., 2007). Similarly, some of the women in the study by Sander et al.'s (2012), revealed how their family and friends discouraged activities, such as household chores and encouraged them to rest. The findings may be different within the studies (Emslie et al., 2007; Sander et al., 2012) because of the different sample included. In Emslie et al.'s (2007) study, all of the participants were undergoing treatment, and in Sander et al. (2012), the participants were both undergoing and had completed treatment. However, Sander et al. (2012), does not make it clear which participants were undergoing treatment or completed treatment, when using individual quotes to support the themes. It could be possible that if the participants are undergoing treatment, their partner's and family members may expect them to rest and recover from their treatment, as they may perceive them to be too tired and weak to participate in PA. All the participants in my study have completed hospital-based treatments, therefore their partners may recognise the importance of remaining active after treatments and so encourage and support the women to be active. Despite the contrasting findings, the importance of support from significant others is highlighted, as they suggest that the women's PA behaviours are influenced by their experiences and perceptions of support from significant others.

#### 6.1.3 The meaning of physical activity

This theme captures the meaning participants held about and their relationship with PA. Differences in attitudes, beliefs and experiences of PA are highlighted in the themes below: *"I've always been active"* and *"I didn't do anything before coming to the class"*.

#### 6.1.3.1 "I've always been active"

Some participants engaged in regular PA before diagnosis and tried to maintain as much PA throughout their treatment. Engaging in fitness classes and dance classes for Mariam and Valerie were perceived as 'normal' activities, therefore, to maintain normality or regain this, they prioritised PA and staying active through their treatments. For these participants in particular, health and fitness has always been an important part of their lives. Although PA was a normal aspect of Mariam and Valerie's life, the meaning of PA appeared to change since being diagnosed. As discussed earlier, PA was used to retain their sense of 'normality', and regain control over their sense of self, through engaging in 'normal' activities such as PA. Brunet et al. (2013), found that PA being a habit for some of the participants

contributed as a motivator to their engagement in it following breast cancer. The description of PA being a "habit" reflects the idea of PA being a 'normal' activity and therefore, the findings from Brunet et al. (2013), reflect those from the present study. As they demonstrate how PA behaviour being or becoming a 'normal' activity, is important for maintaining or reengaging in PA following a diagnosis.

#### 6.1.3.2 "I didn't do anything before coming to the class"

Other women in the current study reported having lower PA levels before their diagnosis, compared to now. Some described themselves as "lazy" and stated that they did not engage in any PA before they were diagnosed. They explain why they have changed their lifestyles and increased their PA levels, to improve their health and well-being and prevent illness or breast cancer recurrence. In particular, Pauline describes her participation in regular PA and exercise classes as "part of my treatment", she also states how she now prioritises PA over her work. Findings from existing literature are in line with these of the current study, as they highlight that breast cancer survivors' perceived health benefits of PA and experiences of increased health and fitness outcomes, contributed to adherence to PA interventions and uptake of self-directed PA (Browall et al., 2018; Brunet, Taran, et al., 2013; Bulmer et al., 2012; Luoma et al., 2014; Midtgaard et al., 2015). As discussed previously, for those who have changed their PA behaviour, they are using PA as a tool to create a new sense of self with regards to living a healthier lifestyle and improving their physical fitness and abilities. Their attitude towards PA and outlook on their lives, in the sense of being healthy, has changed since being diagnosed and completing treatment. This interpretation is highlighted in the findings from Adamsen, Andersen, Lillelund, Bloomquist, and Møller (2017), as they demonstrate how those who were physically inactive before their diagnosis indicated a shift in their PA behaviour and attitudes. They reported the factors which may have led to a change in PA behaviour, some of these factors were: perceptions of the physical, emotional and social benefits of PA with significant others. The participants in the study had participated in an exercise intervention, which involved oncologists and health care professionals giving PA recommendations and counselling, and a 12-week PA intervention which was either hospital-based, supervised high intensity, or a homebased low intensity intervention. Therefore, the participants may have transformed their attitudes and outlook towards PA, due to the awareness of the benefits of PA, due to the information and recommendations of PA covered in the counselling sessions. Again, this is similar to the participants in my study as all of them attended the Moving Forward programme, which covered a session on PA and the benefits of PA after having breast cancer. The participants also take part in a breast cancer specific exercise class regularly, as discussed previously they experienced benefits of participating in the class and this gives them a reason to continue their participation in PA. This further highlights the new meaning of PA for these participants; as their experiences of the PA benefits have transformed their attitudes and offered a new meaning as they use PA as a tool to create a new sense of self, through increasing their health and well-being.

### 6.1.4 The importance of "being with other people who were in the same boat"

Most of the participants appreciated the opportunity to engage in the exercise class with other women who have similar experiences and shared sense of understanding. Some of the women indicated how this factor particularly influenced their decision to increase their PA levels and participate in the exercise class. Maggie in particular stated how she was contemplating returning to the exercise class she went to before her diagnosis, however she did not return because it was not for women who have had breast cancer. This creates the image of feeling a sense of belonging and illuminates the importance of being with other women, with similar experiences. Findings from studies exploring breast cancer survivors' experiences of participating in an exercise intervention were similar. Giving and receiving support to peers, and sharing information was acknowledged as an important factor for the women (Bulmer et al., 2012; Luoma et al., 2014). On the other hand, exercising with other breast cancer survivors, created a sense of normality for the women, as they felt that they were treated 'normally' and didn't feel the need to talk about cancer (Balneaves et al., 2014; Luoma et al., 2014). Findings in my study differed slightly from the findings of Balneaves et al. (2014) and Luoma et al. (2014), as the majority of women appreciated having the opportunity to talk about their breast cancer experiences and discuss problems, to support each other. It could be interpreted that the women in Balneaves et al.'s (2014) and Luoma et al.'s (2014) studies, feel that because of the shared experiences and understandings of cancer between other participants in the exercise intervention; there is no need to ask questions and talk about cancer. The exercise class could provide a focus away from their family and friends, who might treat them differently since being diagnosed and therefore, the importance of not discussing cancer is dominant within these studies. Additionally, experiences of PA and the perceived benefits from participating in PA are very subjective, different individuals may have different views and attitudes. This could be another plausible suggestion for the different findings across the different studies as discussed above.

Additionally, for some there is a sense of a changed identity, as they identify and associate themselves with other women who have had breast cancer. This is illuminated when they discuss the importance of exercising with other women, with similar experiences. The sense of belonging indicates a changed sense of self identity, as they now identify themselves as someone who has had breast cancer, which is different from their 'normal' self. Normal in this context, means their previous self before diagnosis. This is emphasised within Maggie and Paula's quotes which highlight their choices of joining the exercise class because it was specifically for women with breast cancer. Maggie, in particular separates herself from others who have not had breast cancer, when she is describing the people who went to the same exercise class as her, before her diagnosis: "that would then be with people who had not had my experience". As we can see, her experience of her diagnosis has changed her being in the world and then changed her perceptions of herself and sense of identity. She no longer wants to exercise with women who she shares a commonality of having breast cancer.

# 6.2 Bringing it together utilising the Social Cognitive Theory

Researchers have applied theories of behaviour change, to gain a deeper understanding of PA behaviour amongst breast cancer survivors and aid the development of PA programmes (Short, James, & Plotnikoff, 2013). According to Phillips and McAuley (2013), social cognitive theory (SCT) is "one of the more commonly applied theoretical models" (Phillips & McAuley, 2013, p. 783). The SCT is made up of five core constructs which include: knowledge of the health risks and benefits, self-efficacy (an individual's beliefs in their control over performing a specific task), outcome expectations (an individual's expected costs and benefits of performing the task), goal setting, and the perceived facilitators and impediments (Bandura, 2004; Phillips & McAuley, 2013; Short et al., 2013). According to Stacey, James, Chapman, Courneya and Lubans, (2015) these key constructs of the SCT, provide understanding of the factors which determines why individuals adopt and maintain health behaviours. Although there have been numerous research studies exploring the use and effectiveness of SCT to guide PA interventions and understand health behaviours, the research using SCT to illuminate breast cancer survivors' experiences of PA is sparse (Short et al., 2013). Additionally, the SCT framework does not explore in depth the factors which may determine health behaviours, as many of them include objective measures to explore each constructs of the theory, in relation to behaviour change. Whereas, exploring behaviour utilising IPA, provides a deeper insight into individuals lived experiences and therefore, offers a deeper understanding of the meaning of PA and how the individual makes sense of their being in the world (Eatough & Smith, 2006). Below I will relate my research findings to the key constructs of the SCT and highlights the similarities and differences between them.

# 6.2.1 Knowledge of health benefits

According to the SCT, an individual's motivation to adopt or maintain health behaviours is determined by their knowledge of the associated benefits of the health behaviour (Bandura, 2004). Findings from my study illuminate this key construct of SCT, for example most of the women did not receive specific guidelines or advice on what types of PA is effective or safe. Some of the women reported how they were unsure of what types and how much PA was safe and effective after treatment, and how this made them fearful of causing further problems. This prevented them from participating in PA and therefore, suggests that the lack of knowledge of what type of PA is safe and beneficial influences their decisions of engaging in PA. Whereas, it was implied that once the women had attended the Moving Forward programme, which provided specific information with regards to the benefits of PA, this motivated them to engage in PA to improve their health and well-being. The importance of receiving specific advice and gaining knowledge of the benefits of PA was acknowledged within the findings of my study.

#### 6.2.2 Self-efficacy

Most of the women believe that they were improving their health and fitness, and controlling their chances of survival by reducing their risk of cancer recurrence, as a result of participating in regular PA. This captures the notions of self-efficacy described by Bandura (2004), as he states that people who believe that their actions will produce desired changes, will have more incentives to adopt and persevere with a lifestyle behaviour. Self-efficacy is also described as a person's belief in their physical ability to undertake activities and skills effectively (Bandura, 2004; Stacey, James, Chapman, Courneya, & Lubans, 2015). Bandura (2004), claims that if one has a strong belief in their abilities, they are more likely to commit to a behaviour. It could be interpreted that an extract from my research shows some similarities to Bandura's (2004) claim, as a participant stated how their participation in the exercise class made them realise that they were capable of doing resistance based exercises, something which they haven't tried before. However, it is important to note that the participant does not claim to participate in PA because of her awareness and belief in her physical capabilities. She was acknowledging the different PA experiences she has had since joining the exercise class. It could be possible that her ability to do different types of PA and the variety of exercises offered in the class, influences her choices to continue her engagement in the exercise class. Although these factors can be related to the selfefficacy construct, I did not label them as self-efficacy within my analysis. I believe that the meaning of engaging in PA and changing their lifestyles after their diagnosis, is much deeper than the idea of selfefficacy which is proposed in the SCT. My interpretation of the findings adds a deeper understanding to the idea of self-efficacy, as I believe that individual experiences of PA and reasons for engaging in PA behaviour is subjective to that individual and their embodied experience with the world. Therefore, the essential meanings of PA are somewhat deeper than the explanation of self-efficacy.

#### 6.2.3 Outcome expectations and perceived facilitators

Many of the participants acknowledged the benefits of PA, such as; improving their health and fitness, feeling good, improving mood, social opportunities etc. When describing what PA means to them, most of the women mentioned a perceived outcome or benefit of participating in PA. The most commonly reported outcome of PA, was improving overall health, to reduce the chances of cancer recurrence or other illnesses. It was interpreted that for these women, PA provided them with a sense of control over their health and lives, and this motivated them change their PA behaviour and participate in regular PA.

Many of the women describe positive physical benefits which they experience from participating in PA, such as; enhanced mood, improving health and fitness. Most of the participants identified the importance of social support and experienced a sense of shared understanding with those who have similar experiences. It was implied that a contribution of these factors influenced their experience of PA and therefore, their PA behaviour.

Using PA as a tool to control their health and well-being was one of the most dominant themes within my research findings, this conflicts the claims from the SCT. As, Bandura (2004), states that self-efficacy is the central determinant which affects behaviour and influences the other constructs of the theory. Although it could be argued that using PA as a tool to control their health, is associated with their outcome expectations; I believe that my findings provide a deeper insight and perspective of how outcome expectations in relation to health, influence the participants' behaviour. Unlike, the SCT which just provides a detailed description of the term.

### 6.2.4 Goals

According to Bandura (2004), those who set goals are more likely to be motivated to undertake and commit to a health behaviour. My findings did not relate to this construct of the SCT, as none of the participants in the current study mentioned goal setting, although they all continue to engage in the exercise class regularly and most of the participants engage in other PA behaviours. A possible reason for this difference in the findings and theory, might be that the participants engage in PA to improve their health and well-being, this could be interpreted as a long term goal according to the SCT. Additionally, for those who did not engage in PA previous to their diagnosis, adopting change to their lifestyles and committing to PA may be a goal for them. Again, it is important to acknowledge that IPA offers a more holistic approach and the interpretations made in my research provide a deeper insight into the experiences of PA, compared to the SCT.

# 6.3 Summary of the SCT in relation to Phase One: research findings

Utilising IPA to analyse my research illuminated many factors which may relate to the key constructs of the SCT in some ways. Above, I have discussed the relation between my research findings and the key constructs and provided a discussion of the similarities and differences between them. Although, there are some similarities, it is important to acknowledge the difference between utilising the SCT and IPA to understand PA behaviour. SCT does not take into consideration other factors which may influence one's behaviour, as mentioned previously it does explore in depth one's experiences of each constructs and how these relate to behaviour; the constructs included are used to provide a framework of the proposed factors which determine behaviour. Whereas, IPA is a holistic approach which explores individual experiences of a phenomena, to provide a deeper understanding of the meaning of their experience. IPA is concerned with subjective experiences and looking for similarities and differences among a study sample, as opposed to generalising the findings to other populations and contexts (J. A. Smith, 2017).

# 6.4 Strengths and limitations

In this section, I will highlight and discuss the strengths and limitations of Phase One on my research study.

# 6.4.1 Strengths

As discussed in chapters three and four, IPA was chosen as the most suitable approach to explore the phenomena of interest, for Phase One of my research; as it seeks to explore and understand individual meanings of experience (Brocki & Wearden, 2014). Although, this was my first time encountering research using IPA, I believe that after many attempts of analysis and writing up the findings, that I captured the breast cancer survivors' experiences of PA and illuminated the essential meanings of their experience. The flexible approach of IPA allowed me to adjust the stages of analysis, and adapt to my experience and style as a researcher (Smith, 2004). This enabled me to develop my skills as a researcher and understanding of the participants' experiences of PA. The adjusted stages of analysis are highlighted and discussed in more detail in chapter four. Additionally, IPA aims to collect first person accounts of experiences of the research phenomena (Pietkiewicz & Smith, 2014); this fits with my aims and intentions of the research, as I wanted to give each participant a voice and meaning throughout my research. IPA enabled me to do this and provide meaningful insights into their experiences, to increase understanding of the research phenomena.

### 6.4.1.1 The shifting positionalities as an 'insider' and 'outsider' researcher

Although, I have acknowledged and discussed some of the challenges faced because of my relationship with the participants and the shifting positionality of my relationship to the participants; it is important to highlight the advantages of my relationship with the participants and position as a researcher. As discussed previously, the position of a researcher is dynamic and complex, and one's position in the world, regarding their position to the participants is not static (Ryan, 2015). The position as a researcher changes throughout the research process, depending on different participants, their experiences, the context of the interview environment etc (Dwyer & Buckle, 2009). Firstly, I felt that most of the participants were comfortable and open with me during the interviews, because of the relationship we shared before conducting the interviews. Once, I became confident with my interviewing skills, I felt comfortable when interviewing the participants and probing for deeper insights into their experiences. I believe that my relationship with the participants and the trust established between us; enabled both myself as the researcher and the participants to feel comfortable when discussing and exploring the experiences of research phenomena during the interviews. Furthermore, my relationship with the participants enhanced my understanding of their experiences; this aided me throughout the analysis stage of my research (Dwyer & Buckle, 2009). However, as my positionality shifts to an 'outsider' researcher, this enabled me to engage with the data from a different perspective; this enabled me to approach the data openly and focus on the participants' perspectives of their experience (Hayfield & Huxley, 2015).

#### 6.4.1.2 Engaging in Reflexivity

Throughout the research process, I have kept a reflexive audit trail to document the analytical procedures and decisions I have made throughout. As discussed previously, engaging in reflexivity is important throughout qualitative research, to enhance the rigour of the research (Finlay, 2002a). I have discussed my reflections throughout different chapters, relating to my reflections of specific research stages and the decisions I have made, and how these decisions may have impeded the data collection and analysis. This allows the readers to understand how the findings have emerged and how my actions and position as a research may have influenced the findings. Additionally, this process allowed me to develop my skills as a researcher, as I reflected upon my experiences, emotions and feelings throughout this phase of my research.

#### 6.4.1.3 Contribution to research

As discussed previously, qualitative research exploring breast cancer survivors' lived experiences of PA is limited. In particular, research adopting IPA approaches to provide insight into the essential meanings of PA is sparse. Therefore, this study contributes to the field of research and existing knowledge, as it provides new, unique insights into the research phenomena and enables a deeper understanding of breast cancer survivors' lived experiences of PA. The findings from the study may help future research and have beneficial implications for future policies and practice within healthcare.

# 6.4.5 Limitations

The limitations that have emerged during this phase of the research will be discussed in the sections below.

### 6.4.2 Researcher relationship

My relationship and dual role as the researcher and exercise instructor may have limited the collection and analysis of the data. For some of the participants, the detail they provided in the interviews when giving their accounts of their experiences was sometimes limited and vague. It could be possible that they expected me to have previous knowledge and understanding of their experiences, due to my relationship established with them before conducting the research. Additionally, the relationship I had with the participants before conducting the research influenced my decisions during the recruitment process and therefore, limited the sample involved. For example, all the participants are: of a similar age, white females, from the same location and participate in the same exercise class. This limits the variation amongst the sample and limits the transferability of findings to other contexts and groups of 107 people (Robinson, 2014), such as: young breast cancer survivors or to those diverse ethnic backgrounds, as they were not represented in my study. In retrospect, my recruitment method could have been improved and sample could have been more diverse. However, the sample group chosen is appropriate for the aims of the research and IPA methods utilised. Additionally, it is important to acknowledge the similarities between my research findings and findings from existing literature; this illuminates that my findings are similar to wider and more varied sample groups and contexts.

#### 6.4.2.1 Experience as a researcher

This was my first time encountering research, when I began collecting and analysing the data I was an inexperienced researcher. This affected my first interview, as I did not have the experience or skills to successfully conduct the interview. The first interview was very rigid, as I focused on following the interview schedule and did not prompt or explore the participant's responses in depth. With reflection of this experience, I went away and practiced my interviewing skills and attended training on data collection, which involved conducting interviews. I used my reflections and training to develop my skills throughout the remaining interviews. Similarly, when encountering the analytical process for the first time, I did not focus on the meaning of the experience to the participant and I focused mostly on their experiences of diagnosis, without linking it to PA. This had taken some time to grasp and numerous attempts of rewriting my understandings of the participants' experiences. Although the analysis of this phase of my research did take a considerable amount of time, it enabled me to become familiar with each participants' experiences; which enabled my understanding of the meanings of their experiences. However, it is important to acknowledge that my skills and knowledge as a researcher will continue to develop throughout my research career.

### 6.5 Reflexivity

Within this section I aim to make my position as the researcher transparent, during the analytical stage of Phase One of my research study. As discussed previously in chapter 4, in qualitative research, it is fundamental to engage in reflexivity as the researcher plays a central role throughout the different stages of the research. I will illuminate my experiences of using IPA to explore the lived experiences of PA amongst breast cancer survivors.

#### 6.5.1 My experience of using IPA

Before starting this stage of my research, I was unfamiliar and inexperienced with engaging in qualitative research. Although I had a lack of research experience, I wanted to understand the meaning of PA and explore breast cancer survivors' experiences of PA. Therefore, it was clear that a qualitative approach would be most appropriate, with IPA being well suited given its focus on first person experience. My lack of knowledge and experience of qualitative research, in particular IPA; was

somewhat problematic throughout the research process, which caused challenges whilst analysing my research findings. I will discuss these challenges in more detail below. To develop my knowledge and understanding of IPA, I attended training and read existing literature which utilised IPA methods, within different research contexts. However, understanding IPA was a dynamic process throughout my research journey and it was not until I began to engage with my data and using IPA, that I began to truly understand the essential meaning IPA. This became evident throughout analysing my data, as I was faced with numerous challenges because it was my first encounter experiencing IPA.

#### 6.5.2 Analysing the transcripts and writing up the findings

The initial analysis of each transcript was a learning curve for me. I began analysing the transcripts, just skimming the surface of each line and making notes on key words or phrases which I thought were interesting. I clustered the notes together into themes and placed these into a list, I then ideographically wrote up the findings from my initial analysis of each transcript. I believe this helped me to develop my understanding of IPA and become immersed in my data. However, I spent a considerable amount of time considering which theme titles are best suited to their lived experiences and how to write phenomenologically, whist capturing the individual's language and words used. Originally, my themes and words used throughout my written accounts of my analysis, did not capture the lived experiences of PA, instead I focused on the experiences of being diagnosed with breast cancer, and my language was not experiential. I reread studies using IPA methods, and focused on the language they used when writing up the findings and exploring the meaning of the phenomena. From this, I reanalysed the transcripts keeping the phenomena of interest in the forefront of my mind, similar key findings emerged but my interpretation of these changed slightly. With many attempts at writing and rewriting my interpretations of the participants' experience, I finally felt that I had captured and illuminated their experiences and meaning of PA. However, I do acknowledge that there is always room for improvements and each time I return to the data, my interpretations may differ as my relationship with the data and participants continues to evolve.

Once I felt happy with my interpretations and understanding of each individuals' experiences, I brought them together and produced a draft version of the findings. I found this stage of the analysis challenging, as I found it difficult to group their experiences because I had previously been focusing on the individual meanings of their experience. Initially, I wanted to include all quotes from each participant, which illuminated the themes. When I became aware that this was not necessary, I spent a considerable amount of time choosing which quotes illuminated each theme and captured the essential meaning of the experience. I felt my dynamic position between being the researcher and as a friend shift throughout this stage, which often caused challenges when writing up the findings. As my position shifted between being the researcher and as a friend, my relationship with the data shifted slightly. An example of this is, as the researcher I was focusing on which themes best illuminated the themes and meaning of the experience; whereas, when my position shifted from a researcher to a friend, I was most concerned

about how the participants would perceive and respond to my findings. I felt all individual experiences of PA were equally as important and I wanted to give each participant a voice. Therefore, I found it difficult choosing and selecting quotes to capture the meaning of the experience as a whole. Throughout many drafts and conversations with my supervisors, I began to realise that throughout my discussion of each theme, I was giving each participant a voice and capturing each individual meaning of their experiences of PA. Finally, I felt happy with my written account of the findings and felt that the themes illuminate parts of the experience and so the themes together, capture the experience as a whole and illuminates the essential meaning of PA for these participants.

# 7. Phase Two - Method: Health care professionals

Phase Two focused on the exploration of health care professionals' (breast cancer nurses) perspectives and experiences of promoting PA to breast cancer survivors. The method of analysis chosen for this phase of the research is template analysis; this method is flexible and can be used within a phenomenological approach and focuses across cases rather than case-by-case analysis (Brooks et al., 2015). In this chapter I will explain the rationale for shifting from IPA methods of analysis to template analysis, and I will discuss the methods and sample used for Phase Two of the research.

# 7.1 Aims and objectives

The specific aim of Phase Two of the research study is:

To gain insight into breast cancer nurses' perspectives and experiences of promoting PA to breast cancer survivors.

The objectives of Phase Two of the research are:

- 1. To explore various factors which may affect breast cancer nurses' promoting PA to breast cancer survivors.
- 2. To individually interview breast cancer nurses who are involved in the breast cancer treatment pathway

# 7.2 Sampling and recruitment

In this section I will discuss how the sample for this phase was defined and recruited. In total, five breast cancer nurses were invited to participate in the research, all agreed to do so.

### 7.2.1 Sampling method

There were slightly different sampling methods used to recruit the participants in this phase of the research. This is due to the difficulties of recruiting participants and the ethical procedures involved. The initial method involved purposive and convenience criteria, to select and recruit four of the participants. The participants were selected purposely, based upon their shared experiences of their jobs and their knowledge of the phenomenon of interest for this phase of the research (Ritchie, Lewis, Nicholls, & Ormston, 2013). However, due to the ethical considerations, I did not recruit these participants personally; the lead specialist nurse (Julia) granted me access to four participants, including herself and gave me the contact details of the other three breast cancer nurses. These participants were selected conveniently based on their availability, meeting the inclusion criteria and the work and

time constraints of the NHS (Etikan, Musa, & Alkassim, 2016). The other participant (Cathleen) was recruited via snowball sampling technique; this method is described as the researcher gaining access to participant's and their contact information, through information provided by another participant (Noy, 2008). I contacted Cathleen via email, she agreed to participate in the research and we arranged a time and date most convenient for her. Below I will discuss the recruitment procedure and barriers which I faced whilst recruiting participants for Phase Two of this study.

### 7.2.2 Recruitment procedure

Originally I proposed to recruit any health care professionals' who were involved in the breast cancer treatment pathway. I proposed to have a broad/wide inclusion criterion, to increase the number of potential participants. However, due to certain barriers, unfortunately I only had access to five breast cancer nurses.

I gained ethical approval from Calderdale and Huddersfield NHS, Research and Development (R&D) department (see 7.7 below for further details) (Appendix 9). This allowed me to access Calderdale and Huddersfield hospital sites to interview breast cancer nurses. The R&D lead who dealt with my ethics proposal, liaised with a specialist nurse for further consent and access to members of staff. Due to time constraints and pressures of the NHS, I only received approval to access four breast cancer nurses for a maximum of 30 minutes. I co-ordinated with the line manager of the breast cancer nurses; she provided me with the contact details of the potential participants. I originally contacted the participants via email invited them to participate in the study, an information sheet and demographics sheet were attached to the email. For those who did not respond to the email, I contacted them over the phone and spoken to them, or left a voice mail. All of the participants agreed to participants.

Five breast cancer nurses were interviewed, the interviews were conducted within the grounds of both hospital sites, due to the convenience for the participants; before conducting the interviews, the participants signed a consent form (Appendix 3) to agree to participate in the research.

### 7.2.3 Inclusion and exclusion criteria

Individuals who were health care professionals, involved in the breast cancer care treatment pathway, who worked at either Huddersfield or Calderdale hospital sites and were able to speak English were invited to participate in the study.

Individuals' excluded to participate in the research were those who did not speak English, as there are no resources to fund translators, and health care professionals who have no prior involvement in the breast cancer treatment pathway.

### 7.2.4 Sample

In total five breast cancer nurses agreed to take part in the research study. It is important to note that, each participant has been assigned a pseudonym to protect their confidentiality and maintain anonymity.

# 7.3 Data collection procedures

Individual semi-structured interviews were chosen as the method of data collection. This was chosen as the most appropriate method to openly explore the breast cancer nurses' perceptions and experiences of promoting PA advice to breast cancer survivors. The flexible approach of semi-structured interviews, allows the participant or researcher to diverge away from the interview guide and lead the discussion and potentially lead to the discovery of important points which may not have been included in the interview guide, or thought of before the interview (Chadwick, Gill, Stewart, & Treasure, 2008).

A semi-structured interview guide was developed based on previous literature, which involved the exploration of health care professionals' experiences within other fields of research (see Appendix 10). Open ended questions were developed, focusing on areas relating to background information with regards to their experiences of working within the breast cancer treatment pathway, their perceptions and attitudes towards promoting PA to breast cancer survivors in relation to whether they regard this as their role and their previous experiences of promoting or giving PA advice. I was also interested in what factors influence their experiences and perceptions towards promoting PA to breast cancer survivors. The interview guide involved different probes under each question; these were used to coax the participant to elaborate on points or to gain clarification of what they have said, in order to develop a deeper understanding of their perceptions and experiences.

The interviews were conducted within two hospitals; four of them were conducted in a small room and one of the interviews was conducted in the hospital café. The duration of the interviews varied, however the average time was approximately twenty minutes. All interviews were audio recorded with the participants' consent.

# 7.3.1 Building rapport

Building rapport with the participants is essential to establishing a research relationship and in a sense, respect between the researcher and participant (Miller, 2017). Rapport between the participant and researcher, establishes a comfortable environment and allows the participant to feel comfortable discussing their experiences and perceptions of the phenomenon of interest (DiCicco-Bloom & Crabtree, 2006). In reflection, this would have helped me as the researcher, to feel more comfortable and less apprehensive; as I felt that during the interview, once I began to talk to the participants, I felt 113

my apprehensions about the relationship between myself and the participants disappear. This is when I began to relax and my interviewing style improved, as I listened to the participants' responses and felt comfortable to probe them further. Therefore, it could be possible to suggest that, if I had established rapport with the participants prior to the interviews, or conducted a pilot interview, the environment would have been more relaxed and my interviewing style would have been of better quality.

### 7.3.2 Researcher-participant relationship

As suggested previously, the relationship established between the researcher and participant is important, as this effects the collection and interpretation of the research data (Finlay, 2002a). My position as the researcher and my relationship with the participants differs from my relationship with the participants in Phase One of the research study. As discussed previously in chapter four, the position of the researcher is dynamic and the idea of being either an 'insider' or 'outsider' researcher is rejected, due to the shifting researcher positionalities throughout the research process (Soni-Sinha, 2008). Although, my position did shift back and forth as an 'outsider' and an 'insider' researcher; I felt that it was primarily one sided as an 'outsider'. I related this notion of the 'outsider' status, with feeling like an intruder, I often felt like this throughout the data collection process. I believe it is because of a number of factors such as; I did not know the participants personally or previously to collecting the data, I do not share the same experiences as a breast cancer nurse or health care professional and my unfamiliarity with the hospital environment. I felt my position shift slightly throughout the data collection process, as I became more familiar with the hospital environment, I became aware of my similar experiences of working with breast cancer survivors, and with some individuals, I shared the same attitudes towards the importance of PA. However, I only began to realise these commonalities which I shared with the participants later in the data collection stages. It could be possible that I became aware of these, as I became more confident as a researcher, more relaxed within the environment and talking to the breast cancer nurses. Prior to collecting the data and meeting the participants, I was concerned about my relationship with the participants and their perceptions of me as a young researcher and an exercise professional. I often thought that they would perceive me as an intruder or an 'outsider', as I thought that they would see me as a researcher and not a health care professional with experience. Additionally, I thought that my role as an exercise professional would perhaps cause conflict between our views and attitudes towards PA and promotion of PA and therefore, influence the data collection process. However, during the interviews I attempted to keep my role as an exercise instructor separate, as the main focus was to explore the breast cancer nurses' experiences, not my own.

#### 7.3.3 Interview process

All of the interviews were conducted at either Huddersfield or Calderdale hospital sites, between May-July 2017. The duration of the interviews varied, with the average duration being 20 minutes, due to the limited time availability of the participants and only having agreement from the line manager to conduct the interviews with a maximum duration of 30 minutes. Before I started the interviews and began recording, I had an informal conversation with each participant to introduce myself, give more background information about the research topic and hand out a consent form and demographics sheet for them to complete. I felt that the conversation helped to establish a relationship with the participants and build rapport with them before starting the interview. Additionally, this eased my nerves slightly and allowed the beginning of the interview to flow easily. Each participant gave oral consent to participate in the research and for it to be recorded.

The interview began with exploring their experience of working as breast cancer nurse and then progressed onto their experiences and perceptions of giving PA advice. The interview guide was used flexibly and the questions were mostly open ended, allowing the participant to give their personal account of the areas being explored. When I probed the participants, these tended to be closed questions to gain clarity and understanding. During the interviews, I wrote notes with regards to the participant's body language and responses to questions, to refer back to when analysing the data and help me reflect on the interview to understand their meaning of their narrative account.

Following the interviews, I reflected on my thoughts and feelings about the interview and documented these in my reflexive diary. This allowed me to improve my interview skills, and change anything if necessary to enhance the collection of data.

#### 7.3.4 Reflexive accounts of individual interviews

I will discuss the interview setting and my reflections of each interview below. This captures my experiences of the interviews and provides examples of my reflexive accounts. Reflexivity is essential in qualitative research; as the researcher plays a central role in the collection and analysis of research data (Finlay, 2002b). Reflexivity allows the researcher to explore and evaluate how their presence and subjectivity, throughout the research process influences the research findings. It is particularly useful to provide reflexive accounts of the data collection process, to highlight how my role and relationship with the interview environment and participants, affects the findings produced.

#### Interview 1- Davina:

Prior to the interview, I was very nervous and almost apprehensive to meet Davina. Reflecting upon my thoughts and feelings made me realise that I felt this way for a number of reasons such as; not knowing the participant prior to the interview, lack of time or opportunity to build a research relationship, the interview setting within the hospital environment, agonising about the possible power imbalance between myself and the participant, and feeling intrusive. I was aware of the time constraints and pressures within the NHS; as a result of these pressures, I was given a time limit of 30 minutes which I had to abide by. This made me feel as though I was an intruder, who was intruding on the participants' time and profession, by probing about their experiences as a breast cancer nurse and promoting PA. 115

From what I can remember, I have never been in a hospital room prior to conducting the interview, therefore the physical environment of the hospital was unfamiliar and again, this made me feel like an intruder. As I was waiting to meet Davina, I was sitting in the hospital waiting room waiting in this unfamiliar setting added to my nerves. I noticed that I was playing out possible scenarios in my head of how the interview would go, I was practicing the questions which I wanted to ask repeatedly and worrying about interviewing someone who I saw as 'superior' than myself.

When Davina called me into the room, where the interview took place my nerves increased and I felt as if I did not know what to say or how to initiate a conversation. I feel that this was due to not knowing Davina, and not establishing a professional relationship with her before the interview. Despite, my awareness of the limited time to conduct the interview, I felt that it was very necessary to build rapport with Davina, by having an unrelated informal conversation before I began the interview. This helped me to relax slightly and allowed me to begin the interview, however I was concerned about how much time this had taken and unsure how long the interview would last. I realised that my concerns about the time, affected my interviewing style, as I was rushing and not listening fully to her answers and therefore, missing opportunities to prompt further. Additionally, instead of using the interview guide flexibly, I tended to ask the questions word for word and was worried to deviate from them. Reflecting back on this, I realised that this was due to my nerves, preconceptions and lack of interviewing experience.

After the interview, I wrote my reflections of the interview in a diary and I used these to help me prepare for the following interviews and therefore, improve my interview skills.

#### **Interview 2- Judith**

Due to the challenges in my previous interview with Davina (as noted above), I felt nervous to conduct the second interview. Additionally, the interview location was at a different from the first interview (the second hospital site), therefore the unfamiliarity of the environment again made me feel anxious. On the other hand, I felt more prepared as I used my reflexive notes to identify alternative prompts and questions if needed. Before the interview, we chatted informally and I felt comfortable to open up to Judith about my nerves and worries, with regards to the how the interview would go. She reassured me and almost comforted me, which made me feel at ease. This relationship established through this interaction helped during the interview process, as I felt comfortable to ask questions and probe deeper. Therefore, I felt that the interview guide more flexibly; allowing Judith to freely talk about her experiences and lead the conversation.

#### Interview 3- Caitlin

I had met Caitlin after the interview with Judith, as I struggled to arrange an interview with her via email. I met with Caitlin to give her some information of the study and ask if she would like to participate, she 116 agreed and we arranged a time and date for the interview, which was most suitable for her. Having met Caitlin prior to the interview, this helped me feel at ease and more comfortable when conducting the interview. I felt more at ease with Caitlin because she was a younger nurse, who I felt more relatable to.

#### **Interview 4- Cathleen**

It had taken a while to organise an interview with Cathleen due to her busy work schedule and being based at another hospital site the majority of the week. This made me feel under more pressure to ensure that the interview did not over run 30 minutes. I was also anxious about the power dynamics and relationship between us, as we had only communicated with each other previously, over email. Although, Cathleen previously stated that she was happy to participate in the research; I did feel as though the interview may have been a slight burden for her and cause inconvenience because she was so busy. However, these feelings disappeared during the interview, as she had a relaxed charisma and passionate to participate in the research. This passion came across throughout the interview, with relation to her job role and encouraging breast cancer survivors to participate in regular PA. This sense of shared understanding and passion of encouraging breast cancer survivors to become more active and the importance of PA, made me feel like an insider. I felt comfortable to ask questions and probe for deeper discussions.

#### Interview 5- Julia

Despite the previous interviews going well, I was most anxious for the interview with Julia due to previous conversations over the phone and email. She came across quite abrupt and stern over the phone, which made me feel uneasy. I was aware of her professional status, as she was the line manager of the other participants and she granted me permission and access onto the hospital sites to conduct the interviews. This made me anticipate awkwardness between us when we met and during the interview. Our initial meeting before the interview was rushed and the interview appeared to begin almost instantly. Unlike the other interviews, this interview was conducted in the café at the hospital which was very busy and loud. Throughout, I struggled to hear Julia and did not feel comfortable to keep asking for her to repeat herself, this may have led to me missing the opportunity to probe deeper or clarify her meaning. Additionally, there were moments throughout the interview which I could not hear clearly when transcribing.

### 7.4 Managing the data

I transcribed the interviews using express scribe software; I then transferred this onto Microsoft word and amended any typing errors. As a result of the interviews being shorter in duration and the long duration of time between each interview, I transcribed the interviews as soon as possible after the interview was conducted. This allowed me to reflect on how the participant responded, with regards to their body language and pitch therefore, aid my understanding of their meaning. Again, I wrote a note of this to help during the analysis process. The data was then analysed manually by myself and Kiara acting as a co analyst, I will go onto to discuss the method used to analyse the data in more detail below.

### 7.5 Data analysis

For this phase of the research study, template analysis (TA) was the technique utilised to thematically analyse the data. TA is a flexible approach which can be utilised across multiple epistemological positions and different forms of textual data such as focus groups and diary entries. However, the most common data involved in TA are usually interview transcripts (Brooks & King, 2012). The central focus of TA is to develop a hierarchical, coding template, which is initially based on subset of the data (Brooks et al., 2015). The initial template is developed from a priori themes, which are based upon emergent key findings from previous research. It is important to note that, the initial template and a priori themes are tentative, and can be adapted and modified throughout the analysis process (King, 2004). The coding template is created to group together themes and organise them with a hierarchical structure, to represent the themes in relation to the research question (King & Brooks, 2016). King (2012) describes codes as labels which are attached to sections of the text, to identify that it is relating to a theme, which the researcher has interpreted as significant or important, to the experience or phenomena of interest. These codes are placed in the margins, alongside the sections of the text which are highlighted and relate to the code. The higher-order codes are usually broad and provide an overview of the researcher's interpretations and understandings of the participants' experiences and perceptions, whereas, the lower-order codes are more detailed and allow for distinctions to be made between and across cases (King, 2012).

Below I will provide a justification for choosing TA and details of the step by step method of developing the template.

### 7.5.1 Template analysis

The whole research thesis works within a phenomenological framework. TA is a flexible approach which can be utilised within different methodological and epistemological positions (King & Brooks, 2016). TA has been used widely within health research and in particular, can be used within 'contextual constructivist positions' (King, 2004, p.256). Thus, it is acceptable to apply TA within a phenomenological approach. Keeping within the phenomenological approach, I will be using TA from a 'contextualist position'. King and Brooks (2016), acknowledge the central role of the researcher and participant, and all knowledge that is gained through research is 'context specific' and subjective. I have chosen TA over IPA, due to the time constraints and the specific aims of Phase Two of the research.

The aims are to gain insight into the breast cancer nurses' experiences and perspectives of promoting PA and giving PA advice to breast cancer survivors. Unlike IPA, I am not concerned with gaining an in depth understanding of each individual's experiences. The focus is to compare the perspectives and provide a cross analysis of their experiences. Therefore, TA was chosen for practical and theoretical reasons.

# 7.5.2 Developing the template

The initial template was developed using a priori themes, which were emergent key findings from previous research literature, which explored health care professionals' views and attitudes of promoting PA advice. The main themes were very broad, allowing me to keep an open mind when analysing the first transcript, utilising the initial template. The initial template was developed with the help of Dr Kiara Lewis, as she has had previous experiences using TA (Interview guide **for health care professionals:** 

Background information

- 1. How long have you been a health care professional involved in the breast cancer treatment pathway for?
  - -Role within the NHS
  - Prior related experience?

### Physical activity:

- 2. What are your perceptions of advising physical activity to patients following breast cancer treatment?
  - -do you see this as part of your role?
  - -if not why? Whose role (if anyone's) is it?
  - would you view breast cancer patients differently from other cancer patients with regard to advising physical activity? Why/why not?
- 3. What are your experiences of giving physical activity advice to patients following breast cancer treatment?
  - Have you given any advice?
  - If yes: Facilitators? What types? To whom?
  - Please describe an example of a case where you gave such advice.
    - How did you feel in this case? How does that compare to others?
  - If no: Why not? Barriers.

- 4. How do you feel about giving advice and information regarding physical activity to those who have completed breast cancer treatment?
  - Facilitators?
  - Barriers?

NB. For each area of questioning an attempt will be made to facilitate participant's reflection of their lived experiences.

Appendix 11) I tested and applied the initial template on the first transcript, and made modifications to the template throughout the analysis of the first transcript. Cathleen's transcript was chosen as the first transcript because it was rich data, which covered different aspects in depth.

I used a colour coding format when analysing the transcripts, each theme had an identifying colour to make it easier to find the data which represented the themes. I highlighted segments of the text which represented the themes and placed the code in the right hand margin. Most of the a priori themes were not relevant or did not appear within the first transcript, new themes and codes emerged from the data and I added these to the template, I used a red pen to mark the new themes and codes. Due to the large amounts of modifications to the template, I created the second template (see Appendix 12) and applied this to the other four transcripts. Again, modifications were made throughout the process when new interesting themes emerged throughout the transcripts and these were marked in red on the template. The final template was developed and finalised with critical input and agreement from the supervisory team. I will discuss my reflections upon encountering and utilising TA for the first time in chapter eight.

### 7.7 Ethics

Originally, I began to apply for ethical approval and access to breast cancer nurses through the Integrative Research Application System (IRAS). Once, I had gained ethical approval from the local R&D lead for the sites (Appendix 9) I was given a research passport which granted me access onto the sites, which I wanted to recruit participants and collect data from. I kept in contact with the R&D lead and she gave me the contact details of the lead specialist breast cancer nurse; who was the line manager of other breast cancer nurses and became one of my research participants. Originally I proposed to recruit 10 participants and estimated the duration of the interviews as 45-60 minutes, these propositions were rejected almost. Due to limited access to staff and time pressures, I was only given the contact details of four breast cancer nurses (one including the line manager), and a maximum duration of 30 minutes for the interviews.

# 8. Phase Two - Findings

In this chapter I will explore the breast cancer nurses' perspectives and experiences of promoting PA to breast cancer survivors. I will present my interpretation of this phenomenon, utilising template analysis. I will organise the chapter based on the structure of the themes within the final template which was developed. The first main theme explores the breast cancer nurses' perceived responsibility of promoting PA advice, this involves factors which influence if they provide PA advice and the type of information they give. The second main theme explores the nurses' views and perceptions towards services and resources. The third main theme explores the relationship between the breast cancer nurse and individual breast cancer survivors and how this influences the advice they give. The fourth main theme explores the breast cancer survivors, this includes their perceptions of how breast cancer survivors respond to their cancer and its treatment and how they respond to PA. Table 8-1 shows the final template devised. It is important to note that, there was a range of perceptions and attitudes towards promoting PA amongst the breast cancer nurses and some of them were more proactive than others in promoting PA.

Main theme	Second level themes	Third level themes
Perceived responsibility	Scope and limits of	Value/importance of PA
for promoting PA	responsibility	It's part of my role
		Lack of time and opportunities
		Covered elsewhere/ other resources
		Inappropriate
	Encouragement/support	Interpreting individual needs
		Passing responsibility to exercise professionals
External services and resources	Resources	
	Conflicting advice	
Nurse-survivor relationship	Getting to know them personally and building trust	
Perceptions of breast cancer survivors'	Breast cancer survivors' interests in PA	Reluctance to be physically active
characteristics		Determined to be physically active
	Perceptions of breast cancer survivors' barriers to PA	

## Table 8-1 Final Template

# 8.1 Main Theme 1: Perceived responsibility for promoting PA

Breast cancer nurses' personal perceptions and experiences of promoting PA and giving advice, have implications for the services offered to breast cancer survivors. Different factors and personal perceptions/attitudes of promoting PA may influence what types of information are given to breast cancer survivors. The second level themes are: scope and limits of responsibility and encouragement/support.

### 8.1.1 Scope and limits of responsibility

The breast cancer nurses had different attitudes and perceptions of their responsibilities and some acknowledged different factors which limited their responsibility to promoting PA to breast cancer survivors. It seems that these differences of perceptions and attitudes, affected their approach to promoting PA.

#### 8.1.1.1 Value/importance of PA

Many of the breast cancer nurses acknowledged the importance of PA for breast cancer survivors and therefore, they expressed their desire and willingness to promote PA and encourage it to breast cancer survivors:

**Cathleen:** So you know it's difficult for some of them, so that's why I think it is important that we try and encourage them to get back and try to give them that confidence [pause] to go back, to doing their normal activities. Cos' it helps them physically and psychologically as well.

**Caitlin:** I think it just has [pause] a massive impact on people's well-being. I know PA is important for obvious reasons, keeping fit, you know these kinds of things.

Both Cathleen and Caitlin focus on the importance of PA from a holistic point of view, as they describe the benefits of PA relating to 'normality' and indicate how PA improves overall quality of life. Cathleen acknowledges the difficulties that some breast cancer survivors face and highlights the importance of supporting those individuals to return to their pre-diagnosis activities. There is a sense that Cathleen feels that she is helping individuals through their recovery, by offering advice on how to return to "normal activities" and encouraging them to engage in PA. It is perceived that she wants to support individuals which have been under her care and therefore, their recovery to health is her responsibility. Cathleen suggests that she believes that all breast cancer nurses' hold the responsibility to encourage breast cancer survivors to return to 'normal' activities and engage in PA; this is implied as she uses the first person plural noun "we" in the extract above.

Similarly, Davina acknowledges the importance of PA in relation to overall well-being. However, there is a sense that it is not her personal opinions, as she talks about breast cancer survivors' beliefs and feelings towards PA, rather than her own:

**Davina:** I think [PA] it's making their well-being, making them feel like they're doing something and it's making them feel that they feel better, their energy levels are sometimes improved.

It could possible that Davina does not hold any personal values or perceptions towards the importance of PA and therefore, related her response to breast cancer survivors' perceived benefits of PA. Alternatively, she may have perceived that the question relating to the importance of PA was related to her perceptions of breast cancer survivors' beliefs and feelings towards engaging in PA.

In contrast to Caitlin and Cathleen's extract, Julia appears to focus on the importance of PA from a medical point of view. Her extract differs from Davina's also; as she highlights and relates to her personal views towards the importance of PA:

**Julia:** Ultimately at the end of the day I do feel that, you know if we keep ourselves healthier and we keep ourselves fitter then we will reduce our risk of cancer.

Unlike Davina, Julia does not focus on the importance of PA specifically for breast cancer survivors; she refers to the importance of PA in a collective capacity as she says "we", this implies that she is referring to everybody including herself. This emphasises her personal beliefs towards PA and the importance of PA to prevent the risk of developing cancer. This differs from Caitlin and Cathleen's focus in relation to the importance of PA, as they concentrate on the benefits of PA improving breast cancer survivors' overall health and well-being after being diagnosed and receiving treatments. Whereas, Julia focuses on the diagnostics and preventing cancer and she indicates that she is relating to any time point, not just soon after a cancer diagnosis. It is important to acknowledge that the breast cancer nurses' personal attitudes and perceptions towards PA may influence the information they give to breast cancer survivors, with regards to PA. It could be possible that for those nurses who focus on the importance of PA relating to preventative benefits, or those who do not acknowledge the importance of PA, may be less proactive when prescribing PA. However, other factors may also influence their PA promotion behaviour also.

#### 8.1.1.2 It's part of my role

The majority of the participants acknowledged that promoting PA is a part of their role and some highlighted the importance of promoting PA to breast cancer survivors. However, there appear to be different attitudes towards the context in which PA promotion is most important. For example, Cathleen and Caitlin indicate that it is important to promote PA whenever possible, to help breast cancer survivors

return to normal; whereas Julia indicates that it is particularly important to promote PA to those who are osteoporotic or at risk of osteopenia, rather than all breast cancer survivors:

**Cathleen:** It's part of our role, because they've got to get, they've got to try and get back to as much normality as they can after their diagnosis and treatment. So it is up to us and the thing is if they don't get [pause] mobilise their arm and use it, they will have long term problems with their arm, if they don't after they've had surgery. So it's important that they do start to use their arm but in the right way.

**Caitlin:** I think it's a part of every health care professional's role that patient comes into contact with, to promote health and well-being. I don't think it's sits just in one place, so I think it's everyone's role [pause] but in particular, erm it's something I feel happy advising on.

**Julia:** Yes because that's part of a health, health professional's contributes [pause] it's very difficult to sit back and say to people "oh it's OK carry on with your lifestyle", when actually exercise is what they needed. Especially if you give them treatment that affects their joints erm because then you know weight bearing exercises is good for women, who are proved to be osteoporotic or osteopenic. We encourage weight bearing exercise [pause] so yeah it's part of the parcel, part of the treatment we give.

In the extracts above, the breast cancer nurses emphasise the importance of promoting PA and perceive it as part of their role as health care professionals; to encourage breast cancer survivors' to lead a healthy lifestyle and return to 'normality'. Julia and Cathleen particularly emphasise the importance of their role, implying that they have the knowledge and power to encourage breast cancer survivors' to do more PA, therefore they have the responsibility to promote PA. Additionally, Julia implies that as her role includes providing treatment which causes physical problems and limitations; promoting PA to overcome these problems should be just as much part of her role and of the treatment information given to breast cancer survivors. They acknowledge that, it is their responsibility to support and provide care to help improve their "patients" survival outcomes and QoL and promoting PA is part of that responsibility. It is suggested that those who acknowledge the importance of PA, may be more likely to promote PA, as they feel that it is their responsibility and part of their role to improve their patients' QoL. Again, the image of collectiveness and breast cancer nurses working as a group to promote PA, rather than as individuals, is created throughout the extracts above.

When I asked Judith whether she believes it is part of her role to promote PA she replies:

Judith: yeah I do, yeah erm it's probably something that maybe we don't do.

Although, Judith believes that promoting PA is part of her role she implies that she does not actively promote PA. Note how she collectively refers to other breast cancer nurses, as she assumes that others 125

do not promote PA, she also indicates that promoting PA is not always incorporated into routine care, despite it being a part of their role as a health care professional. Interestingly, Davina did not explicitly discuss promoting PA as her responsibility although she does provide examples of encouraging PA to breast cancer survivors. Therefore, it could be possible that she perceives PA promotion differently to encouraging PA. This is also similar to Judith's narratives throughout her interview, as she indicates that she does not actively promote PA, however she provides examples of encouraging PA.

#### 8.1.1.3 Lack of time and opportunity

For some, it appears that these breast cancer nurses are faced with obstacles, when giving PA advice or promoting PA to breast cancer survivors, such as lack of time and opportunities:

**Julia:** erm and erm people return to work very quickly because of the demands and pressures financially and both physically so actually you know [pause] exercise is probably pushed to one side by health care professionals. Whereas, we can advocate it, we don't always promote it erm and that's just because it's something probably else that we do or something else to add to our tick list, or something to do and also as well, it's actually getting that right opportunity to do it because when they are diagnosed with treatment, with cancer, we don't particularly discuss it. When they are coming back for their results, they're more interested in whether or not they're gonna' need chemotherapy or radiotherapy or tamoxifen, and then you may never see them again in a follow up situation.

Although Julia implies that PA should be promoted by health care professionals, she discusses reasons why it is perhaps "pushed to one side". The time constraints and work pressures of the NHS cause implications for promoting PA, as Julia discusses how there is a lack of opportunities to discuss PA with each individual. There is a sense that it is almost inappropriate or not a priority to discuss PA with the individuals, due to the lack of time and opportunities given to see each individual. Discussing diagnostics and treatments are perceived to be of higher importance and their main priority, as it is a compulsory part of the treatment pathway. It is important to acknowledge the distinction she implies between "encouraging" and "promoting", as she suggests that it is their responsibility to support and encourage PA; whilst, it is not their responsibility to promote it to breast cancer survivors. Again, this implies that some breast cancer nurses perceive encouraging PA differently, to promoting PA.

Similarly, Davina mentions how discussing PA is not a part of routine care, and due to lack of time and opportunities to see individuals, as a result she does not discuss PA unless the breast cancer survivors initiates the conversation:

**Davina:** We don't routinely discuss exercise because we haven't got in our time to see patients. We've only got really an hour when they come back from their results, to go through everything and there's an awful lot to go through in that hour. So it's not something we structurally talk about unless the patients bring it up, whether it is something we would recommend.

Again, it is implied that PA is not high priority within the time that the breast cancer nurses have with each individual. The notion of PA promotion being 'pushed to one side' is reflected within Davina's extract, as she states that it is not something they talk about "unless the patient brings it up". It could be possible that the individual breast cancer nurses' perceptions and attitudes towards PA could influence whether or not PA is promoted and discussed with individuals. There is also a sense that it is not appropriate to discuss PA during the time they have to see each individual, as Davina states "there's an awful lot to go through", implying that their responsibilities are to discuss other, higher priority issues within such a short time.

#### 8.1.1.4 Covered elsewhere or within other resources

For other breast cancer nurses, other resources appeared to be useful and often the preferred methods utilised to promote PA, rather than personally giving face to face information. Additionally, for some it appears that the existence of external resources and facilities such as The Moving Forward course places a limit to their own responsibilities, as it is perceived that they do not think it is necessary to promote PA because other services cover this:

Judith: I don't, we don't, well I personally don't necessarily give advice in terms of exercise [pause] if the questions asked, I will give an answer.

#### LE: Yeah

**Judith:** Because I know that it is covered on the Moving Forward course and now all patients will be going onto that course. Not just the low to moderate risk, even the higher risk patients are going on. So for all patients, I know that it's going to be covered [pause] exercise, so it's not something that I bring up because I know it's going to be addressed in a different format.

Here, Judith assumes that all breast cancer survivors will attend The Moving Forwards programme, which covers a talk specifically on PA; therefore, she implies that it is not necessary to discuss it herself. However, although all breast cancer survivors are invited to attend the course, not all of them access the programme; therefore, they will miss the opportunity to receive this information. It is indicated that she only gives advice specifically relating to PA unless she is asked; this reflects other breast cancer nurse's approach to PA promotion as mentioned previously.

Julia also implies that discussing diagnostics and treatments is higher priority, when she sees each individual; therefore, limiting the opportunities to promote PA. Similar to Judith, Julia also suggest that she relies on The Moving Forward programme to promote PA and cover other topics:

**Julia:** There's a lot more diagnostics, so we don't have that one to one personal advice. We tend to but then on the other hand now we have the Macmillan Moving Forward programme, which is our 'living with and beyond breast cancer' area forum that we hold for all patients and all patients are invited to that. So they can pick up things from that.

The lack of opportunity to provide personal information and advice regarding PA, to breast cancer survivors appears to be dismissed here again. It appears that the opportunities for breast cancer survivors to receive information on the Moving Forward programme, is beneficial for breast cancer nurses in particular, as it takes the pressures from them to cover so much information in little time. Therefore, they do not make it their responsibility or priority to promote PA or give advice because it is already covered on the Moving Forward programme.

#### 8.1.1.5 Inappropriate

As seen in the previous extracts above, promoting PA and giving advice is not a priority for some of the breast cancer nurses. For some, PA is not discussed with breast cancer survivors unless they are asked for information specifically. Interestingly, when I asked Davina about her experiences of giving PA advice she replied:

**LE:** So in regards to your roles throughout diagnosis and treatment care, do you have any experiences of giving any information or advice in regards to PA?

**Davina:** Not unless patients ask about PA and I always ask what they've done before and I try and encourage them to go back to what they were doing as before.

Although there is a sense of encouraging breast cancer survivors to return to pre cancer levels of PA, there appears to be a lack of specific information and advice given to them. It is also important to acknowledge how Davina does not discuss PA, unless she has been specifically asked about it. Again, there is a sense of avoidance, as it is almost disregarded as an important aspect of topics to cover with breast cancer survivors throughout their recovery.

Similarly, Julia discusses how the topics discussed during follow up meetings are guided by the patient:

**Julia:** For some patients it will veer around to exercise and diet and lifestyle choices and some patients it won't. You have to leave it up to the patient to dictate what they want to tell you; you cannot dictate to them what you think they need to know.

Julia indicates that PA is not always discussed, unless it is initiated by an individual. The description provided of dictating information with regards to PA, creates the image of giving orders in an authoritative manner, again this reflects the idea that discussing PA is almost insensitive and therefore, it is avoided unless someone asks specifically for information. It could be possible to suggest that the breast cancer nurses' perception of their responsibility for promoting PA and their attitudes towards the importance of PA influences their approach to PA promotion, and those who do not see it as a priority, will not actively promote PA.

### 8.1.2 Encouragement/support

In the interviews the breast cancer nurses gave examples of when they have encouraged survivors to increase their PA levels or offered support to helping them return to 'normal' activities. It appears that the level and types of encouragement and support given, is dependent upon and in response to their interpretation of the individuals' needs. Again, dependant on the individual breast cancer survivor, some of the nurses pass on the responsibility of giving specific PA information to exercise instructor/professionals.

#### 8.1.2.1 Interpreting individual needs

The descriptions of encouragement and support given to the breast cancer survivors appear to be tailored to the specific needs of each individual. Although some of the breast cancer nurses admitted to not giving PA advice, due to whatever reason, all of them gave examples of how they have or would actively encourage PA and offer guidance with returning to 'normal' PA:

**Davina:** I normally say "try and erm increase your exercise you know, if you're going for a walk", especially initially post op [operation] or while they are having chemo, just trying to encourage them to exercise. You know? "Walk a little bit further, you know maybe walking round the block to start off with and then a bit further each time" and then they know that they are doing, you know they are improving their energy levels.

**Judith:** I erm [pause] actively encourage people [pause] even immediately post op [operation], first day post op, they need to get up and do exercise but in whatever form. They might not particularly go to the gym but they need to get up and walk round and go out for walks and things.

**Julia:** If they come into clinic and having significant problems with joint stiffness or joint aches and pains. We would advise them to do exercise such as swimming where it's non weight bearing, just to get the joints moving. We'd then maybe increase their exercise and erm [pause] their exercise levels such as you know, walking, increase the amount of walking.

As we can see, the breast cancer nurses are actively encouraging the breast cancer survivors to gradually build up the amounts of PA they do. Julia gives an example of encouraging PA, if someone has a specific problem which PA can help with. She indicates that she would not usually promote PA, unless she believed that PA would help the individual manage their problem, which in this case was pain; or if it was initiated by the individual. Similarly, Davina implies that she tailors the advice she gives, in relation to what stage and type of treatment the individual is at. Whereas, the other breast cancer nurses describe how they actively encourage PA whenever it is possible and initiate this as soon as possible. This highlights the different perceptions and attitudes towards promoting PA amongst the breast cancer nurses. However, it is important to note how Davina's extract conflicts with her previous comments, for example within the extract above she suggests that's she actively encourages breast cancer survivors to participate in PA initially after their surgery. Whereas, previously she states that she only gives advice, if someone has specifically asked for it, it could be possible that she is giving an example of when she has encouraged an individual to increase their PA, when they have asked her specifically about what PA they can do. Another, plausible suggestion could be that some of the breast cancer nurses appear to perceive promoting PA and encouraging breast cancer survivors to increase their PA as two separate things. Perhaps they perceive promoting PA as offering structured advice and specific information with regards to PA, whereas encouraging someone to do more PA and move more may be perceived to be general information.

Cathleen gives an example of when she supported an individual, to help them feel confident again to return to swimming. The idea of giving personal support and time to help the individual build their confidence is shown within the extracts below:

**Cathleen:** Yeah well first of all this particular lady, I made sure that she had a proper prosthesis and what that you can use for going swimming in. Cos' she was concerned that everybody were gonna' notice, even though we give them a prosthesis to wear [pause] and there are erm the swimwear that's specially designed for women who have had breast surgery. OK? but she just were having none of this so I actually got this women an appointment with the prosthetic ladies, she got a lovely swimming costume and we were able to get her a proper prosthesis, that you can wear when you go swimming, it's more like a sponge.

LE: Yeah.

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**Cathleen:** And it's better than a normal prosthesis that we use and er we tried and tried and she eventually, she did get back in the water but it took a lot of time [pause] a lot of encouragement and a lot of talking.

Cathleen creates the sense of providing more than just advice and encouragement; she personally supported the individual and prioritised her time to helping her find the best prosthesis for her. Cathleen's attitude differs to others and their PA promotion behaviour as discussed previously, particularly in terms of how they rely on other resources to help promote PA to breast cancer survivors. For Cathleen it appears to be more personal to her, to help breast cancer survivors and prioritising her role to supporting them throughout their journey. She highlights the challenges that breast cancer survivors may face after having breast cancer surgery and how these may prevent them from returning to activities which they did before their diagnosis and treatment. This could perhaps cause challenges for breast cancer nurses when promoting PA and trying to encourage breast cancer survivors to increase their PA levels. Cathleen indicates the difficulties faced when encouraging this particular lady to return to swimming, however, she highlighted the importance of the support and persistence from the breast cancer nurses, as she states the lady eventually returned to swimming with a lot of support and encouragement.

On the other hand, Cathleen also discusses how she had to advise an individual to 'slow' down almost. This illuminates how she tailors her advice to suit the individual and their response to PA:

**Cathleen:** We had a lady that had horses and she says "what about my horses?" and I says "well you can't ride your horses now you're gonna', you've had surgery, you've got stitches in, you know, if you fell off, you could really make things a lot worse, you know you might have to go back to theatre". I had to really lay it on the line cos' she was determined erm but she did listen and she didn't but as soon as possible [pause] she wanted to get back with her horses and on that horse.

LE: Yeah.

**Cathleen:** And she did but we have to be firm with them in, we have to warn them about, you know? What could happen, if they do go back to normal activities and that was normal activity for her every day. You know? So the majority listen to us but you will get the odd one or two who will cheat a little bit.

It was perceived that she changed her approach and guidance with regards to PA here, as she thought it would be potentially harmful for the survivor to return to 'normal' activities, which was horse riding. She describes how she had to '*lay it on the line'*, indicating that she had to be forceful and direct, to emphasise the importance of gradually building up towards doing 'normal activities'. She creates the image of warning the survivor off, from doing 'normal' activities soon after they received their treatments. 131

#### 8.1.2.2 Passing on the responsibility to exercise instructors/professionals

Two of the breast cancer nurses stated how they would advise survivors to speak to an exercise instructor if they returned to the gym or exercise classes:

**Davina:** I normally say if they go to the gym that they should speak to whoever is doing the class, you know like if it's a zumba class or something, try and speak to them either before they go to the class or as they go to the class and say "look I've had breast cancer", so they know that they're there and the might be some exercises that they know they shouldn't be doing.

**Judith:** If they go to the gym for example I always ask them to make sure that their trainer, the person who is in the gym know that they've had surgery and to build up any exercise tolerance fairly slowly and not go erm hell for leather.

It was perceived that the breast cancer nurses are passing on the responsibility of protecting the survivors from harm, onto the exercise instructors. As both of the breast cancer nurses emphasise the importance of the exercise instructor being informed of their physical limitations, as a result of their breast cancer surgery. The idea of gradually building up PA intensity and taking it slowly is repeated within Judith's extract as she says *"build up any exercise tolerance fairly slowly and not go erm hell for leather"*. It is important to note how they both indicate different implications for PA such as, Davina indicates that some exercises are not safe to do. Whereas, Judith indicates that the exercise intensity should be light. It could be possible that the breast cancer nurses have different perceptions on what PA is safe and effective for breast cancer survivors and therefore, provide different information with regards to PA. Additionally, it could be possible that the breast cancer nurses avoid giving specific advice with regards to specific types of PA recommendations and information because they are not exercise professionals and possibly do not feel confident. Therefore, they could rely on the resources which provide specific information for the breast cancer survivors and pass on the responsibility to other professionals such as exercise professionals.

### 8.2 External services and resources

As discussed above some of the participants rely on external resources and facilities for the promotion of PA to breast cancer survivors. However, this theme will highlight the breast cancer nurses' perceptions of how external services and resources facilitate or hinder their promotion of PA.

### 8.2.1 Resources

Some of the breast cancer nurses describe the different resources which are given to breast cancer survivors, with regards to more specific PA advice. It appears that the resources facilitate the breast cancer nurses, with regards to promoting PA:

**Cathleen:** All women excuse me [pause] that have breast surgery, will have surgery in their arm as well, for the lymph nodes so that's quite important. We give them an exercise leaflet on exercises to do after the surgery Ok?

**Caitlin:** I mean we get a standard form if you like with it, from breast cancer care. Erm which we promote to all our patients following surgery, erm and there just basic exercises to get everything moving from the axillary basically to prevent cording.

**Judith:** They have an exercise programme in their packs that they asked to do more or less straight away, gentle exercise to keep their shoulder movements.

As mentioned previously, many of the nurses rely on resources such as booklets, exercise information sheets and The Moving Forward programme to pass on information regarding PA. Although, these resources and facilities limit the responsibility of the breast cancer nurses promoting PA themselves, they facilitate them in encouraging PA to breast cancer survivors. As it could be possible that, for some breast cancer nurses they do not feel confident or have enough time to give specific information with regards to PA themselves. Therefore, rather than giving personal face-to-face information, they hand out the booklet and exercise sheets to give specific information and exercises to breast cancer survivors. It seems likely that they rely on resources because they have been devised by exercise professionals, therefore they regard the information within the resources as safe and effective.

#### 8.2.2 Conflicting advice

Only one of the nurses gave a specific example of conflicting advice between another health care professional and the advice which breast cancer nurses give to breast cancer survivors after they have completed their treatments:

**Judith:** One prime example today there's a lady who had surgery on Monday, [she] asked to see me today because her wound has been bleeding and she was very worried. She went to A+E last night because it was bleeding, not haemorrhaging or profusely bleeding. [She] went to A+E, saw a doctor at A+E at [omitted name of the hospital] and the doctor told her that "she had started doing exercises far too soon and she should stop straight away erm not do anymore exercise and come and see us [breast cancer nurses]". Now our advice is "as soon as you are able, you start the exercise programme, get your shoulder moving, not excessive but just gentle

shoulder movements". The problem is that we [pause] we're giving advice and then people who are not as knowledgeable, have this service and the recovery are then conflicting our advice.

From the data shown above and the tone of Judith's voice when describing this scenario, it is suggested that the advice which professionals are giving, from other services are hindering the advice which the nurses are giving to breast cancer survivors. It is indicated that she perceives the inconsistency amongst health care professionals from different disciplines as an annoyance almost, as they are conflicting the advice and service provided from breast cancer nurses. Her description of others "not being as knowledgeable", was directed towards other health care professionals who are not involved in the breast cancer treatment pathway; and therefore, indicating that they should not be giving advice on something which they are "not as knowledgeable" about.

### 8.3 Nurse-survivor relationship

This theme only arose within one of the interviews, that with Cathleen. However, for her, it seemed to be very important to build a relationship with the breast cancer survivors who she came into contact with. It is important to note, how others did not discuss the importance of their relationship with breast cancer survivors, or acknowledge the importance of 'getting to know them personally', in relation to promoting PA or supporting each survivor. Additionally, the data suggests that Cathleen is more proactive with promoting and encouraging PA. This indicates that her attitudes towards her relationships with breast cancer survivors are reflected within her approach to promoting and encouraging PA.

### 8.3.1 Getting to know them personally and building trust

Cathleen implies that it is important to know each breast cancer survivor personally, to gain their trust, and to learn and understand about them, which therefore is helpful when promoting PA and encouraging them to move forward from their diagnosis:

**Cathleen:** You begin to get, you begin to build a relationship up with them and you get to know, you know them so well and you know why they saying the things that they're saying and it's trying to get them to change their mind and just move forward a little bit.

**Cathleen:** We get to know them as much as we can, they'll tell us things that they won't tell anybody else. You know they do, they begin to, they trust, you have to build up that trust, they'll begin to trust us [pause] and you can sort of not read them but you can [pause] you can tell by body language and how they react. From the first day you meet them and when they get their diagnosis, we learn a lot from that...

The image of creating a relationship and building trust with the breast cancer survivors is depicted as an essential part of her role. There is a sense of building a personal relationship with each individual, to understand how they are feeling, and therefore, provide the appropriate support and care for each individual. With regards to PA, it is perceived that through knowing about the individual, Cathleen can understand why they may not want to participate in PA and this influences what advice and support she gives. The idea of gaining trust, indicates that the breast cancer survivors will trust the advice and information that she gives them and therefore, she has the power to possibly motivate them to change their lifestyle choices.

Additionally, Caitlin also highlights the importance of understanding each individual with regards to their concerns about PA:

**Caitlin:** well it's finding out what the main key concerns are [pause] and advising how you can manage those and doing just starting with what people can [do]. The little things, the little changes they can make, to building up to the bigger ones, to the bigger PA. So it might be going for a walk erm starting that and it's just about building confidence int' [isn't] it from then?

There is a sense here, that the importance of gaining insight into an individual's thoughts and feelings towards PA, enables breast cancer survivors' to help that individual overcome their barriers to PA and encourage them to increase their PA gradually. Again, it appears that she perceives it as her and other breast cancer nurses' responsibility to help breast cancer survivors' build their confidence, to help them participate in PA. It could be suggested that for these breast cancer survivors' they adopt their approach to promoting PA depending on the individual's needs and characteristics; as they highlight the importance of gaining insight and understanding into the individual's personal feelings and attitudes towards PA, to help them overcome possible barriers and therefore encourage them to participate in PA.

### 8.4 Perceptions of breast cancer survivors' characteristics

The data suggest that the breast cancer nurses' perceptions of the individual's characteristics may influence their PA promotion behaviour.

### 8.4.1 Breast cancer survivors' interests in PA

Most of the breast cancer nurses discuss their perceptions of the breast cancer survivors' towards PA and receiving PA advice. They describe how some are reluctant to return to 'normal' activities and PA, whereas others are determined to return to their pre-diagnosis PA levels and activities. It can be indicated the breast cancer nurses' perceptions of how the survivor will respond to PA, may influence the breast cancer nurses' approach to PA promotion.

#### 8.4.1.1 Reluctance to be physically active

Below Cathleen discusses how the information and advice she gives, alters depending how she perceives and expects the individual will respond to PA:

**Cathleen:** Others just think "no I can't be bothered, I just don't wanna' do it", you know [pause] so it's just getting that even balance int' it.

**Cathleen:** Yeah well the ones that are adamant they want to get back to normal as soon as possible, we give them all an information pack and it's got information on exercise classes and things like that, yoga, Pilates erm aqua fit, things like that erm but they're not usually interested in things like that, that they've got their own regime that they've got. But the ones that are not keen on it, we introduce that for them and tell them and we try and get them to sort of you know, give the places a ring, give it a whirl or I'll get them in touch with another patient.

There is a sense that Cathleen offers more support and information for those who may be reluctant to participant in PA, since being diagnosed and having treatment. As mentioned before, Cathleen highlighted the importance of building a relationship with the breast cancer survivors, to get to know them personally and to understand their barriers to PA and help them overcome their barriers. The extract above emphasises how she changes her approach, with regards to the advice and support she gives based on the individuals' attitudes towards PA. For example, she creates the sense that for those who are determined to engage in PA, she does not offer guidance or support, as they do not need it. Whereas, those who are less determined or reluctant, she offers more support and guidance to encourage them to participate in PA.

Similarly, Davina also describes how she encourages those who are frightened to return to their 'normal' activities since having surgery:

**Davina:** I think a lot of patients are scared of going back to what they did before like if they went to the gym, they're scared about going back doing exercises in the gym because they're worried that they are gunna' undo some work that they've had done, you know from the surgery [pause] so I you know normally would say "well go back, you know reduce the amount of repetitions that you doing, you know like if you're doing any weights, get the smaller weights", and things like that.

For Davina, she perceives that breast cancer survivors are 'scared' to do PA after surgery because they may cause further harm. She provides an example of how she advises and encourages those who are 'scared' of causing further problems and indicates that she tailors her advice depending on the individuals' attitudes towards PA.

Julia, indicates that if an individual is not interested in participating in PA, promoting PA will not be effective:

**Julia:** it's not something that you can push onto a patient, so if a patient doesn't want to hear it they will just ignore it.

Julia implies that if she perceives an individual to not be interested in PA, then she will not promote PA. This supports the suggestion that the breast cancer nurses' perceptions of the individuals' interests in PA may influence their approach to promoting PA.

#### 8.4.1.2 Determination to be physically active

The breast cancer nurses discussed their perceptions of why they think some breast cancer survivors are determined to do PA. Caitlin and Judith both describe how the survivors' PA behaviour and lifestyle before their diagnosis, influences their PA after their treatments:

**Caitlin:** I think once it's there yeah [pause] that's always their aim and when you monitor them in clinic after their treatment, one of the first things they'll say is you know, when you say "how are you feeling?". They'll say "oh I've been back out, I'm doing my running". Then you know they're on the mend and that's a marker for them as well, I think. Something they aim for after treatment is to get back to what they were.

**Judith:** I think that's just a general mind-set of how they were prior to their diagnosis, some people are more fit than others, some people want to get back into [pause] the life that they had before breast cancer diagnosis and if that includes exercise that they did, then by getting back into the exercise it's a way of saying to them that, your pushing your diagnosis to one side and getting back to some sort of normality. I also think that people may embark on doing exercises because there is probably a big shift in the general population to say that "the fitter you are, the better you are in terms of risk recurrence".

The data in the extracts above suggest that Caitlin and Judith perceive that those who were active before their diagnosis, returning back to their 'normal' activity levels and fitness is a goal or focus for the breast cancer survivors. Therefore, they are more determined to do PA and perhaps do not need advice or encouragement from the breast cancer nurses.

Similarly, Julia describes how an individual's personality and career influence one's lifestyle choices and behaviour:

**Julia:** So it depends on the type of patients, you tend to find the younger patients are more interested in nutrition and diet and lifestyle change, erm the more academic per, er the people who have got careers so your solicitors, your teachers, your nurses, your erm health professionals or even police, or fire women or anything like that. They tend to be the ones who are more active in finding out [pause] more about breast cancer and what they can do to alleviate it. Whereas, you can sometimes find the ladies who are from manual work or who don't work, tend to put that to one side.

Julia perceives that those who are younger and have academic or professional careers, are often those who are more determined to lead a healthier lifestyle. She indicates that they are more obliged to receive information with regards to PA and health, whereas, those who are not in academic careers are less likely to welcome this information. As a breast cancer nurse with years of experiences, it could be possible that she has experienced people who are younger, or work in a profession actively seeking for information with regards to PA and health and therefore, why she has these perceptions. It seems that breast cancer nurses perceive that those who are determined to engage in PA, will actively seek PA information if necessary; or that those who were active before their diagnosis and therefore determined to return to PA do not encouragement or support, as they are already determined. This further suggests that the nurses' approach to PA promotion is affected by how they perceive that breast cancer survivors respond to PA with regards to their interest and characteristics.

### 8.4.2 Perceived breast cancer survivors' barriers to PA

The breast cancer nurses discussed breast cancer survivors' perceived barrier towards PA, again the nurses appeared to adapt their approach to promoting PA dependent on their perceptions of the individual's barriers. Some indicated that the survivor's barriers would prevent them from promoting PA. Their perceptions of the breast cancer survivors' barriers towards PA varied between the nurses, for example; some focused on physical limitation caused by treatments and others discussed a variety of individual factors relating to body image, confidence and the difficulties of adapting to their change body. This highlights the different perceptions and approaches to breast cancer survivors' perceived barriers, as some adopt a holistic approach more than others.

As we can see from the extracts below, Cathleen and Caitlin's appear to have an open and empathetic attitude towards breast cancer survivors' perceived barriers; as they discuss a variety of factors which act as potential barriers to PA for breast cancer survivors:

**Cathleen:** It's like a stigma [pause] it's as though they feel that everybody knows that they've had breast cancer and that's what stops them from going back to doing what they enjoy and it's trying to get them to understand that [pause] they can go back to what they used to do and what they enjoyed and that it will help them to get [pause] to get on with their life.

**Cathleen:** it's the tiredness and the fatigue and sometimes it can make them feel like, they'll have a low day, where they'll get up and they'll think "I can't be bothered to get dressed, I just want a pyjama day". They'll be quite emotional but then the day after they'll feel different. But that is one of the barriers as well, it's the tiredness and the fatigue that stops them from trying to make the effort and do what they enjoy.

**Caitlin:** I think perhaps following [pause] diagnosis and for example a mastectomy. I think the barriers would be there for the ladies who perhaps going into the gym for their first time. When they've had a mastectomy, they've got a prosthesis. I think there's all kinds of erm of of of struggles to get over isn't they? There's obviously the outgoing of what they look like, I think managing their prosthesis and getting something comfortable to wear, something that was supportive as well and again swimming and things like that.

**Caitlin:** I think if you're having chemotherapy, you're fatigued, you haven't got the energy to do [pause] erm [pause] much PA.

The extracts above, reflects the previous theme '*Getting to know them personally and building trust*', as they highlight the breast cancer nurses' attitudes and perceptions towards the breast cancer survivors' perceived barriers. They appear to focus on the barriers from a holistic view, as they discuss the variety of barriers which breast cancer survivors' can experience, with regards to physical and psychological barriers. Additionally, within the extracts above, both Cathleen and Caitlin appear to relate to the breast cancer survivors' feelings and the problems they face after being diagnosed and receiving treatments. This is indicated through their language and descriptions of how an individual might feel, if they experienced the barriers discussed. Furthermore, this creates a sense that they are empathetic and understanding towards the breast cancers' perceived barriers, as discussed before they both adopt their approach to PA promotion and level of support given to each individual based on their needs. Therefore, it could be possible that they offer more encouragement and support to those who are less determined to engage in PA and tailor their support based on the individual's barriers to PA. Whereas, for other breast cancer nurses it is perceived that their perceptions of breast cancer survivors' barriers to PA could impede on the effects of promoting and encouraging PA.

In contrast to Cathleen and Caitlin attitudes towards the breast cancer survivors' perceived barriers to PA; Julia seems less empathetic towards the breast cancer survivors' possible barriers, this is indicated throughout her descriptions in the extracts below:

**Julia:** Time, always time, too tired, erm can't afford to go to the gym. ermm haven't got time to go to slimming class, you know not motivated, something will be happening tomorrow, well if I can, if I diet, I just won't lose it anyway because the tablets make it too difficult for me to diet. So those kind of excuses.

**Julia:** I think a lot of it is the patient's perceived barriers, I think they feel that because they don't have the stamina because they are tired from the treatment, that by doing exercise, that will cause them to be more tired.

Julia's perceptions of the breast cancer survivors' perceived barriers to PA, appear to be less understanding and she creates the image that she is almost mimicking the survivors; this is implied through her language and tone when describing the different barriers, including her use of the word "excuses". Additionally, there is a sense that she feels that those who have these perceptions towards PA, will not be easily encouraged and therefore, it could be possible that she does not actively promote PA or offer advice to encourage them to be more active.

Furthermore, other breast cancer nurses focus on barriers relating to physical problems and implications for PA. Judith and Davina focus on the breast cancer survivors' worriers and fears of causing physical problems and interrupting their recovery from surgery:

**Judith:** I think they are frightened to do any physical exercise because the fear of damaging any erm healing structures in the arm pit.

**Davina:** I think a lot of patients are scared of going back to what they did before like if they went to the gym, they're scared about going back doing exercises in the gym because they're worried that they are gunna' undo some work that they've had done, you know from the surgery.

Both Judith and Davina acknowledge the difficulties that breast cancer survivors may face after surgery and adapting to the physical changes. Similarly, Judith discusses joint stiffness and pain as another physical response and perceived barrier to PA for breast cancer survivors:

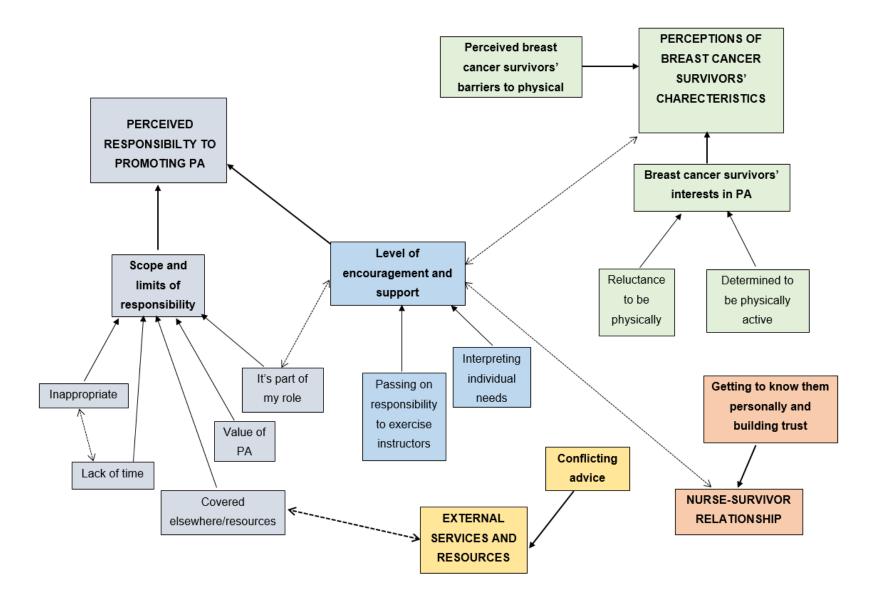
**Judith:** Erm [pause] I think one of the big barriers is the side effects of the medications that we use. One of the tablets that we use, the aromatase inhibitor group of tablets can make the joints fairly stiff and obviously that will impede any exercise they do because it's painful, so obviously that slows people down.

Judith appears to be empathetic and understanding towards how the treatment may affect the breast cancer survivors. She acknowledges the pain caused and how this may prevent breast cancer survivors from participating in PA. Therefore, she may be mindful of this when encouraging PA. It seems likely that the breast cancer nurses' perceptions of how the breast cancer survivor responds to their treatment, may influence how they encourage or promote PA.

### 8.5 Conclusion

I have described the themes which arose from the thematic analysis of the breast cancer nurses' transcripts. I have discussed these in the order of the template, which was developed from utilising TA. The intention was to examine the meaning of the breast cancer nurses' experiences and perceptions of promoting PA to breast cancer survivors. The themes capture the different factors which influence the breast cancer nurses' experiences of promoting PA.

The analysis demonstrated that the breast cancer nurses' experiences of promoting PA were influenced by a number of factors, as discussed within the different themes. Some of themes often overlapped with one another, this can be seen in Figure 1 It appears that there were different perceptions and attitudes towards promoting PA to breast cancer survivors amongst the participants. The findings appear to indicate that the nurses' perceptions and attitudes towards promoting PA, affected their approach to promoting and actively encouraging PA. Another finding was that those who perceived promoting PA as their responsibility and those who valued the importance of PA, were more proactive than others who had conflicting attitudes and perceptions. Additionally, the breast cancer nurses' perceptions of the breast cancer survivors' perceived barriers also affected their PA promotion behaviour. For example, it seemed that the breast cancer nurses approach to promoting and encouraging PA, was influenced by their perceptions of how the survivors' experienced and responded to their diagnosis and treatment, which in turn affected their attitudes towards PA. Most of the breast cancer nurses adapted their approach to promoting PA, to suit the individual needs of the cancer survivor; some offered more support and encouragement to those who appeared to be reluctant to participate in PA, due to numerous barriers. Whereas, for other breast cancer nurses it was perceived that those who were reluctant to engage in PA and the breast cancer survivors' perceived barriers, impeded on their promotion of PA. Other factors such as time and lack of opportunities to discuss PA with breast cancer survivors, were also perceived as key factors which limited some of the breast cancer nurses' responsibility. It was interpreted that other external resources which provided specific PA information for breast cancer survivors, limits their responsibility and reduces the pressures which breast cancer nurses may face, with regards to time and covering information. For some, they suggested that it was not necessary to discuss PA with the survivors, as it was covered elsewhere in the resource packs and on The Moving Forward programme by exercise professionals. Different breast cancer nurses' perceptions and attitudes towards the factors mentioned above were different, their approach to PA promotion were also different. This indicates that PA promotion is subjective and may be inconsistent across the participants within my study, and potentially across different breast cancer nurse populations.



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Figure 1 : Illuminates the interaction between the themes identified in Phase Two- Breast cancer nurses' experiences and perspectives of promoting PA.

# 9. Phase Two - Discussion

In this chapter I will discuss the themes separately, in relation to findings from existing literature, to explore how my findings related to previous literature. I will then discuss the strengths and limitations of this phase of my research. Finally, I will reflect on my experience of utilising template analysis (TA) throughout the analysis stage, of Phase Two of my research study.

# 9.1 Discussion

It was interesting to explore their perceptions of their role and experiences of promoting PA to breast cancer survivors, to see how these were similarly and differently experienced and to identify what might have influenced their experiences. There are differences in the breast cancer nurses' perceptions and attitudes towards significant features of their experiences, such as the *scopes and limits of responsibility* and so forth; these are identified and the meaning of these are explored throughout the findings section in chapter eight. It appears that the breast cancer nurses' altered perceptions and attitudes towards the different features of their experience, affects how they promote PA; suggesting that there are inconsistencies amongst the participants, with regards to PA promotion, despite the fact that they have the same role within the same hospital. I will explore the key findings from this phase of my research and provide a discussion of how they relate to existing literature below. It is important to note that there is limited research, which adopts qualitative methods to explore health care professionals' (HCP) experiences and perspectives of promoting PA, in particular within a specific cancer context. Therefore, the literature used for discussion within this chapter is somewhat limited.

### 9.1.1 Perceived responsibility for promoting PA

This theme captures the breast cancer nurses' attitudes towards and experiences of promoting PA to breast cancer survivors. Within this main theme, there are second level and third level themes which are displayed in Table 8-1. These themes illuminate the breast cancer nurses' perspectives which influence their approach to promoting PA, however, it is important to acknowledge that there were differences among the participants with regards to their perceptions and attitudes towards promoting PA. Below I will discuss the second level themes: *scope and limits of responsibility* and *encouragement and support* and explore the key meanings of these, in relation to existing literature.

### 9.1.2 Scope and Limits of responsibility

This theme illuminates the participants' attitudes towards and perceptions of their responsibility for promoting PA. Although most of the participants perceived that it was a part of their role to promote PA to breast cancer survivors, not all of them appeared to be proactive towards promoting PA. It appeared that those who were more proactive in promoting and encouraging PA to breast cancer survivors did

not perceive that there were any factors which limited their responsibility to promote PA. Whereas, those who did not appear to be as proactive or share the same attitudes when promoting PA, they perceived more factors which limited their responsibility for promoting PA; for example; lack of time and opportunities to discuss PA, the relatively low priority given to promoting PA, and the fact that PA advice and information is covered elsewhere. I will discuss these perceptions below and relate them to findings from existing literature.

In this study it was found that all of the participants acknowledge the importance of PA for breast cancer survivors; however, there are differences amongst the participants' perceptions of the importance of PA. Some of the nurses acknowledge the importance of PA from a medical perspective, for example for enhancing recovery and helping with the management of treatment related side effects. Whereas, others appear to view the importance of PA more holistically, as they describe the importance of PA for helping the breast cancers survivors return to normality, and improving their overall quality of life. Interestingly, from the findings, it appears that those who focus on the importance of PA more holistically, emphasise the importance of their role to promote PA and imply that they actively promote PA. While, those who focus on the importance of PA from a medical perspective, some acknowledge that it is their role to promote PA but some explicitly state that they do no actively promote PA unless an individual asks about PA, or if an individual has physical problems which is related to their treatment. Therefore, suggesting that an individual's perceptions of the importance of PA, influences their approach to PA promotion. This is similar to a recent qualitative descriptive study (Smith-Turchyn et al., 2016), which aimed to examine HCPs barriers and facilitators of PA promotion to women with breast cancer. They reported that the differences in the advice and information which the HCPs offered to breast cancer survivors; reflected differences between the participants' perceptions of the benefits and importance of PA. However, Smith-Turchyn et al. (2016), compared the differences in attitudes towards the benefits of PA amongst different HCPs, and the findings highlighted above highlight the differences between physicians and nurses or other HPCs. Additionally, Smith-Turchyn et al. (2016), found differences between physicians' perceptions of the benefits of PA and nurses or other HCPs' perceptions of the benefits. These findings support the assumption that the HCPs' perceptions towards the PA and the benefits of PA influence their approach to promoting PA. However, Smith-Turchyn et al. (2016), implied that the differences between the HCPs' perceptions of the benefits of PA and the information that they give to breast cancer survivors are a consequence of their role (physician, nurse or other). My findings do not support this suggestion, as the findings were similar to Smith-Turchyn et al.'s (2016) study, which highlighted differences relating to the participants' perceptions of the importance of PA and how they promote PA, although they all have the same role as breast cancer nurses. Conversely, I believe that the participants' interpretation of their responsibility to promote PA impacts their likelihood of promoting PA, not the job role itself, and their perception of the importance of PA also influences their PA promotion behaviour. Thus, suggesting that the individual perceptions and attitudes towards PA and their responsibility to promote PA is subjective, as a result PA promotion appears to be.

Interestingly, those who do not appear to actively promote PA regularly, imply that they have a lack of time and opportunities with each cancer survivor to discuss or promote PA. It seems that for these nurses, PA is a lower priority of discussion during the meetings that they have with the breast cancer survivors. It was apparent that for some of nurses who focused on the medical perspectives, they indicated that discussions regarding diagnostics such as: results, treatment and coping with a diagnosis is a higher priority, over PA; therefore, it was suggested that they do not discuss PA unless an individual prompts the discussion or seeks PA advice. This highlights their focus on the medical perspectives, rather than focusing on the individual's needs in relation to whether they want to receive PA information; furthermore, this reflects their approach to promoting PA. Findings from existing literature highlight similar differences amongst the participants' views towards the suitability of timing and when is best to promote PA (Fong et al., 2018; Smith-Turchyn et al., 2016). Some participants, in Smith-Turchyn et al. (2016) study, discussed the appropriateness and effectiveness of discussing PA within the time they have to see each individual, as diagnosis and treatment are usually at the forefront of discussion and a priority within the time they have. Differences amongst HCPs' views regarding when PA should be discussed and promoted to cancer survivors were highlighted, and this caused inconsistency with PA promotion amongst the participants in the studies (Fong et al., 2018; Smith-Turchyn et al., 2016). From the breast cancer nurses' narratives and extracts from my study, it is appropriate to imply that there are inconsistencies among the nurses regarding what type of information is given to breast cancer survivors and how often.

It was highlighted that the breast cancer nurses who perceived that they had a lack of time and opportunities to promote PA, these factors appear to limit their responsibility for promoting PA; in turn they appear to rely on other resources to promote PA, such as the exercise leaflet and the Moving Forward Programme. All breast cancer survivors are invited to attend the programme, which involves educational talks and activities to help them to cope and adjust to life after breast cancer treatment (Breast cancer care, n.d.-a). One breast cancer nurse specifically states that she does not promote PA, due to the programme involving an information session on PA *"why reinvent the wheel"*. It is appropriate to presume that because there are specific professionals covering different topics such as PA, that the breast cancer nurses feel that it is not their responsibility to deliver specific PA information. However, the nurses who describe themselves as actively promoting PA. This highlights the differences between the nurses' attitudes and perceptions towards their responsibility for promoting PA, which in turn appear to influence their approaches to PA promotion.

The majority of previous research using on quantitative methods to explore the barriers and facilitators of PA promotion among HCPs; there appears to be similar findings in relation to the HCPs' perceptions of factors which impede the promotion of PA. Lack of time and contact with cancer patients were reported as significant barriers to PA promotion (Cantwell et al., 2018; Fong et al., 2018; Hardcastle et al., 2018; Haussmann, Gabrian, et al., 2018; Haussmann, Ungar, et al., 2018; Nadler et al., 2017; Smith-145

Turchyn et al., 2016). However, other barriers were reported amongst existing literature which did not emerge from my findings, such as; lacking specific knowledge and educational resources relating to PA, lack of PA facilities and resources (Cantwell et al., 2018; Fong et al., 2018; Hardcastle et al., 2018; Haussmann, Gabrian, et al., 2018; Haussmann, Ungar, et al., 2018; Nadler et al., 2017; Smith-Turchyn et al., 2016). None of the participants within my study perceived there to be a lack of educational resources, training and PA facilities provided specifically for breast cancer survivors. Interestingly, all of the participants in my research discussed how they utilised different resources and facilities, which provide specific PA information and facilities for women who have had breast cancer; to facilitate them to promote and encourage PA. The participants within my study, work within the same hospital and have knowledge of the local facilities which offer PA information and opportunities, they also give out the same resources i.e. resource pack, as part of routine care. Whereas, the participants involved in the other studies, do not have access to educational resources and knowledge of local facilities. Therefore, the absence of these factors are reported as significant barriers to PA promotion amongst these studies (Cantwell et al., 2018; Fong et al., 2018; Hardcastle et al., 2018; Haussmann, Gabrian, et al., 2018; Haussmann, Ungar, et al., 2018; Nadler et al., 2017; Smith-Turchyn et al., 2016); resulting in the differences between my research findings and the findings of these studies. Although the findings differ between my research and existing literature, they all highlight the importance of patient educational resources to facilitate PA promotion. Additionally, the findings from the other studies suggest that if HCPs had access to resources, this would facilitate the promotion of PA; however, for some of the breast cancer nurses in my study it appeared that external resources limits their responsibility for promoting PA. This illuminates that although resources may be useful to some when promoting PA; the individual's interpretation of their role and attitudes towards their responsibility for promoting PA influences their PA promotion behaviour.

## 9.1.3 Encouragement and support

This theme illuminates how the breast cancer nurses adapt their approach to promoting PA, depending on how they interpret the individual needs of each breast cancer survivor. The findings highlight the differences in relation to the types of encouragement and support offered to individuals amongst the breast cancer nurses. It is indicated that the support and encouragement given is dependent on how the breast cancer nurse interprets the needs of each individual.

Some of the breast cancer nurses provided more support and encouragement to those who were reluctant to engage in PA after their diagnosis. Cathleen and Caitlin both describe experiences where they have given individuals extra support and guidance, to help them return to the activities which they did before their diagnosis but are too afraid since completing their treatment. This reflects the notion of these nurses adopting a holistic approach to supporting individuals and promoting PA; as they value the importance of the understanding the individual's needs and barriers to PA. Again, there is a difference between the other nurses' approach to offering support and encouragement with relation to

promoting PA; the other nurses appeared to focus on general PA guidelines and advice, which reflects a medical perspective. These nurses describe that they only provide PA information if an individual seeks specific advice or if they are experiencing physical limitations. These findings suggest that the breast cancer nurses' individual attitudes towards their responsibility for promoting PA and the importance of PA may influence the type of support and encouragement they offer to breast cancer survivors, with regards to PA. This assumption is supported by Haussmann, Gabrian et al. (2018), as they suggest that the HCPs' subjective bias and beliefs of PA, influences their PA promotion behaviour. There is a lack of literature which specifically explores what type information or advice HCPs provide when promoting PA, therefore it is difficult to discuss my findings in relation to other literature. However, Smith-Turchyn (2016), revealed that the complexity of individual breast cancer survivors' characteristics such as; breast cancer treatments received, age, and risk of comorbidities and psychosocial issues, may hinder HCPs promotion of PA behaviour. This illuminates the perception of HCPs adapting their approach of promoting PA to the individual needs of each individual. Furthermore, previous literature which explores communication styles between clinician and patient, suggests that the communication style adopted by the clinician may influence a patient's health outcomes (Arora, 2003; Street Jr, Makoul, Arora, & Epstein, 2009). According to Street et al. (2009), if a healthcare professional is empathetic, values the patient's experiences and expresses their support; this may establish trust between the healthcare professional and patient, which in turn may improve their self-efficacy in self-care and management of their disease or illness, which may lead to positive health outcomes. This communication style is also known as patient-centred (Stewart, 1984). Although this study (Street et al., 2009), does not focus on or relate the influence of communication to PA behaviour amongst cancer survivors; it could be recommended that the breast cancer nurses should adopt a patient-centred approach when promoting PA. Therefore, suggesting that the encouragement and support they offer should be empathetic and adapted to meet the individual's perspectives, in which the individual should be involved in the decision process of what information is discussed in the meetings with the breast cancer nurses.

## 9.1.4 Nurse-survivor relationship

This theme highlights some of the breast cancer nurses' perceptions of the importance of their relationship with breast cancer survivors. It is indicated that those who acknowledge the importance of their relationship with breast cancer survivors, are more proactive when promoting PA and offer more support and guidance to help them overcome barriers.

There are differences between the breast cancer nurse's attitudes towards the importance of establishing a relationship with each breast cancer survivors. Interestingly, only Cathleen and Caitlin discuss and acknowledge the importance of their relationship with individuals. They suggest that the relationship built with each participant facilitates them to encourage and promote PA, as they get to know the individuals personally and therefore, they build trust with them which helps them to encourage

and promote PA. It is indicated that their attitude and perceptions of their relationship with breast cancer survivors influences their approach to promoting PA, as these participants described themselves as more proactive and supportive when promoting PA. Additionally, for Cathleen in particular, the importance of getting to know each individual personally and knowing about their barriers to PA, influences the support and encouragement she gives. For example, she discusses how she invested a lot of time and support helping an individual who did not want to return to swimming because she had a mastectomy and was concerned about her body image. Cathleen arranged for the woman to have a prosthesis fitted, and helped her to build her confidence and therefore, overcome her barriers and return to swimming. Some of the HCPs in Haussmann, Gabrian et al.'s (2018) study, valued the importance of their relationship with cancer patients. However, this made them reluctant to promote PA, as they felt it would "jeopardise" their relationship, if they perceived that the individual was not interested in PA. This difference in the findings may highlight the subjective views and attitudes towards the importance of PA and their perceptions of their responsibility for promoting PA. Although the other breast cancer nurses within my study did not discuss their relationship with breast cancer survivors, some acknowledge the importance of the cancer survivors initiating which topics get discussed, to prevent information being "dictating" to them.

## 9.1.5 Perceptions of breast cancer survivors' characteristics

This theme is somewhat similar to the third level theme: *interpreting individual needs*, however it relates to the breast cancer nurses' perceptions and interpretations of the breast cancer survivors' characteristics; in relation to their interests in and perceived barriers to PA and how this influences their promotion of PA. The two second level themes are: *Breast cancer survivors' interests in PA* and *Perceived breast cancer survivors' barriers*.

#### 9.1.5.1 Breast cancer survivors' interests in PA

The breast cancer nurses discussed their perceptions of the breast cancer survivors' attitudes towards PA. They acknowledged that those who were determined to engage in PA did not need encouraging to increase their PA levels; whereas those who were reluctant to participate in PA or uninterested, may need more support and encouragement. Therefore, this implies that the breast cancer nurses adapt their approach to promoting PA, based on their perceptions of the breast cancer survivors' attitudes towards PA.

Some of the breast cancer nurses revealed that they did not discuss PA unless an individual initiated the conversation. From the data, it is suggested that those who perceived that the breast cancer survivors were not interested or reluctant to engage in PA, were less likely to promote PA. One nurse stated that "PA is not something you can push onto a patient, so if a patient doesn't want to hear it they will just ignore it", she further reports "you cannot dictate to them what you think they need to know". Therefore, suggesting that if the individual is not interested in PA it is not necessary to promote PA 148

because it would not be effective. Whereas, other breast cancer nurses who also acknowledged that some breast cancer survivors are often reluctant to return to or engage in PA; discuss how they would offer more guidance and support, or tailor the type of PA they promote dependent on the individual needs to help the individual overcome their barriers. Again, the different approaches to promote PA may be influenced by the breast cancer nurses' own attitudes towards PA and perceptions of their responsibility for promoting PA. It could be possible that those nurses who do not promote PA if they perceive that the individual is reluctant to engage in PA, perhaps does not think it would be effective and therefore, they will discuss other things which they perceive to be of higher priority. Other existing literature support this, findings from Smith-Turchyn et al. (2016) reveal that patients having a negative attitude towards exercise was the most commonly reported perceived patient barrier. Also, Haussmann, Gabrian et al. (2018), revealed similar findings which identified that HCPs who perceived patients to be "lacking interest" in PA were less likely to promote PA because they did not want to tell them how to spend their time. However, if a patient was active before their diagnosis the HCPs would promote PA to them, to help them to reengage in PA (Haussmann, Gabrian, et al., 2018). A quantitative study also identified "a patient lack of interest" as a barrier to PA promotion among HCPs (Hardcastle et al., 2018); although this study does not explore how this barrier influences PA promotion specifically, it does reflect the findings from my study.

Again, the breast cancer nurses approach to promoting PA appears to be different if they perceive that the individual is determined to engage in PA or return to PA. It appears that the breast cancer nurses perceive that those who were active before their diagnosis, are most likely to be determined to return to their pre-diagnosis activities to gain a sense of 'normality'. Some acknowledge that having a breast cancer diagnosis can cause breast cancer survivors to revaluate their lifestyle and change their PA behaviour. The breast cancer nurses indicated that those who were determined to return to PA or engage in PA after their treatment, initiated conversations about PA and asked for advice from the breast cancer nurses. As discussed before, some of the breast cancer nurses would only promote PA if an individual asks for information regarding PA. HCPs in Haussmann, Gabrian et al.'s (2018) study reported that promoting PA to those who were interesting and willing to engage in PA was worthwhile.

# 9.2 Summary of findings

Findings from my research study and existing literature suggest that PA promotion amongst HCPs is inconsistent, and numerous factors may influence an individual's PA promotion behaviour. I have explored a variety of factors which were meaningful to the breast cancer nurses' experiences of promoting PA and I have considered how they factors affect their experiences. Existing literature has frequently identified a variety of factors as 'barriers and facilitators' of promoting PA amongst HCPs, to explain the behaviour; however, research exploring the meaning of these factors to provide a unique insight and understanding of their experiences is sparse. Additionally, there is limited research exploring breast cancer nurses' experiences and perceptions of promoting PA.

The majority of the nurses in my research perceived that promoting PA was a part of their role although some emphasised more than others, the importance of their position as a breast cancer nurse to help encourage breast cancer survivors engage in PA. Interestingly, the findings illuminated how the breast cancer nurses' personal attitudes and perceptions towards the domains discussed above; may influence their approach to promoting PA. However, there are some differences between my research and existing literature; such as, all of the studies identified that the lack of exercise specific knowledge and information resources were barriers to PA promotion. Additionally, some of the studies acknowledged that the lack of specific knowledge, led to the HCPs not feeling confident to promote PA. These factors were not identified in my study, as all of the breast cancer nurses had access to information resources which they give to all breast cancer survivors and other resources such as The Moving Forward programme. The differences between the findings from my study and existing literature findings may be a result of the different research design and methods used. For example, the majority of the research applied quantitative methods to examine HCPs' barriers and facilitators of promoting PA to cancer survivors, therefore factors were identified but not explored to gain a deeper understanding of how these factors may influence the HCPs' PA promotion behaviour. Additionally, some of the studies included HCPs from different oncology disciplines and positions, and some focused on their experiences of promoting PA to cancer survivors undergoing treatment. It could be possible that the different sample groups and research contexts involved in the research studies influence the research outcome and therefore lead to different findings.

It is important to illuminate that the majority of existing literature focuses on identifying external domains such as; resources, facilities, time and so forth, which affect PA promotion amongst HCPs. However, the findings from my study highlight the importance of the individual, in relation to their attitudes and perceptions towards their role and responsibility for promoting PA. This was evident across the breast cancer nurses' accounts of their experiences and attitudes towards promoting PA; in which, there were differences between the breast cancer nurses in my study. Although the nurses had the same role, worked in the same hospital and therefore, received access to the same training and resources; their attitudes to their role and responsibility for promoting PA were different, this appeared to influence their approach to PA promotion.

# 9.3 Strengths and limitations

In this section I will discuss the strengths and limitations of this phase of my research.

## 9.3.1 Strengths

## 9.3.1.1 Utilising TA

The flexibility of TA analysis enabled me to explore my research data with an open mind and gain new insights into the experiences of promoting PA amongst the breast cancer nurses in my study. My initial template involved a priori themes, which were emergent key findings from existing literature; through applying the template to the first interview transcript, the a priori themes were modified and omitted wherever necessary. The new template developed, involved themes which predominantly emerged from my research findings, and therefore, illuminating the unique insights of the participants' experiences. Despite facing challenges with naming the theme titles and creating a cross case analysis, I believe that the process allowed me to become familiar with the research data resulting in me gaining a deeper understanding of their experiences. I discussed my findings with members of the research data; to ensure the quality of the template and findings emerged from my analysis (Brooks & King, 2012).

## 9.3.1.2 Contribution to knowledge

Utilising phenomenology enabled me to gain a unique insight into breast cancer nurses' experiences and perspectives of promoting PA and giving PA advice to breast cancer survivors. Phenomenology is concerned with examining human experience and making sense of the meaning of the experience. Existing research examining HCPs' PA promotion behaviour mainly focuses on proving an explanation of the behaviour; within a cognitive or behavioural context, rather than exploring the meaning of their experiences. Therefore, it could be argued that there is limited knowledge and understanding of HCPs' experiences of promoting PA to cancer survivors; more specifically breast cancer nurses. My research contributes to existing knowledge, as my findings provide a new unique insight into breast cancer nurses' experiences and perspectives of promoting PA; which highlight the importance of the individual nurse and how their attitudes towards their role and responsibility for promoting PA may influence their approach to promoting PA. Additionally, I am aware that this is the first research study to utilise phenomenology to explore PA promotion among breast cancer nurses.

## 9.3.1.3 Engaging in reflexivity

Throughout the research process, I have reflected upon my position as a researcher and the challenges I faced, my feelings towards these challenges, presumptions before collecting the data, what happened during the data collection and analysis process' and what I have learnt from the different stages 151

throughout the research process. Reflecting on the different stages did not only allow me to learn and develop my skills as researcher, it allowed me to understand how my position has influenced the research process and outcome (Palaganas, Sanchez, Molintas, Visitacion, & Caricativo, 2017). For example, as discussed previously the biggest challenged faced during this phase of the research was conducting the interviews, due to my prior assumptions and feelings. It could be suggested that my feelings towards the power dynamics and my position as a researcher and exercise professional, influenced the data collected during the interviews. However, it is important to note that acknowledging my position as the researcher and reflecting on these factors and how they may have impacted the data, enhances the rigour of the research (Berger, 2015). Additionally, it is important to acknowledge how my position may impact the research, as the researcher is a central tool throughout the research process, therefore, the analysis of the research and the findings are subjective. Consequently, the research findings may vary within different research contexts.

## 9.3.2 Limitations

#### 9.3.2.1 Sample

This phase of my research study involved five breast cancer nurses, who work within the same hospital organisations. It is important to acknowledge that these factors may impact the research finding. For example, as a result of the participants all being female, breast cancer nurses and working within the same organisations; the findings cannot be applied to wider sample populations, research contexts and environments (Mason, 2017). However, generalising the research findings is not a concern of phenomenological research, as the concern is to understand human experiences of a phenomenon within a specific context or a specific (Giorgi, 2008). Furthermore, the participants involved in my research were selected purposively, to explore their experiences of promoting PA as breast cancer nurses; they were also selected based on convenience sampling as a result of the NHS pressures and lack of staff availability. Therefore, the size of the sample was out of my control, although TA usually involves large sample sizes, however, according to Brooks & King (2012) TA can be utilised with small sample groups.

#### 9.3.2.2 Role/position as a researcher

As discussed previously, I have engaged in reflexivity to make my position as a researcher transparent. However, some may argue that the central role of the researcher may be problematic, as it can have an impact on the data collection and analysis phases of the research. A prominent example of this from my experience is how my prior assumptions and feelings towards the interview impacted the initial interview process. In chapter 7, I reflect in more detail upon my prior assumptions and feelings towards conducting the interviews and my perceptions of the power status between myself and the participants. However, I will briefly discuss this here, to provide an example of how my position as a researcher may have impacted upon the research outcome. I felt that my feelings and pre assumptions affected my 152 interviewing style within the first interview; I did not feel confident to probe into the participant's answers deeper, as I felt that I was intruding on their professionalism. Also, I followed the interview questions rigidly because I was conscious of the time given to conduct the interviews. As a result, the interview duration was significantly short and there was a lack of depth to some aspects of the interview when I did not probe for further clarification; ultimately this may have affected my understanding of the participant's experience. Although it is expected that qualitative researchers face the interview and research, with an open mind to allow unexpected findings to emerge (Lopez & Willis, 2004); I found this a challenge because I did not know what to expect regarding the participant's responses to the questions. This made me feel unprepared for the first interview, as my prompts did not relate to the participant's responses.

## 9.4 Reflexivity

In this section, I will focus on my reflections related to my experiences during the second phase of my research. Previously, in chapter seven I reflected upon my experiences of conducting the interviews, therefore in this section I will focus upon the practicalities and my experiences of analysing the data. For this Phase, I utilised TA to thematically analyse the data, however, as with Phase One of the study; my phenomenological position as a researcher was maintained.

### 9.4.1 My experiences of using template analysis

As discussed previously, the aims of Phase Two are: to gain insight into the breast cancer nurses' experiences and perspectives of promoting PA and giving PA advice to breast cancer survivors, with a focus to compare their perceptions and provide a cross analysis of their experiences. As discussed previously in chapter seven, TA is an appropriate technique to utilise for this phase of my research rather than IPA. Although it was not my first time encountering data analysis, it was the first time I have utilised TA, as a result I faced some challenges throughout the process. I had conducted the interviews quite some time before beginning the analysis stage, therefore, I had to become familiar with each participant and their interviews again before attempting to analyse the data. For this, I re-listened to the interview recordings and read my reflexive log to immerse myself in the data; this enabled me to understand the contexts of the conversations and recapture the experience of the interview. I then made notes whilst listening to the interview recordings and reflecting upon the experience, this aided the development of the individual reflections which are discussed in chapter seven. Reflecting on the experience helped me to understand how my prior assumptions and feelings towards the participants and the status difference between us, may have influenced the data collection process; I kept this reflection at the forefront of my mind when analysing the data. Furthermore, reflecting upon my position as a researcher, allows the reader to have an insight into the research process and also understand how the findings may have been influenced by my position (Finlay, 2002b).

Before I began the analysis, I had to become familiar with TA and how to approach the data utilising this technique. Although IPA and TA are similar approaches, I found it difficult to switch from utilising IPA for my data analysis in Phase One of my research, to then utilising TA in this phase. I developed a template using a priori themes, which were identified as key findings from existing literature, I utilised this initial template on the first transcript which I analysed. As an inexperienced researcher encountering TA for the first time, this was a challenge for me because the themes were very broad and I felt as though I was not acknowledging the participant's whole experience; I was just focused on finding the a priori themes and coding parts of the text which were only significant to the themes. Reflecting upon this experience, I decided to read more research studies which have utilised TA, to understand how they analysed their data and developed their final template. After sometime reading other research studies, the flexibility of the initial template and a priori themes became apparent and my understanding of TA increased. Therefore, I felt happy to continue the analysis process, with a different approach; as I focused on the transcript as a whole, utilising the initial template whilst adding to it as new findings emerged within the first transcript. After completing the analysis of the first transcript, it was almost like a light bulb moment for me as I finally grasped how to utilise TA. I continued the analytical process with the remainder of the transcripts and made modifications to the template throughout, which aided the development of the final template. However, developing the initial template and writing up my findings was a challenging process due to numerous factors. Similar to Phase One, deciding on the title for each theme was challenging for me, and I spent a considerable amount of time considering possible theme titles. Another challenge that I faced was, grouping the codes from each transcript and attempting to create a cross case analysis; as I found each participant to be very different because they appear to have different perceptions and attitudes towards promoting PA. After some time spent dwelling over each transcript, the key findings and writing and rewriting the themes, I felt happy with my final choice of theme titles and developed the final template.

# 10. Synthesis of findings and discussion

In the previous chapters I have presented and discussed the analytical findings of both phases of research and how these related to the findings of previous literature. Additionally, I have reflected upon my experiences of the processes involved during the phases. The intention of this research was to explore the meaning of the experience of PA amongst breast cancer survivors. Thus, the study involved semi-structured interviews to explore the breast cancer survivors' lived experiences and meaning of PA and breast cancer nurses' experiences and perceptions of promoting PA to breast cancer survivors. I have utilised a phenomenological approach to inquiry, to gain a unique insight and deeper understanding of the phenomena.

This final chapter integrates and discusses the key findings from both phases of the research study, to illuminate the overall meaning of the phenomenon. I will discuss the implications of these findings and contributions to knowledge. I will also consider the strengths and limitations of this research, and provide some suggested recommendations for future research and practice.

# 10.1 Contribution to knowledge

This thesis has contributed to knowledge in the area of breast cancer survivors and PA, through illuminating unique insights into breast cancer survivors' lived experiences of PA and breast cancer nurses' perspectives and experiences of PA promotion. To my knowledge this is the first research study which has involved both breast cancer survivors and breast cancer nurses. These unique insights may inform future health care services and practice in relation to promoting PA.

In this discussion, to illuminate the contributions to knowledge through comparing the findings with existing literature, discussing the implications for practice, my reflection of the research process and considerations of the strengths and weaknesses.

# 10.2 Key findings

In chapters five, six, eight and nine, I thematically presented the findings from both phases of the research. The themes identified have captured different meanings and experiences of PA from both breast cancer survivors' and breast cancer nurses' perspectives. In chapters five and six, I presented and discussed the findings from Phase One of the research which were the breast cancer survivors' accounts of their lived experience of PA. I utilised IPA, to obtain a unique insight and deeper understanding of the participants' individual experiences of PA, the themes identified capture the meanings of the participants' experience. In chapters eight and nine, I presented and discussed the findings of Phase Two of the research; which focused on breast cancer nurses' perspective and

experiences of promoting PA. I utilised Template Analysis within a phenomenological approach to analyse and capture the participants' meanings of their experience.

In this chapter, I integrate the findings from both phases of the research study, to highlight the key issues that have emerged, and relate these to previous literature. These are displayed in Table 10-1.

Overarching key themes	Phase One theme	Phase two theme	Brief description/interpretation of the
			themes
Overarching key themes The meaning of PA	Phase One theme         PA is an important part of their lives, the         breast cancer survivors utilise PA as a         tool to make sense of and adapt to a         'new normal'.         Those who were regularly active before         they were diagnosed, utilised PA as a         tool to gain a sense of normality and to         make sense of their 'new normal'.         Whereas, those who did not participate         in PA before their diagnosis, utilised PA	Phase two theme Breast cancer nurses' perceived importance/benefits of PA for recovery from breast cancer and treatments.	
	as a tool to adapt to gain a sense of control and understanding of their 'new normal'. For instance, they adapted their lifestyles and now participate in		two breast cancer nurses focus on the importance of PA to improve well-being and regaining a sense of normality. Additionally, most of the breast cancer nurses do not actively promote PA. It was highlighted in

# Table 10-1 Synthesis of key findings

	PA, as they believe it will improve their		chapter 9 that those who focused on the
	health and prevent cancer recurrence.		holistic benefits of PA, actively promoted
			PA. In comparison to,
The importance of relationships	Reliance on support from significant	Establishing trust and relationship	Within phase one, it was highlighted that
	others, peers and health care	with patients.	breast cancer survivors rely on the support
	professionals during and following		from others when coping with a cancer
	cancer diagnosis/treatments.		diagnosis and recovery from treatments.
			Interestingly, those who described
			themselves as inactive relied on the support
			and encouragement from significant others
			when engaging in PA. In addition, many of
			the breast cancer survivors described
			feeling abandoned after completing their
			treatments and wished for more follow up
			care/support from breast cancer nurses.
			Whereas, only two breast cancer nurses'
			discussed the importance of establishing
			trust and forming a professional relationship
			with their patients.
Lack of PA advice/promotion	Perceptions and experiences of	Perceptions of their role and	There were significant differences between;
	receiving a lack of PA advice from	experiences of promoting PA.	breast cancer survivors' needs in relation to

haalth aava profossionala Desire to	augment with engening in DA frage backt
health care professionals. Desire to	support with engaging in PA from health
have received specific and	care professionals and the breast cancer
personalised PA information from	nurses' perceptions of their roles and
breast cancer nurses.	experiences of promoting PA. The majority
	of the breast cancer survivors highlighted
	the desire to have received more specific
	and personalised information and support
	from breast cancer nurses and other health
	care professionals. Whereas, some of the
	breast cancer nurses did not perceive that
	promoting PA was a part of their role and
	therefore, they did not actively promote PA
	or give personalised PA advice. Whilst,
	others admitted that it was part of their role
	to promote healthy and active lifestyles,
	however they do not actively promote PA
	due to numerous factors.

# 10.2.1 Utilising PA as a tool to make sense of and adapt to 'a new normal'

Women affected by breast cancer experience ongoing complex challenges after completing treatment including: bodily changes, effects on relationships, fears of recurrence, emotional vulnerability (Trusson et al., 2016). They reveal that these challenges cause ongoing disruption to the participants' daily lives and continual renegotiation of self-identity.

A wife, mother and grandmother, living with metastatic breast cancer Karyn Williams (Karyn Williams, 2016); wrote a poem "The New Normal"; a short extract from the poem is given below:

... I wonder if there really is a cure...

I wonder why they would hide it if there is.

I wonder if I should walk more, run more,

I wonder if I should grow kale.

Overthinking,

the new normal.

The poem captures her experiences and meaning of "a new normal" post diagnosis. Throughout the poem she creates the image of ongoing "wonder", within this particular extract there is a sense of her revaluating self- expectations and she continues to consider her faith and beliefs. She implies that being diagnosed has disrupted her 'normal life' (her life before she was diagnosed), which has led her to revaluate and identify her life now (living with breast cancer) as "the new normal". Additionally, it was indicated that alterations to her perceptions and meaning of life, led her to re-evaluate and re-consider daily tasks and beliefs which she once held in her 'normal life'; this creates the image of her adapting to her "new normal".

For the participants in this study, the sense of "a new normal" is evident throughout their accounts of their experience. All of the participants revealed experiencing disruptions to their 'normal' life as a result of treatments. The experiences and meanings of the disruptions were different across the participants' accounts, however there was a shared sense of disruption to one's perceptions of self-identity and 'normality' amongst the participants. Some of the participants experienced changes to their physical appearance as a result of the treatment; changes in physical features such as hair loss or breast removal, led to the perception that they were a different person. This highlights the disruption caused to one's perception of self-identity, as they are aware that their body is different to what it was 'normally' (before treatment). Another experience of disruption comes from changes to physical abilities and

movements, as a result of breast cancer treatments. Often this related to a limited range of movement which involved the shoulder or arm, on the side which was affected by surgery. Changes to the participant's body and its physical abilities, caused disruption to their 'normal state'; preventing them from engaging in activities which they would 'normally' do. The participants' awareness of the body being unable to do things which it would usually do - such as mundane daily tasks or leisure based PA - led to disruptions of their sense of self.

It appeared that the participants utilised PA to gain a sense of control and understanding of their 'new normal'. There were differences amongst the participants regarding the meanings of PA and how they utilised PA to gain a sense of control; the meanings of PA were dependent on their experiences of disruption caused by treatments and their pre-cancer experience with PA. Some of the participants used PA to gain control over their health and ultimately perceived they had gained control over cancer recurrence. For these participants, it appeared that the diagnosis had made them conscious of the importance of their health, as they adapted their lifestyle and increased their PA levels. They believed that living a healthy and more active life would improve their health, and therefore prevent cancer from returning. Most of the participants stated that they did not regularly participate in PA before their diagnosis; however, since being diagnosed they now participate in regular PA, to improve their health and fitness. This implies that the meaning and importance of PA has altered for these participants; it appears that PA now holds a 'new' significant meaning and purpose within their lives, which was once non-existent before their diagnosis. It is implied that for these participants, experiencing a diagnosis disrupted their relationship with the world and caused them to reflect upon and renegotiate the meanings of their well-being and health, which in turn led them to revaluate their lifestyle choices and increase their PA levels.

The participants' new outlook on the importance of their health and their new meanings towards PA, highlights the concept of utilising PA to adapt to a 'new normal' and create a 'new self'. It is indicated that engaging in regular PA to improve their health and ultimately control their risk of cancer recurrence has become the 'new normal' for these participants. Bury (1982, p.178), conceptualises chronic illness as a "biographical disruption". Bury suggests that chronic illness disrupts "normality"; the 'everyday' structures of life which are usually taken for granted become disrupted (Bury, 1982; S. Williams, 2000). Bury (1982), further states that the disruption of chronic illness affects how people identify themselves and causes people to re-examine self-expectations and behaviour. According to Trusson et al. (2016) and McCann, Illingworth et al. (2016) the concept has been used within existing research to explore and understand the experiences of illness. As a result of people living longer and experiencing ongoing side effects of treatments, cancer can be identified as a "chronic illness" (McCorkle et al., 2011). This concept could be used to aid the understanding of the participants' experiences and altered meanings towards PA post-treatment.

Interestingly, most of the breast cancer nurses acknowledged the importance of PA in relation to: aiding the recovery process from treatment, managing treatment related side effects, improving health and decreasing the risk of cancer recurrence. This supports the notion that experiencing a diagnosis disrupts 'normality', as the importance of PA is focused around cancer and adapting to the 'new normal', which is interpreted as living with and beyond breast cancer. Additionally, some of the breast cancer nurses particularly encouraged PA to breast cancer survivors, if they were experiencing physical limitations as a consequence of breast cancer treatments. Again, this illuminates the idea of utilising PA as a tool to adapt to the 'new normal', in this context the consciousness of limitations to physical abilities and movements were interpreted as the 'new normal'. According to Trusson et al. (2016), women experience long-term implications and "embodied reminders" of breast cancer diagnosis and treatments, such as changes to their bodies and physical abilities. Some of the breast cancer nurses discuss the implications which breast cancer survivors' might experience after surgery and other treatments; they describe how these may impact their well-being and prevent them from engaging in activities which they did before their diagnosis. Two breast cancer nurses in particular (Cathleen and Caitlin) highlighted the importance of encouraging PA to breast cancer survivors, to help them regain a sense of 'normality' and improve their well-being. They acknowledged that breast cancer survivor's experience changes to the body as a result of treatments, which can disrupt an individual's perception of themselves and their 'normal' activities. Therefore, they adopt their approach and offer more support to those who are reluctant to reengage in activities which they did before their diagnosis, to regain a sense of 'normality' by returning to activities which they considered as 'normal' and engaged in before their diagnosis.

Similarly, it was apparent that some of the participants utilised PA to gain control over their body's physical abilities, which were affected by cancer treatments and to regain a sense of 'normality'. These participants described themselves as active before their diagnosis and they describe PA as an important part of their lives. However, they experienced physical limitations as a result of the breast cancer treatments, which prevented them from participating in the activities which they would 'normally' engage in; this in turn disrupted their everyday lives and perceptions of self. Experiencing fatigue and pain which limited their physical abilities, appeared to affect the participants' perceptions of themselves and sense of control. The disruption to their physical abilities led them to reflect upon and revaluate the meaning of their relationship with the world (Benner & Benner, 1994). It appeared that the meaning of PA had changed for these participants, as it was once something which they considered as part of their everyday life; whereas, the disruption to their PA and physical abilities made them conscious of their bodies' movements and abilities, therefore the meaning of PA was altered and it appears that they now utilise PA as a tool to regain their physical abilities and sense of 'normality'. Similar findings arose from Roger et al's. study (2014), as they identified that participants living with a neurological condition remained engaged in activities which they engaged in before their diagnosis, to retain a sense of self. However, they altered their goals to adapt to their limitations and disruptions caused by their conditions. This is evident in Marian and Valerie's accounts of their experiences of reengaging in PA post-162

treatment, as they described how they had to adapt their performance to their physical limitations as "taking it easy" when returning to their 'normal' PA. Furthermore, this supports the idea of adapting to their 'new normal'.

The breast cancer survivors' experiences and perceptions of PA appeared to be influenced by their beliefs about PA and PA behaviour before their diagnosis. For example, some of the breast cancer survivors who were active before their diagnosis had different views and meanings of PA; compared to those who were not active before and now use PA as a tool to improve their sense of control over cancer recurrence. This finding is similar across the breast cancer nurses and their PA promotion behaviour. For example, it was evident that the breast cancer nurses who focused on the importance of PA from a holistic approach (i.e. that it enables patients to regain 'normality' and improve overall health and well-being) described themselves as actively promoting PA and support breast cancer survivors to re-engage in PA. This could be interpreted as a similarity to the breast cancer survivors who described themselves as active before their diagnosis, and therefore, utilised PA to regain a sense of 'normality' and retain their sense of self; which they appeared to lose through the disruptions caused by treatment. Whereas, other breast cancer nurses and survivors focused on the importance of PA from a medical perspective, as they suggested that PA is utilised as a tool to aid recovery from treatments and improve health to prevent recurrence.

## **10.2.2** The importance of relationships

Experiencing a cancer diagnosis disrupts one's self-identity and relationship with the world; which in turn impacts social relationships with significant others such as: partners, friends and family (Zebrack, 2000). Following a cancer diagnosis and treatment, the disruption to one's sense of self and relationship with the world, causes cancer survivors to "search for meaning" and make sense of their experience (Lee, 2008, p. 780). According to van der Speck et al. (2013), experiencing "connectedness", maintaining close relationships with significant others and establishing new relationships with peers, were identified as the most important sources of meaning in cancer survivors (van der Spek et al., 2013). All of the breast cancer survivors within my research expressed that relationships with significant others such as: family, friends and peers who have shared similar experiences, were important to either help them cope with their 'new normal' or positively influence their PA behaviour.

Some of the breast cancer survivors appeared to rely on the support from significant others to help encourage and motivate them to engage in PA, whereas others described the importance of experiencing support from significant others as an enjoyable factor, which added to their PA experience. Again, the differences in their perceptions of support and how this influences their PA experience appears to relate to their previous PA behaviour and their attitudes towards PA. It was evident throughout the data that the participants who were actively engaged in PA before their diagnosis did not rely on the support from others to encourage or motivate them to engage in PA because it was something which they have always done and enjoyed. However, they did reveal the desire for specific advice from a HCP, regarding what types of PA and how much PA is safe after completing their treatments. Whereas, those who were not active before their diagnosis appeared to rely on the support from others such as: partners, families, peers and HCPs to motivate them to engage in PA.

Although the participants acknowledged and appreciated the support from family and friends, which helped them to adapt to 'normality' after their diagnosis and treatments, some of the participants described feeling isolated during their cancer experience and after completing treatments. These women expressed the need to share their experience with other breast cancer survivors, who understand; thus, indicating a desire to feel a sense of belonging and 'normality'. The importance of establishing relationships with peers who have similar experiences is revealed throughout the majority of the participants' accounts of their experiences of participating in a breast cancer specific exercise class. Most of the participants expressed feeling supported by the other women and a sense of shared understanding was evident throughout their accounts. The exercise class gave the women the opportunity to discuss their experiences with one another; it appeared that through these discussions, they gained a sense of normality, as they shared similar experiences and understanding of their feelings and emotions towards their treatments. Other qualitative literature has identified that breast cancer survivors who experience social support and building relationships with peers, find it contributes to their experiences of participating in an exercise intervention (Bulmer et al., 2012; Luoma et al., 2014). Furthermore, a couple of the participants within my study explicitly described how they avoided returning to exercise classes which they did before their diagnosis, or joining an exercise class which was not specifically targeted at women who have had breast cancer. It appeared that they separated themselves from the activities which had been a part of their previous 'normality' before they were diagnosed and they searched for a new activity which was specifically related to their 'new normal'. In this case, these women preferred and prioritised the exercise class for women who have had breast cancer; thus, illuminating the notion of re-evaluating one's identity after being diagnosed and the importance of establishing a relationship with peers to gain a sense of belonging and 'normality'.

There was a sense that some of the women felt abandoned since completing their hospital based treatments and they desired ongoing contact and support from their breast cancer nurse. This indication was more explicit in a few of the participant's extracts, as they described their expectations with regards to follow up care; some of them had constant worry looming over them in relation to treatment side effects and wondering whether they were 'normal'. It appeared that they wished for regular check-ups with HCPs for reassurance and expertise, to help them feel 'normal' and supported after completing their treatments. Although many of the women were uncertain of changes to their bodies and expressed the need for expert opinion and support, from breast cancer nurses and other HCPs, they did not contact the nurses or initiate discussions for advice. Some of the women expressed that their concerns and worries would be a burden to the breast cancer nurses and this prevented them from contacting them

for advice. It seemed that if they had have had scheduled arrangements for regular check-ups, they would have discussed their concerns to a HCP. Another survivor mentioned that her concerns were related to physical changes and during this period she wanted to see a breast cancer nurse face-to-face, to show her physical changes rather than describe them over the phone was apparent. The lost sense of support and safety from the oncologist team, initially after treatment and during the post treatment phase is illuminated in some of the survivors' narrative accounts. This could suggest that their after care needs were not met by the HCPs and the follow-up care system. However, a study produced contrasting findings, which showed that telephone-follow up care by breast cancer nurses provided participants with information and support they desired to help cope after their treatment. As discussed, the women in my study did not utilise the telephone service to discuss their concerns; therefore, they did not experience whether or not the service was helpful. This could be a possible reason for the different findings between my study and Beaver et al's. (2009).

The breast cancer nurses' perceptions of follow up care reflected significantly different views than those of the breast cancer survivors. All of the breast cancer nurses described the Moving Forward Programme and support groups as points of contact for the breast cancer survivors once they have finished their treatments. They appear to pass on the responsibility of care and support from them, onto external services; this illuminates the different needs and expectations amongst the breast cancer survivors and nurses. Interestingly, only two of the breast cancer nurses (Cathleen and Caitlin), discussed the importance of establishing a relationship with breast cancer survivors. They believed that establishing a relationship enabled them to gain insight and understanding of individuals' barriers to PA; and therefore, this knowledge helped them to support the individual with overcoming these barriers. Understanding the participants' and gaining their trust appeared to be a central approach to promoting PA for these nurses, as they tailored their support and promotion of PA to the individuals' needs. The findings from my research highlighted differences with regards to the breast cancer nurses' approaches to promoting PA and supporting individual survivors with their perceived barriers towards PA. The differences could reflect the breast cancer nurses' perceptions of their relationships with patients and preferred communication styles in an oncology setting. The relationship established between HCPs and patients, and the style of communication used are described as either doctor-centred or patient-centred (Dowsett et al., 2000; Ong, de Haes, Hoos, & Lammes, 1995; Wanzer, Booth-Butterfield, & Gruber, 2004). Patient-centred approaches have been defined as; those in which has greater emphasis on patient and family involvement in the decision making process and the HCP adopts affective behaviours such as empathy and reassurance (Epstein & Gramling, 2012; Stewart, 1984; Zachariae et al., 2003). Whereas, the doctor-centred style involves the 'physician' adopting controlling behaviours within the decision making processes, and often appears to be less empathetic towards patients (Dowsett et al., 2000). The communication style and relationship style between the patients and HCPs both interact with one another (Mazor et al., 2013). For example, the communication style adopted by the HCP may affect the relationship established between them and the patient, and vice versa. Existing literature suggests that patient-centred styles lead to greater patient satisfaction, better health outcomes and 165

patient well-being (Dowsett et al., 2000; Epstein & Gramling, 2012). However, the majority of the research exploring the communication styles of professionals within a health care setting largely involves quantitative methods and the focus on cancer care is limited. Nonetheless, the notion that the approach adopted by the HCP and the relationship established between them and the patient, affects the patients' outcomes and satisfaction with care; is supported in my research findings. This can be seen with regards to two specific contexts of which the participants describe. Firstly, in the post treatment period, some participants felt abandoned by the breast cancer nurses after completing their treatments and appeared to be uncertain of the side effects of their treatments and what their future holds. Secondly, within the PA context, those who reported that they did not receive support or information regarding PA were uncertain of what PA is safe after completing their treatments; this prevented them from engaging in PA until they attended the Moving Forward Programme. These examples illuminate how the lack of specific information and support provided by breast cancer nurses, in this instance affected the breast cancer survivors' wellbeing and PA behaviour.

Although it is apparent that the need for ongoing supportive care from HCPs was perceived by the women in this study to be unmet, the majority of the women appeared to replace the need for support from HCPs, with the support received from the exercise instructor. The majority of the participants acknowledged and appreciated the relationship established with the exercise instructor. For many of the women, the guidance and supervision provided by the instructor positively influenced the women to maintain their engagement in the exercise class. Interestingly, some of the women described how being supervised and monitored throughout the exercise classes, made them feel as though someone was 'finally' taking "interest" in them and their recovery; this emphasises the notion of their supportive needs being unmet by other HCPs. Additionally, it illuminates the importance of engaging with professionals who are knowledgeable of breast cancer and receiving their support and encouragement in relation to PA. Existing literature which has explored breast cancer survivors' experiences of participating in a supervised exercise intervention, revealed similar findings; which suggests that the relationship established with the exercise instructor positively influenced the survivors' adherence to the exercise interventions (Fisher et al., 2015; Kampshoff et al., 2014; Ormel et al., 2018; L. Smith et al., 2017). It is apparent that the participants within my study felt that the exercise environment was safe and the exercises involved in the class were suitable and appropriate for their physical abilities. It is possible to presume that the women may have felt a sense of shared understanding with the exercise instructor because the instructors are knowledgeable of breast cancer and empathetic towards the consequences of treatment.

## 10.2.3 Limited PA advice

All of the participants suggested or implied the need for more information and support from HCPs, in regards to PA after completing treatments. Despite all of the breast cancer survivors attending the Moving Forward Programme and receiving specific information with regards to PA, from an exercise

professional, the majority of participants wished to receive information specifically from the breast cancer nurses before attending the programme. Most of the participants described feeling worried and fearful of causing further physical problems, as a result of not knowing what PA is safe after completing their treatments. The desire to receive specific information sooner was particularly evident for Marian and Valerie, who wanted to return to PA as soon as possible. Findings from previous research, also reveal the desire for individuals to receive PA advice after cancer treatments, from HCPs (Rogers, Markwell, Verhulst, McAuley, & Courneya, 2009; L. Smith et al., 2017; K. Williams, Beeken, Fisher, & Wardle, 2015). Across the participants' accounts of their PA experiences, it seemed that the lack of specific information given to the breast cancer survivors prevented them from engaging, or for some, re-engaging in PA. Recent reviews of the literature, support these findings from my research, they suggest that the lack of specific PA information and encouragement provided by HCPs are barriers to PA engagement amongst breast cancer survivors (Browall et al., 2018; Midtgaard et al., 2015). This illuminates the importance of HCPs and their role with regards to promoting PA and influencing cancer survivors to adopt favourable lifestyle behaviours (Jones & Courneya, 2002; K. Williams et al., 2015). Although the breast cancer survivors wished to receive specific PA advice and encouragement from the breast cancer nurses, it was evident from my study that not all of the breast cancer nurse participants actively promoted PA or discussed PA with breast cancer survivors.

The majority of the breast cancer nurses appeared to rely on resources such as; exercise leaflets and the Moving Forward Programme to provide specific PA information. It appeared that these resources therefore limited some of the breast cancer nurses' sense of responsibility for promoting PA. Additionally, those who did not appear to actively promote PA perceived that they had a lack of opportunities to discuss PA and it was not a high priority to discuss it within the time they had with each individual. It was apparent that these nurses only discussed PA when they thought it was necessary to do so for example, if an individual initiated the discussion or if they were experiencing physical problems associated with their treatments. This reflects the notion of the doctor-centred approach, as discussed earlier in this chapter (10.2.2); as the nurses decided what they discussed within the follow up treatment with the survivor. Although they discussed PA if an individual sought out information, it appears that they do not involve the survivors in the decision making process with regards to what they want to discuss in the follow up meeting. It is evident that the breast cancer survivors wished to receive PA advice from healthcare professionals, this highlights that their needs were not met and therefore, it is possible to suggest that these survivors were not satisfied with the follow up care and the promotion of PA from the HCPs.

Recent government strategies and interventions highlight the importance of HCPs' promoting a healthy lifestyle to improve cancer outcomes (Department of Health, 2011; Department of Health et al., 2010; P. a. p. Department of Health, 2012). The improving outcomes strategy (Department of Health 2011), reports that HCPs should offer cancer survivors: support to self-manage, education and information to enhance their abilities to engage in PA, access to appropriate PA programmes and specialist support.

Additionally, the strategy emphasises the importance of providing a patient-centred approach, allowing the patients to have choice and control during the decision making process throughout their cancer journey. According to The Department of Health (2011), providing the patients with the appropriate support and information to help them, make the most appropriate decisions and choices about their treatments and lifestyle choices will improve their cancer outcomes. As discussed, all of the breast cancer nurses provide survivors with information packs and resources to help them lead a healthier lifestyle and engage in PA; however, it is apparent that the breast cancer survivors have the desire to receive personalised information from them. The difference between the nurses' approaches to promoting PA and lifestyle advice, and the breast cancer survivors' needs allows questions to be raised with regards to the health care provision during the post treatment period of care. Furthermore, although it is evident that the nurses are promoting PA when and if they interpret that it is necessary for the individual; my study highlights the differences towards their perceptions of their role and approaches to PA promotion. Therefore, highlighting that organisational and government factors are not strongly shaping their interpretation of their role and provision of PA promotion.

## 10.3 Quality of the research

In chapter four, I introduced Tracy's (2010), eight-point quality conceptualisation framework and justified why I have chosen this to evaluate the quality of my research. In this section, I will discuss how my research meets the framework.

#### The eight markers are:

**Worthy topic:** Tracy states that good research is interesting, significant, relevant and timely. As highlighted, the findings from this study provide a unique insight into the experiences of PA for breast cancer survivors and those who work with them. These findings contribute to a deeper understanding of the experiences of engaging in and promoting PA; which might be useful to inform health care services and provision of PA.

**Rich rigour:** Rigour involves consideration of the data collection and analysis procedures. Throughout this thesis I have documented the different phases of the research process, I have described and explained what methods and procedures were utilised and justified the reasons. I have provided a thorough description and explanation of the themes developed throughout the analysis and documented the evidence of the development of the themes to ensure that they are appropriate.

**Sincerity:** This relates to transparency and authenticity of the research. This can be achieved through reflexivity; throughout the research process. I have used an audit trail throughout my research journey, where I noted my personal feelings, preconceived ideas, pre-understandings and my position as the researcher. I have described how these may have influenced the research process; these have been

documented and explained throughout the thesis in specific chapters, in relation to the different phases of the research.

**Credibility:** This relates to the trustworthiness and plausibility of the research. This can be achieved through providing detailed accounts and descriptions of how the findings have emerged. Again, engaging in reflexivity and providing detailed accounts of the research process and my position as the researcher enables credibility of the research findings.

**Resonance:** This relates to the impact and value of the research. According to Tracy, aesthetic merit and generalisation both lead to resonance or impact. Aesthetic merit is described as "the text is presented in a beautiful and evocative way". The data and findings are written in a language with reflects the voices of the participants and intertwines with the research methodology, which is interpretative phenomenology. This illuminates the findings in a sense which is related to the participant's accounts as closely as possible. Thus, enabling a richer interpretation and understanding of the phenomenon.

**Significant contribution:** This is the significance of the research study. As discussed previously, the findings have provided a unique insight into the breast cancer survivors' experiences of PA and breast cancer nurses experiences and perspectives of promoting PA. These enable a richer understanding of the meanings and experiences of PA, which might be useful for future research and healthcare provision. I hope the unique findings discussed in this chapter and throughout the thesis, encourage other healthcare professionals to actively promote PA and consider their role of promoting PA.

**Ethical:** includes factors such as; procedural, relational and exiting ethics. For this research I have gained ethical approval by The University of Huddersfield's school research ethic panel and HRA approval. The relationship I have established with the participants was/is respectful and caring. I have a personal relationship with the participants and I share a connectedness with them. Finally, exiting ethics involves ethical practices beyond data collection stages, such as considerations of how the data will be displayed. I have avoided using any information that leads to identifying the participants and the language I have used to present the findings, reflects the words of the participants.

**Meaningful coherence:** does the research study accomplish what it sets out to? To achieve meaningful coherence, the research design, data collection and analysis methods are appropriate for the theoretical framework and research goals. Another, is to ensure that the research study interconnects for example, the findings attend to the research questions. The methodology chosen for this research study, is the most suitable approach for my research aims and position as a researcher. Utilising interpretative phenomenology illuminated unique perspectives and insights, which in turn enabled a deeper understanding of the phenomenon.

## 10.4 Implications for future research and practice

In the introduction chapter, I stated how my passion for and interest in understanding breast cancer survivors' experiences and meanings of PA, were inspiring factors which led me to embark on this PhD study. It was my intention to explore and draw on breast cancer survivors' lived experiences of PA, to gain a unique insight and meaning of their experience; further, I intended to explore breast cancer nurses' perspectives towards their roles and responsibilities of promoting PA. I will discuss the implications of my research findings, for future research and practice in this section.

My interpretation of the breast cancer survivors' accounts of their experiences of PA, and the meanings it held for them, are presented in this chapter and earlier chapters. As we can see, experiencing breast cancer diagnosis and treatments can disrupt an individuals' sense of 'normality'; which causes them to reflect upon their relationship with the world and re-evaluate their lifestyle choices (Bury, 1982). It appeared that the breast cancer survivors utilised PA as a tool to help make sense of and adapt to their 'new normal'; although there are some differences between the survivors' personal meanings towards PA and how they utilise PA, it is evident that PA has become an important aspect of their lives after experiencing a cancer diagnosis. However, some of the breast cancer survivors struggled to return to PA, as they appeared fearful of causing further physical damage because they did not know what PA was safe and effective after their treatments. Although, the breast cancer survivors attended the Moving Forward Programme, it seemed that some of the breast cancer survivors desired more support and personalised information with regards to PA from the breast cancer nurses after completing their treatments. Whilst it is not the focus of phenomenological research to generalise the findings, it is possible that these implications to PA provision and follow up care, might be similar in other populations (Mason, 2004). The findings provide a unique insight and may help health care providers understand breast cancer survivors' needs, in relation to PA advice and support from health care professionals. The divergent perspectives highlight the need for the breast cancer nurses to actively promote PA with a holistic and subjective approach. It is recommended that breast cancer nurses acknowledge the individual's needs, understands the cancer survivor's personal experiences and perceptions towards PA, when promoting PA. This may overcome the issues relating to the breast cancer survivors' experiences and perceptions towards the lack of PA knowledge and support received from breast cancer nurses.

Furthermore, the different attitudes and perceptions towards PA, between the breast cancer survivors and the breast cancer nurses within my study highlight additional implications for healthcare provision and policy. The findings highlighted differences in relation to their attitudes towards and perceptions of the importance of the nurse-survivor relationship and the importance of PA during the post-treatment and recovery period. As mentioned, PA was an important aspect of the breast cancer survivors' lives to either adapt to or make sense of their 'new normal', since completing treatments; however, not all of the breast cancer nurses prioritised PA promotion. Additionally, it is apparent that the breast cancer 170

nurses wished for personalised support from the breast cancer nurses during the post-treatment period. These findings concur with the accounts from the breast cancer nurses, as the majority of them imply that they pass on the responsibility to external resources; which help and support breast cancer survivors to cope with breast cancer. Although, the breast cancer survivors attended and utilised services, the need for continued support from the breast cancer nurse was apparent; therefore, illuminating the importance of the continued support network and relationship with the breast cancer nurse, to possibly improve breast cancer survivors' outcomes and PA participation.

The differences amongst the breast cancer nurses with regards to their attitudes and perceptions of their roles and PA promotion also illuminate practical implications for future healthcare provision. Although the breast cancer nurses had the same job role and worked within the same workplace, it was evident that they held different beliefs about their roles and responsibilities for promoting PA; which in turn appeared to influence their PA promotion behaviour. This indicates that the policies and strategies such as the cancer outcome strategy (Department of Health, 2011), may provide them with the basic knowledge of the importance of PA and its benefits for improving cancer outcomes. However, it may be that specific education and training for breast cancer nurses about the importance of their role and responsibility to promote PA may overcome this issue.

In summary, this thesis has contributed to existing literature as it provides new and unique insights into both breast cancer survivors' lived experiences of PA and breast cancer nurses' perspectives of their roles in promoting PA. The unique insights into the breast cancer survivors' experiences and meanings of PA could help inform future healthcare provision and influence PA promotion amongst health care professionals. In addition to this, the findings from both of the studies highlight the different perspectives between the two groups and more specifically between the breast cancer nurses. This illuminates the need for more qualitative research, which a) uses interpretative phenomenological methods to further investigate this phenomenon, to obtain a richer understanding of the breast cancer nurses' perspectives in relation to their roles and PA promotion and b) combines both sample groups to gain further understanding of the individual perspectives between both cancer survivors and health care professionals. Further research in this field will help to provide a deeper understanding and hopefully inform future health care service provision, with regard to PA promotion. In conclusion, it is recommended that more research utilising interpretative phenomenological methods is needed and specific training and education with regard to PA promotion, for breast cancer nurses would be beneficial to increase PA promotion within this field.

# 10.5 Personal reflection- being an exercise instructor, becoming a researcher

Throughout this thesis, I have reflected on my experiences of specific phases of the research and how my position as a researcher may have influenced the outcomes of these particular phases. For this 171

section of the chapter, I will discuss my experience of this research journey as a whole and reflect upon my development from being an exercise instructor with very little research experience, to becoming a researcher.

I began my PhD journey with very little experience of research and independent study, as I continued straight from undergraduate study; in which my undergraduate degree did not have an extensive research methods element involved. The environment and expectations were a startling contrast from what I was used to as an undergraduate; I often doubted and questioned my capabilities and knowledge, this continued throughout the research journey. At the start of my PhD journey, I felt detached and alienated almost, from the people around me within the research environment; I could not relate to or understand the language 'experienced researchers' were using. Or at least, in my mind I had labelled them as 'experienced researchers' because I felt that they knew more and had experienced more than I had at this stage. However, throughout my research journey I often compared myself to other researchers and questioned my belonging within the researcher environment. I believe that my feelings and doubt towards myself as a researcher impacted on specific aspects of my research experience and transformation from an exercise instructor to becoming a researcher. For example, especially at the beginning stages of my PhD, I often shied away from social events or opportunities with other post graduate researchers because I was afraid of what other people would think of me or if they would judge my skills as a research. My presumptions of what others thought about me prevented me from creating connections with peers, which often led to me feeling isolated throughout the research journey. It was not until I began to attend postgraduate skills courses, to develop my skills and knowledge as a researcher, that I started to talk to other researchers and share my experiences with them. I began to realise that my thoughts and feelings towards how others would perceive me to be and questioning my skills as a researcher, were somewhat common amongst almost all post graduate researchers. This led me to start believing in myself and my skills as a researcher, and I began to feel less alienated within the research world. Engaging in reflexivity throughout my research journey allowed me to make sense of my experiences and understand how these may have affected my development as a researcher. For example, it made me realise how much I worried about the lack of knowledge and skills I had as a researcher; once I realised this, I began to prioritise developing my skills and knowledge, to aid my research journey.

One of the major challenges I faced throughout this research was trying to understand and adopt the language used within phenomenology. Before starting this research, I had never heard of phenomenology or come across any research which involved phenomenological methods. The transformation from a novice researcher with very limited knowledge and skills, to becoming a PhD researcher adopting a phenomenological methodology, was a constant struggle. This struggle is evident throughout my written interpretations of the research findings; although my writing and communication skills have developed over the years, I believe that development is a continual process and so, there are still areas for improvement and my transformation into becoming a phenomenological

researcher is still ongoing. Despite the difficulties of engaging in phenomenology, this methodology is the most appropriate and well suited to my passion and research interests; which are to provide an understanding of breast cancer survivors' lived experiences of PA and their meanings of these experiences. Van Manen (Van Manen, 1990, p. 163), describes how phenomenological research may have a transformative effect on the researcher:

Phenomenology projects and their methods often have a transformative effect on the researcher himself or herself. Indeed, phenomenological research is often itself a form of deep learning, leading to a transformation of consciousness, heightened perceptiveness, increased thoughtfulness.

I believe that van Manen's (1990) suggestion reflects some of my developments and transformation throughout this research journey. Not only have I gained a deeper understanding of breast cancer survivors' experiences of PA and breast cancer nurses' perspectives and experiences of promoting PA; I have also become more reflective and aware of my personal relationship with the world and others.

Before I started this journey, I knew collecting and analysing the research data would be a challenge because of the sensitive nature of the phenomenon. However, it was not until I began interviewing the breast cancer survivors, when I realised how sensitive the issue was and how affected I would become from listening to each individual experiences. I often found myself changing the subject or avoiding deeper probing to gain a deeper understanding, when an individual became upset during the interview. This may have influenced the data being collected and it could be possible that; additionally, the outcome of the data collected may be different if I responded differently to the participants in this situation. However, I did not want to upset them anymore and I did not feel comfortable in that situation to continue with my questions, as I did not think it was necessary or acceptable.

## **10.6 Strengths and limitations**

There are a variety of strengths and limitations within this research study. I will discuss these issues in this section below.

## 10.6.1 My position as a researcher

My position as a researcher and an exercise instructor has both strengths and limitations to the research study. Firstly, as an inexperienced researcher, this was my first time undertaking a research study and therefore, this limited specific aspects of the research process. These have been exposed and discussed in more detail within the reflexivity sections of chapters four, six, seven and nine. In particular, I believe that my lack of experience at the beginning stages of this research, with regards to conducting interviews potentially limited the data being collected. I was faced with numerous challenges during the data collection process for both phases of this research study; I experienced different challenges because of the different research contexts involved.

Before beginning the data collection process for Phase One of the research study, I was aware that I would be faced with some challenges during the data collection process such as nerves, forgetting questions or running out of questions. However, I naively thought that once I had started the very first interview, my nerves would settle and as long as I followed the interview transcript rigidly, then the interview would go smoothly. Additionally, I believed that my relationship with the breast cancer survivors and position as an 'insider' status, would enable the participants and myself to feel comfortable during the interview and therefore, assist with the process. Unfortunately, this was not the case. It is generally considered not to be good practice for the interview guide to be followed rigidly when utilising semi-structured interviews (Qu & Dumay, 2011); semi-structured interviews are flexible to allow the participants to talk freely about their experiences and therefore, allow unexpected findings to emerge. As a result of my inexperience and rigidly following the interview guide, it is possible that certain aspects of the participant's experience did not emerge. Retrospectively, I would have conducted pilot interviews before starting the research, this would have been valuable as a novice researcher to assess my skills and prepare for the interviews.

Another possible limitation of Phase One, relates to my position as an 'insider' researcher; although my position shifted and continuously moved between being an 'insider' and 'outsider' (see chapter four), I experienced some challenges of being an 'insider' researcher. For example, upon reflection and listening to the audio recording of the interviews, I realised that sometimes the participants did not expand upon their descriptions or explanations of their experiences, as they presumed that I already had some understanding as an exercise instructor and because of my relationship with them. Therefore, it could be possible that my relationship with the participants prior to conducting the research could have affected the dynamics of the interview and limited the data collection process. However, I believe that having an 'insider' status enabled the participants to open up and freely discuss their experiences with me; which in turn, made me feel more comfortable to probe deeper when necessary and to gain a deeper insight into their experiences.

My presumptions about conducting the interviews and my position as the researcher during Phase Two of the research study, differed from those in Phase One. Unlike Phase One, I was apprehensive to conduct the interviews because of my unfamiliarity with the hospital environment and the participants involved in the research study. Additionally, my position as a researcher was primarily of an 'outsider' status, I often felt as though I was an intruder and I presumed that there would be a power divide between myself and the breast cancer nurses; this added to my apprehensions towards conducting the interviews. My apprehensions and presumptions particularly affected the first interview, sometimes I did not feel comfortable to probe deeper into the participant's experiences as I felt as though I was intruding on the participants' work. However, it is important to note that my interviewing skills developed throughout the data collection process, as I gained more experience and became familiar with the hospital environments. This was evident in the remaining interviews, as I probed deeper, to gain more understanding of their experiences.

Despite the challenges faced in relation to my position as a researcher, I have kept an audit trail and reflected upon my experiences throughout the research process and documented how my position may have influenced the research process. These have been exposed throughout the thesis in specific sections relating to different phases of the research process. Reflexivity is an essential component of qualitative research studies to ensure the trustworthiness of the research study (Berger, 2015; Finlay, 2002b).

## **10.6.2 Participant sample groups**

Due to the methodological approach utilised within this thesis, both sample groups were recruited specifically based upon their experiences of the phenomenon being investigated. All participants were female, white and from the same geographical location. More specifically, the majority of the participants in Phase One are over 50 years of age and they all participate in the exercise class held at the University. Additionally, in Phase Two, all of the participants with the exception of one, work in the same hospital as a breast cancer nurse. The homogeneity of the group could be a limitation, as the findings are context specific and therefore the findings of this research study are not applicable to other populations or settings. Furthermore, the breast cancer nurses' physical activity levels were not explored in the interviews. This may have impacted the findings as their own experiences and meanings of physical activity may have implications of physical activity promotion. However, because this was not explored in the research study, this is unknown and provides a suggestion for future research. Below in section 10.6, I will discuss recommendations for future research, to overcome these limitations. However, one would argue that generalising the findings is not a central focus or concern of phenomenological research inquiry; the main concern is to understand individual experiences and meanings of their experiences of the phenomenon under investigation. Therefore, purposively selecting the participants based upon their experiences is the most suitable method to gain a unique insight into the phenomenon. In addition to this, selecting and combing both breast cancer survivors and breast cancer nurses provides a unique insight into the differing perspective of their experiences towards PA and PA promotion; it is to my knowledge that no other research studies have combinied both. Therefore, this provides a contribution to knowledge and could influence future health healthcare provision, in particularly PA promotion.

## 10.6.3 The utilisation of interpretative phenomenology

The overall aim of this research study is to explore both the breast cancer survivors' lived experiences of PA (PA) and breast cancer nurses' perspectives and experiences of promoting PA. However, there are specific aims which are diverse for Phase One and Phase Two of the research study. Phase One is concerned with exploring the individual experiences of PA amongst breast cancer survivors; whereas, Phase Two is less concerned with individual experiences. However, the main concern is to explore breast cancer nurses' perspectives and experiences of promoting PA. Furthermore, my focus is to understand the participants' experiences of the phenomenon through interpretation. Therefore, interpretative phenomenology was chosen as the most suitable approach for this research study. As discussed in chapter three, phenomenology is concerned with exploring lived experiences of a phenomenon and attempts to understand the meaning of this experience to the individual (Spinelli, 2005). There are a variety of research methods within phenomenology, which are suitable for specific research questions; this enables flexibility of choice and enables the researcher to utilise different methods to collect, analyse and present the research findings (Van Manen, 1990). This is suitable for the purpose of this research study, in relation to the different aims of Phase One and Phase Two. Utilising both IPA and TA separately to structure the data analysis for both phases of the research study, have enabled me to gain a unique insight into both the breast cancer survivors' and the breast cancer nurses experiences and illuminate and combine my understandings of their experiences.

As previously discussed, the findings from this research cannot be cannot be applied to wider sample populations, research contexts and environments; some may argue that this is a limitation. However, generalising the research findings is not a concern of phenomenological research, as the concern is to understand human experiences of a phenomenon within a specific context or a specific (Giorgi, 2008). Despite this, phenomenology is a valuable method used within health science research and is specifically valuable for my research study, to explore the lived experiences of the phenomenon and illuminate the meanings of the experiences to the individual.

# **10.7 Recommendations for future research**

Some of the limitations of the research study (as discussed above), have highlighted that there are certain aspects which would benefit from being addressed in future research. These are highlighted in this section below.

Within this current study there is a lack of diversity in both samples. Focusing on breast cancer survivors' experiences of PA within ethnically diverse populations such as, black, Asian and minority ethnic (BAME) groups would offer more insight as different experiences may emerge. Furthermore, qualitative studies including breast cancer survivors and breast cancer nurses from diverse age groups and geographical locations should be considered to enhance the understanding of the phenomenon. In addition, the interviews were conducted with breast cancer survivors who regularly participate in an exercise class and phase two of the research involved only breast cancer nurses. Although these findings provide a unique insight and enhanced understanding, which could be used to inform future research and service provision a wider range of people should be included and interviewed in future research, to explore diverse experiences and perspectives. For example, interviewing different health care professionals such as physiotherapists, medical oncologists and GP's in relation to their perspectives and experiences of promoting PA. Equally, interviewing breast cancer survivors who participate in different types of PA such as individual and other group based PA. Interviewing a broader

range of participants would also add to the contribution of knowledge and understanding of the phenomenon as a whole.

Another suggestion for future research would be to include exercise professionals, to gain an understanding of their perspectives and experiences of delivering exercise and PA to breast cancer survivors should be considered. This would provide an alternative insight into the phenomenon and might offer further understanding.

Phase two explored breast cancer nurses' perspectives and experiences of promoting PA to breast cancer survivors. However, the research did not explore their personal physical activity levels. There is a possibility that their personal experiences of PA could influence how they promote PA. Therefore, it is recommended that future research investigates this, to obtain further knowledge and understanding of their experiences and perspectives of promoting PA.

The interviews were only conducted once and for the majority of the breast cancer survivors, these were conducted two and three years since being diagnosed. Conducting a longitudinal research study to explore breast cancer survivors' experiences of PA over a longer time frame, would be valuable to gain a deeper understanding of the meanings of PA and experiences throughout different time frames since diagnosis. Again, different experiences of PA may be identified throughout different times since diagnosis. Therefore, longitudinal research studies amongst this population is recommended.

Overall, this thesis has demonstrated the importance of exploring first person experiences relating to PA, whether it is for people who have cancer or for those who work with cancer survivors. Further research can help us to develop an understanding of practice that will potentially influence future provision and help others.

## **10.8 Concluding thoughts**

Before beginning this work, I had no prior agenda, other than to gain a deeper understanding of what PA means to breast cancer survivors and to illuminate their experiences. I value the voices of individual's and believe that understanding their meanings of their experience is important. My review of the existing literature highlighted that there are very few studies utilising phenomenological methods, to understand breast cancer survivors' lived experiences of PA. Additionally, there were no studies that had combined the experiences and perspectives of both breast cancer survivors and breast cancer nurses. Through utilising phenomenology and combining both groups of participants for this thesis, this has enabled a richer understanding of the experiences of PA from both perspectives. Furthermore, the findings highlighted potential implications for healthcare practice, with regards to the relationship between the survivors and nurses and suggestions for specific training for breast cancer nurses about the importance of their role and responsibility to promote PA.

I hope that this research study will help others and inspire health care professionals to listen to the needs of breast cancer survivors and encourage them to actively promote PA. Furthermore, I hope this research inspires others to undertake similar research, to expand and develop the knowledge and understandings of this important phenomenon.

# **Reference list**

- Allemani, C., Weir, H. K., Carreira, H., Harewood, R., Spika, D., Wang, X.-S., . . . Group, C. W. (2015). Global surveillance of cancer survival 1995–2009: analysis of individual data for 25 676 887 patients from 279 population-based registries in 67 countries (CONCORD-2). *The Lancet, 385*(9972), 977-1010. doi:10.1016/S0140-6736(14)62038-9
- Arora, N. K. (2003). Interacting with cancer patients: the significance of physicians' communication behavior. *Social Science & Medicine*, *57*(5), 791-806.
- Bailey, J. (2008). First steps in qualitative data analysis: transcribing. *Family Practice*, 25(2), 127-131. doi:10.1093/fampra/cmn003
- Balneaves, L. G., Van Patten, C., Truant, T. L., Kelly, M. T., Neil, S. E., & Campbell, K. L. (2014). Breast cancer survivors' perspectives on a weight loss and physical activity lifestyle intervention. *Support Care Cancer, 22*(8), 2057-2065. doi:10.1007/s00520-014-2185-4
- Bandura, A. (2004). Health promotion by social cognitive means. *Health Educ Behav*, *31*(2), 143-164. doi:10.1177/1090198104263660
- Benner, P. E., & Benner, P. (1994). *Interpretive phenomenology: embodiment, caring, and ethics in health and illness*. Thousand Oaks, Calif: Sage Publications.
- Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219-234. doi:10.1177/1468794112468475
- Biggerstaff, D., & Thompson, A. R. (2008). Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research. *Qualitative research in psychology*, *5*(3), 214-224. doi:10.1080/14780880802314304
- Blaikie, N. (2007). Approaches to social enquiry: Advancing knowledge: Polity.
- Borch, K. B., Braaten, T., Lund, E., & Weiderpass, E. (2015). Physical activity before and after breast cancer diagnosis and survival the Norwegian women and cancer cohort study. *BMC Cancer, 15*(1), 967. doi:10.1186/s12885-015-1971-9
- Bradbury-Jones, C. (2007). Enhancing rigour in qualitative health research: exploring subjectivity through Peshkin's I's. *Journal of Advanced Nursing*, *59*(3), 290-298. doi:10.1111/j.1365-2648.2007.04306.x
- Breast cancer care. (n.d.-a). Moving forward after breast cancer treatment. Retrieved from <u>https://www.breastcancercare.org.uk/information-support/support-you/moving-forward-after-breast-cancer-treatment</u>
- Breast cancer care. (n.d.-b). Primary breast cancer. Retrieved from <u>https://www.breastcancercare.org.uk/information-support/facing-breast-cancer/diagnosed-breast-cancer/primary-breast-cancer</u>

- Breast cancer care. (n.d.-c). Side effects. Retrieved from <u>https://www.breastcancercare.org.uk/information-support/facing-breast-cancer/going-through-treatment-breast-cancer/side-effects</u>
- Brenner, D. R., Neilson, H. K., Courneya, K. S., & Friedenreich, C. M. (2014). Physical Activity After Breast Cancer: Effect on Survival and Patient-Reported Outcomes. *Current Breast Cancer Reports*, 6(3), 193-204. doi:10.1007/s12609-014-0147-y
- Brocki, J., & Wearden, A. (2014). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. In B. Gough (Ed.), *Qualitative research in psychology* (Vol. 3): SAGE Benchmarks in Psychology.
- Brooks, J. (2015). Learning from the lifeworld: Introducing alternative approaches to phenomenology in psychology. *The psychologist, 28*(8), 642-643.
- Brooks, J., & King, N. (2012). Qualitative psychology in the real world: the utility of template analysis.
- Brooks, J., McCluskey, S., Turley, E., & King, N. (2015). The utility of template analysis in qualitative psychology research. *Qualitative research in psychology*, *12*(2), 202-222.
- Browall, M., Mijwel, S., Rundqvist, H., & Wengström, Y. (2018). Physical Activity During and After Adjuvant Treatment for Breast Cancer: An Integrative Review of Women's Experiences. *Integrative Cancer Therapies*, *17*(1), 16-30. doi:10.1177/1534735416683807
- Brunet, J., Sabiston, C. M., & Burke, S. (2013). Surviving breast cancer: Women's experiences with their changed bodies. *Body Image*, *10*(3), 344-351. doi:10.1016/j.bodyim.2013.02.002
- Brunet, J., Taran, S., Burke, S., & Sabiston, C. M. (2013). A qualitative exploration of barriers and motivators to physical activity participation in women treated for breast cancer. *Disability and rehabilitation*, *35*(24), 2038-2045.
- Bull, F. C. (2010). New physical activity guidelines in the UK: Review and Recommendations. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/att achment\_data/file/213743/dh\_128255.pdf
- Bulmer, S. M., Howell, J., Ackerman, L., & Fedric, R. (2012). Women's Perceived Benefits of Exercise During and After Breast Cancer Treatment. *Women & Health*, 52(8), 771-787. doi:10.1080/03630242.2012.725707
- Burns, E., Fenwick, J., Schmied, V., & Sheehan, A. (2012). Reflexivity in midwifery research: The insider/outsider debate. *Midwifery*, *28*(1), 52-60. doi:<u>https://doi.org/10.1016/j.midw.2010.10.018</u>
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness,* 4(2), 167-182. doi:doi:10.1111/1467-9566.ep11339939

- Cancer Research UK. (2015). Exercise guidelines for cancer patients. Retrieved from <u>http://www.cancerresearchuk.org/about-cancer/coping/physically/exercise-guidelines</u>
- Cancer Research UK. (2017a). Decisions about your treatment. Retrieved from <u>http://www.cancerresearchuk.org/about-cancer/breast-</u><u>cancer/treatment/treatment-decisions</u>
- Cancer Research UK. (2017b). Invasive lobular breast cancer. Retrieved from <u>http://www.cancerresearchuk.org/about-cancer/breast-cancer/stages-types-grades/types/invasive-lobular-breast-cancer</u>
- Cancer Research UK. (n.d.). Breast cancer survival statistics. Retrieved from <u>http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer/survival</u>
- Cantwell, M., Walsh, D., Furlong, B., Moyna, N., McCaffrey, N., Boran, L., . . . Woods, C. (2018). Healthcare professionals' knowledge and practice of physical activity promotion in cancer care: Challenges and solutions. *European journal of cancer care, 27*(2), e12795. doi:doi:10.1111/ecc.12795
- Carson, D., Gilmore, A., Perry, C., & Gronhaug, K. (2001). *Qualitative Marketing Research*. London: SAGE Publications.
- Casla, S., Hojman, P., Márquez-Rodas, I., López-Tarruella, S., Jerez, Y., Barakat, R., & Martín, M. (2015). Running away from side effects: physical exercise as a complementary intervention for breast cancer patients. *Clinical and Translational Oncology*, 17(3), 180-196. doi:10.1007/s12094-014-1184-8
- Caspersen, C. J., Powell, K. E., & Christenson, G. M. (1985). Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. *Public health reports*, 100(2), 126.
- Chadwick, B., Gill, P., Stewart, K., & Treasure, E. (2008). Methods of data collection in qualitative research: interviews and focus groups. *BDJ*, 204(6), 291-295. doi:10.1038/bdj.2008.192
- Clifford, B. K., Mizrahi, D., Sandler, C. X., Barry, B. K., Simar, D., Wakefield, C. E., & Goldstein, D. (2018). Barriers and facilitators of exercise experienced by cancer survivors: a mixed methods systematic review. *Supportive Care in Cancer, 26*(3), 685-700. doi:10.1007/s00520-017-3964-5
- Colaizzi, P. F. (1978). Psychological research as the phenomenologist views it. In R. S. Valle & M. King (Eds.), *Existential-Phenomenological Alternatives for Psychology* (pp. 6): Oxford University Press.
- Collis, J., & Hussey, R. (2009). *Business research: a practical guide for undergraduate & postgraduate students* (3rd ed.). Basingstoke: Palgrave Macmillan.
- Courneya, K. S. (2017). Exercise guidelines for cancer survivors: are fitness and qualityof-life benefits enough to change practice? *Current Oncology*, 24(1), 8-9. doi:<u>http://dx.doi.org/10.3747/co.24.3545</u>

- Courneya, K. S., Segal, R. J., McKenzie, D. C., Dong, H., Gelmon, K., Friedenreich, C. M., . . . Mackey, J. R. (2014). Effects of exercise during adjuvant chemotherapy on breast cancer outcomes. *Med Sci Sports Exerc, 46*(9), 1744-1751. doi:10.1249/mss.00000000000297
- Cramer, H., Lauche, R., Klose, P., Lange, S., Langhorst, J., & Dobos, G. J. (2017). Yoga for improving health-related quality of life, mental health and cancer-related symptoms in women diagnosed with breast cancer. *Cochrane Database of Systematic Reviews*(1). doi:10.1002/14651858.CD010802.pub2
- Creswell, J. W. (2012). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (3 ed.). London: Sage Publications Inc.
- Creswell, J. W., Hanson, W. E., Clark Plano, V. L., & Morales, A. (2007). Qualitative Research Designs:Selection and Implementation. *The Counseling Psychologist*, *35*(2), 236-264. doi:10.1177/0011000006287390
- Cummins, C., Kayes, N. M., Reeve, J., Smith, G., MacLeod, R., & McPherson, K. M. (2017). Navigating physical activity engagement following a diagnosis of cancer: A qualitative exploration. *European journal of cancer care, 26*(4), e12608. doi:doi:10.1111/ecc.12608
- Daley, A. J., Bowden, S. J., Rea, D. W., Billingham, L., & Carmicheal, A. R. (2008). What advice are oncologists and surgeons in the United Kingdom giving to breast cancer patients about physical activity? *Int J Behav Nutr Phys Act, 5*, 46. doi:10.1186/1479-5868-5-46
- Department of Health. (2011). *Improving Outcomes: AStrategy for Cancer*. UK Retrieved from <a href="https://assets.publishing.service.gov.uk/government/uploads/system/uploads/att">https://assets.publishing.service.gov.uk/government/uploads/system/uploads/att</a> <a href="https://assets.publishing.service.gov.uk/government/uploads/system/uploads/att">https://assets.publishing.service.gov.uk/government/uploads/system/uploads/att</a> <a href="https://assets.publishing.service.gov.uk/government/uploads/system/uploads/att">https://assets.publishing.service.gov.uk/government/uploads/system/uploads/att</a> <a href="https://assets.publishing.service.gov.uk/government/uploads/system/uploads/att">https://assets.publishing.service.gov.uk/government/uploads/system/uploads/att</a>
- Department of Health, Macmillan Cancer Support, & NHS Improvement. (2010). *The National Cancer Survivorship Initiative Vision*. Retrieved from <u>http://webarchive.nationalarchives.gov.uk/20100809113601/http://www.improve</u> <u>ment.nhs.uk/cancer/LinkClick.aspx?fileticket=4apVUSvGcow%3d&tabid=214</u>
- Department of Health, P. a. p. (2012). *Let's Get Moving A physical activity care pathway. Commissioning Guidance*. UK Retrieved from <u>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/att</u> <u>achment data/file/216262/dh 133101.pdf</u>
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education, 40*(4), 314-321. doi:doi:10.1111/j.1365-2929.2006.02418.x
- Dieli-Conwright, C. M., Lee, K., & Kiwata, J. L. (2016). Reducing the Risk of Breast Cancer Recurrence: an Evaluation of the Effects and Mechanisms of Diet and Exercise. *Curr Breast Cancer Rep, 8*(3), 139-150. doi:10.1007/s12609-016-0218-3
- Dowsett, S. M., Saul, J. L., Butow, P. N., Dunn, S. M., Boyer, M. J., Findlow, R., & Dunsmore, J. (2000). Communication styles in the cancer consultation: preferences for a patient-centred approach. *Psycho-Oncology*, *9*(2), 147-156.

doi:doi:10.1002/(SICI)1099-1611(200003/04)9:2<147::AID-PON443>3.0.CO;2-X

- Dwyer, S. C., & Buckle, J. L. (2009). The Space Between: On Being an Insider-Outsider in Qualitative Research. *International Journal of Qualitative Methods*, 8(1), 54-63. doi:10.1177/160940690900800105
- Eatough, V., & Smith, J. (2006). I was like a wild wild person: Understanding feelings of anger using interpretative phenomenological analysis. *British Journal of Psychology*, *97*(4), 483-498.
- Emslie, C., Whyte, F., Campbell, A., Mutrie, N., Lee, L., Ritchie, D., & Kearney, N. (2007).
   'I wouldn't have been interested in just sitting round a table talking about cancer'; exploring the experiences of women with breast cancer in a group exercise trial. *Health Education Research*, 22(6), 827-838. doi:10.1093/her/cyl159
- Epstein, R. M., & Gramling, R. E. (2012). What Is Shared in Shared Decision Making? Complex Decisions When the Evidence Is Unclear. *Medical Care Research and Review*, 70(1\_suppl), 94S-112S. doi:10.1177/1077558712459216
- Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics*, 5(1), 1-4.
- Ferlay J, Soerjomataram I, Ervik, M., Dikshit R, Eser S, Mathers C, . . . Bray F. (2013).GLOBOCAN 2012 v1.0, Cancer Incidence and Mortality Worldwide: IARCCancerBaseNo.11.Retrievedhttp://globocan.iarc.fr/Pages/fact sheets cancer.aspx

Finefter-Rosenbluh, I. (2017). Incorporating Perspective Taking in Reflexivity: A Method to Enhance Insider Qualitative Research Processes. International Journal of Qualitative Methods  $U_6$ ctx ver=Z39.88-2004&ctx\_enc=info%3Aofi%2Fenc%3AUTF-8&rfr\_id=info%3Asid%2Fsummon.serialssolutions.com&rft\_val\_fmt=info%3Aofi% 2Ffmt%3Akev%3Amtx%3Ajournal&rft.genre=article&rft.atitle=Incorporating+Per spective+Taking+in+Reflexivity&rft.jtitle=International+Journal+of+Qualitative+ Methods&rft.au=Finefter-Rosenbluh%2C+Ilana&rft.date=2017-04-11&rft.pub=SAGE+Publications&rft.eissn=1609-4069&rft.volume=16&rft.issue=1&rft\_id=info:doi/10.1177%2F160940691770353 9&rft.externalDocID=10.1177\_1609406917703539&paramdict=en-US U7 Journal Article, 16(1). doi:10.1177/1609406917703539

- Finlay, L. (2002a). Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2(2), 209-230. doi:10.1177/146879410200200205
- Finlay, L. (2002b). "Outing" the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, 12(4), 531-545. doi:10.1177/104973202129120052
- Finlay, L. (2006). The body's disclosure in phenomenological research. *Qualitative research in psychology*, *3*(1), 19-30. doi:10.1191/1478088706qp051oa

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- Finlay, L. (2009). Debating Phenomenological Research Methods. *Phenomenology & Practice, 3*(1), 6-25.
- Fisher, A., Williams, K., Beeken, R., & Wardle, J. (2015). Recall of physical activity advice was associated with higher levels of physical activity in colorectal cancer patients. *BMJ Open*, 5(4). doi:10.1136/bmjopen-2014-006853
- Fong, A. J., Faulkner, G., Jones, J. M., & Sabiston, C. M. (2018). A qualitative analysis of oncology clinicians' perceptions and barriers for physical activity counseling in breast cancer survivors. *Supportive Care in Cancer*, 26(9), 3117-3126. doi:10.1007/s00520-018-4163-8
- Frie, R. (2010). A hermeneutics of exploration: The interpretive turn from binswanger to gadamer. Journal of Theoretical and Philosophical Psychology, 30(2), 79-93. doi:10.1037/a0021570
- Gair, S. (2012). Feeling Their Stories: Contemplating Empathy, Insider/Outsider Positionings, and Enriching Qualitative Research. *Qualitative Health Research*, 22(1), 134-143. doi:10.1177/1049732311420580
- Giorgi, A. (1985). *Phenomenology and psychological research*. Atlantic Highlands, N.J;Pittsburgh, Pa;: Duquesne University Press.
- Giorgi, A. (2007). Concerning the phenomenological methods of Husserl and Heidegger and their application in psychology. *Collection du Cirp*, 1(1), 63-78.
- Giorgi, A. (2008). Concerning a Serious Misunderstanding of the Essence of the Phenomenological Method in Psychology. *Journal of Phenomenological Psychology*, *39*(1), 33-58. doi:10.1163/156916208X311610
- Goldschmidt, D., Schmidt, L., Krasnik, A., Christensen, U., & Groenvold, M. (2006). Expectations to and evaluation of a palliative home-care team as seen by patients and carers. *Supportive Care in Cancer, 14*(12), 1232-1240. doi:10.1007/s00520-006-0082-1
- Granger, C. L., Connolly, B., Denehy, L., Hart, N., Antippa, P., Lin, K.-Y., & Parry, S. M. (2017). Understanding factors influencing physical activity and exercise in lung cancer: a systematic review. *Supportive Care in Cancer*, 25(3), 983-999. doi:10.1007/s00520-016-3484-8

Guba, E. G. (1990, 1990). The Paradigm dialog, Newbury Park, Calif;London;.

- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of qualitative research*, 2(163-194), 105.
- Hardcastle, S. J., Kane, R., Chivers, P., Hince, D., Dean, A., Higgs, D., & Cohen, P. A. (2018). Knowledge, attitudes, and practice of oncologists and oncology health care providers in promoting physical activity to cancer survivors: an international survey. *Supportive Care in Cancer*. doi:10.1007/s00520-018-4230-1
- Haussmann, A., Gabrian, M., Ungar, N., Jooß, S., Wiskemann, J., Sieverding, M., & Steindorf, K. (2018). What hinders healthcare professionals in promoting physical

activity towards cancer patients? The influencing role of healthcare professionals' concerns, perceived patient characteristics and perceived structural factors. *European journal of cancer care, 27*(4), e12853. doi:doi:10.1111/ecc.12853

- Haussmann, A., Ungar, N., Gabrian, M., Tsiouris, A., Sieverding, M., Wiskemann, J., & Steindorf, K. (2018). Are healthcare professionals being left in the lurch? The role of structural barriers and information resources to promote physical activity to cancer patients. *Supportive Care in Cancer*. doi:10.1007/s00520-018-4279-x
- Hayfield, N., & Huxley, C. (2015). Insider and Outsider Perspectives: Reflections on Researcher Identities in Research with Lesbian and Bisexual Women. *Qualitative research in psychology*, *12*(2), 91-106. doi:10.1080/14780887.2014.918224
- Hebdon, M., Foli, K., & McComb, S. (2015). Survivor in the cancer context: a concept analysis. *Journal of Advanced Nursing*, *71*(8), 1774-1786. doi:10.1111/jan.12646
- Hefferon, K., Murphy, H., McLeod, J., Mutrie, N., & Campbell, A. (2013). Understanding barriers to exercise implementation 5-year post-breast cancer diagnosis: a large-scale qualitative study. *Health Educ Res, 28*(5), 843-856. doi:10.1093/her/cyt083

Heidegger, M. (2010). Being and time: Suny Press.

- Holloway, I., & Wheeler, S. (2010). *Qualitative research in nursing and healthcare* (3rd;3. Aufl.; ed.). Ames, Iowa;Chichester;: Wiley-Blackwell.
- Husebø, A. M. L., Dyrstad, S. M., Søreide, J. A., & Bru, E. (2013). Predicting exercise adherence in cancer patients and survivors: a systematic review and meta-analysis of motivational and behavioural factors. *Journal of Clinical Nursing*, *22*(1-2), 4-21. doi:doi:10.1111/j.1365-2702.2012.04322.x
- Ihde, D. (1986). *Experimental phenomenology: an introduction*. Albany, NY: State University of New York Press.
- Irwin, M. L. (2009). Physical activity interventions for cancer survivors. *British Journal of Sports Medicine*, *43*(1), 32-38. doi:10.1136/bjsm.2008.053843
- Irwin, M. L., Smith, A. W., McTiernan, A., Ballard-Barbash, R., Cronin, K., Gilliland, F. D., . . . Bernstein, L. (2008). Influence of pre-and postdiagnosis physical activity on mortality in breast cancer survivors: the health, eating, activity, and lifestyle study. *Journal of Clinical Oncology*, 26(24), 3958.
- Jones, L. W., & Courneya, K. S. (2002). Exercise discussions during cancer treatment consultations. *Cancer Pract*, *10*(2), 66-74.
- Kampshoff, C. S., Jansen, F., van Mechelen, W., May, A. M., Brug, J., Chinapaw, M. J., & Buffart, L. M. (2014). Determinants of exercise adherence and maintenance among cancer survivors: a systematic review. *International Journal of Behavioral Nutrition* and Physical Activity, 11(1), 80. doi:10.1186/1479-5868-11-80
- Keogh, J. W. L., Olsen, A., Climstein, M., Sargeant, S., & Jones, L. (2017). Benefits and Barriers of Cancer Practitioners Discussing Physical Activity with their Cancer

Patients. Journal of Cancer Education, 32(1), 11-15. doi:10.1007/s13187-015-0893-1

- Khan, N. F., Harrison, S., Rose, P. W., Ward, A., & Evans, J. (2012). Interpretation and acceptance of the term 'cancer survivor': a United Kingdom-based qualitative study. *European journal of cancer care, 21*(2), 177-186. doi:10.1111/j.1365-2354.2011.01277.x
- Khan, N. F., Rose, P. W., & Evans, J. (2012). Defining cancer survivorship: a more transparent approach is needed. *Journal of Cancer Survivorship*, 6(1), 33-36. doi:10.1007/s11764-011-0194-6
- King, N. (2004). Using templates in the thematic analysis of text. In C. Cassell & G. Symon (Eds.), Essential Guide to Qualitative Methods in Organizational Research. London: SAGE Publications Ltd. Retrieved from <u>http://sk.sagepub.com/books/essentialguide-to-qualitative-methods-in-organizational-research</u>. doi:10.4135/9781446280119
- King, N. (2012). Doing template analysis. *Qualitative organizational research: Core methods and current challenges, 426.*
- King, N., & Brooks, J. M. (2016). *Template analysis for business and management students*: Sage.
- King, N., & Horrocks, C. (2010). Interviews in Qualitative Research: Sage.
- Langdridge, D. (2007). *Phenomenological psychology: theory, research and method* (1 ed.). Harlow: Prentice Hall.
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative research in psychology*, *3*(2), 102-120. doi:10.1191/1478088706qp062oa
- Larsson, I. L., Jonsson, C., Olsson, A. C., Gard, G., & Johansson, K. (2008). Women's experience of physical activity following breast cancer treatment. *Scand J Caring Sci, 22*(3), 422-429. doi:10.1111/j.1471-6712.2007.00546.x
- Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, *2*(3), 21-35.
- Lee, V. (2008). The existential plight of cancer: meaning making as a concrete approach to the intangible search for meaning. *Supportive Care in Cancer, 16*(7), 779-785. doi:10.1007/s00520-007-0396-7
- Li, T., Wei, S., Shi, Y., Pang, S., Qin, Q., Yin, J., . . . Liu, L. (2016). The dose-response effect of physical activity on cancer mortality: findings from 71 prospective cohort studies. *British Journal of Sports Medicine, 50*(6), 339-345. doi:10.1136/bjsports-2015-094927

- Livsey, L., & Lewis, K. (2017). Breast cancer survivors' perceptions of participating in a supervised exercise intervention: An exploratory review of the literature. *Women* & *Health*, 1-20. doi:10.1080/03630242.2017.1372844
- Lopez, K. A., & Willis, D. G. (2004). Descriptive Versus Interpretive Phenomenology: Their Contributions to Nursing Knowledge. *Qualitative Health Research*, 14(5), 726-735. doi:10.1177/1049732304263638
- Loprinzi, P. D., Cardinal, B. J., Winters-Stone, K., Smit, E., & Loprinzi, C. L. (2012). Physical activity and the risk of breast cancer recurrence: a literature review. *Oncol Nurs Forum*, *39*(3), 269-274. doi:10.1188/12.onf.269-274
- Luoma, M. L., Hakamies-Blomqvist, L., Blomqvist, C., Nikander, R., Gustavsson-Lilius, M., & Saarto, T. (2014). Experiences of breast cancer survivors participating in a tailored exercise intervention -a qualitative study. *Anticancer Res, 34*(3), 1193-1199.
- Mackey, S. (2005). Phenomenological nursing research: methodological insights derived from Heidegger's interpretive phenomenology. *International Journal of Nursing Studies*, 42(2), 179-186. doi:10.1016/j.ijnurstu.2004.06.011
- Macmillan Cancer Support. (2016a). Targeted (biological) therapies for breast cancer. Retrieved from <u>https://www.macmillan.org.uk/information-and-support/breast-cancer/treating/targeted-biological-therapies/targeted-and-biological-therapies-explained/what-are-targeted-biological-therapies.html</u>
- Macmillan Cancer Support. (2016b). Types of breast cancer. Retrieved from <u>https://www.macmillan.org.uk/information-and-support/breast-</u> <u>cancer/understanding-cancer/types-of-breast-cancer.html</u>
- Macmillan Cancer Support. (2017). What is cancer? Retrieved from <u>https://www.macmillan.org.uk/information-and-support/breast-</u> <u>cancer/understanding-cancer/what-is-cancer.html</u>
- Madabhavi, I., Patel, A., Sarkar, M., Anand, A., Panchal, H., & Parikh, S. (2017). A Study of Use of "PORT" Catheter in Patients with Cancer: A Single-Center Experience. *Clinical Medicine Insights: Oncology, 11*. doi:10.1177/1179554917691031
- Marzorati, C., Riva, S., & Pravettoni, G. (2017). Who Is a Cancer Survivor? A Systematic Review of Published Definitions. *Journal of Cancer Education*, *32*(2), 228-237. doi:10.1007/s13187-016-0997-2
- Mason, J. (2017). Qualitative researching: Sage.
- Mayer, D. K. P., Nasso, S. F. M. P. P., & Earp, J. A. P. (2017). Defining cancer survivors, their needs, and perspectives on survivorship health care in the USA. *Lancet Oncology, The, 18*(1), e11-e18. doi:10.1016/S1470-2045(16)30573-3
- Mazor, K. M., Gaglio, B., Nekhlyudov, L., Alexander, G. L., Stark, A., Hornbrook, M. C., . . . Arora, N. K. (2013). Assessing Patient-Centered Communication in Cancer Care: Stakeholder Perspectives. *Journal of Oncology Practice*, 9(5), e186-e193. doi:10.1200/jop.2012.000772

- McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L. S., Lorig, K., & Wagner, E. H. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians, 61*(1), 50-62. doi:doi:10.3322/caac.20093
- McDonough, M. H. (2011). The Development of Social Relationships, Social Support, and Posttraumatic Growth in a Dragon Boating Team for Breast Cancer Survivors. *Journal of sport & exercise psychology*, 33(5), 627-648. doi:10.1123/jsep.33.5.627
- Midtgaard, J., Hammer, N. M., Andersen, C., Larsen, A., Bruun, D.-M., & Jarden, M. (2015). Cancer survivors' experience of exercise-based cancer rehabilitation a meta-synthesis of qualitative research. *Acta Oncologica*, *54*(5), 609-617. doi:10.3109/0284186X.2014.995777
- Miller, T. (2017). Telling the difficult things: Creating spaces for disclosure, rapport and 'collusion' in qualitative interviews. *Women's Studies International Forum*, 61, 81-86. doi:https://doi.org/10.1016/j.wsif.2016.07.005
- Moustakas, C. (1994). Phenomenological research methods: Sage.
- Mullan, F. (1985). Seasons of survival: reflections of a physician with cancer. *The New England Journal of Medicine, 313*(4), 270-273. doi:10.1056/NEJM198507253130421
- Nadler, M., Bainbridge, D., Tomasone, J., Cheifetz, O., Juergens, R. A., & Sussman, J. (2017). Oncology care provider perspectives on exercise promotion in people with cancer: an examination of knowledge, practices, barriers, and facilitators. *Supportive Care in Cancer*, 25(7), 2297-2304. doi:10.1007/s00520-017-3640-9
- National Cancer Institute. (1996-2014). NCI Dictionary of Cancer Terms: Survivor. Retrieved from <u>https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivor</u>
- NHS. (2015). Physical activity guidelines for adults. Retrieved from <u>https://www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-adults.aspx</u>
- NHS. (2016). Breast cancer in women Retrieved from <u>https://www.nhs.uk/conditions/breast-cancer/</u>
- Noy, C. (2008). Sampling Knowledge: The Hermeneutics of Snowball Sampling in Qualitative Research. *International Journal of Social Research Methodology*, 11(4), 327-344. doi:10.1080/13645570701401305
- Office for National Statistics. (2018). Cancer regristration statistics, England: first release, 2016. Retrieved from <u>https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/con</u> <u>ditionsanddiseases/datasets/cancerregistrationstatisticscancerregistrationstatistic</u> <u>sengland</u>
- Ong, L. M. L., de Haes, J. C. J. M., Hoos, A. M., & Lammes, F. B. (1995). Doctor-patient communication: A review of the literature. *Social Science & Medicine*, 40(7), 903-918. doi:<u>https://doi.org/10.1016/0277-9536(94)00155-M</u>

- Ormel, H. L., Schoot, G. G. F., Sluiter, W. J., Jalving, M., Gietema, J. A., & Walenkamp, A. M. E. (2018). Predictors of adherence to exercise interventions during and after cancer treatment: A systematic review. *Psycho-Oncology*, 27(3), 713-724. doi:10.1002/pon.4612
- Palaganas, E. C., Sanchez, M. C., Molintas, M., Visitacion, P., & Caricativo, R. D. (2017). Reflexivity in qualitative research.
- Palesh, O., Scheiber, C., Kesler, S., Mustian, K., Koopman, C., & Schapira, L. (2018). Management of side effects during and post-treatment in breast cancer survivors. *The Breast Journal*, 24(2), 167-175. doi:doi:10.1111/tbj.12862
- Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health and Mental Health Services Research*, *42*(5), 533-544. doi:10.1007/s10488-013-0528-y
- Pedersen, B., Groenkjaer, M., Falkmer, U., Mark, E., & Delmar, C. (2016). "The ambiguous transforming body" – A phenomenological study of the meaning of weight changes among women treated for breast cancer. *International Journal of Nursing Studies*, 55, 15-25. doi:https://doi.org/10.1016/j.ijnurstu.2015.10.011
- Petty, N. J., Thomson, O. P., & Stew, G. (2012). Ready for a paradigm shift? Part 1: Introducing the philosophy of qualitative research. *Manual Therapy*, *17*(4), 267-274. doi:10.1016/j.math.2012.03.006
- Phillips, S. M., Dodd, K. W., Steeves, J., McClain, J., Alfano, C. M., & McAuley, E. (2015). Physical activity and sedentary behavior in breast cancer survivors: New insight into activity patterns and potential intervention targets. *Gynecologic Oncology*, 138(2), 398-404. doi:10.1016/j.ygyno.2015.05.026
- Phillips, S. M., & McAuley, E. (2013). Social cognitive influences on physical activity participation in long-term breast cancer survivors. *Psycho-Oncology*, 22(4), 783-791. doi:doi:10.1002/pon.3074
- Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal*, 20(1), 7-14.
- Pinto, B., Dunsiger, S., & Stein, K. (2017). Does a peer-led exercise intervention affect sedentary behavior among breast cancer survivors? *Psycho-Oncology*, 26(11), 1907-1913. doi:10.1002/pon.4255
- Ponterotto, J. G. (2005). Qualitative Research in Counseling Psychology: A Primer on Research Paradigms and Philosophy of Science. *Journal of Counseling Psychology*, *52*(2), 126-136. doi:10.1037/0022-0167.52.2.126
- Popay, J., Rogers, A., & Williams, G. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research*, 8(3), 341-351.

- Pullen, T., Sharp, P., Bottorff, J. L., Sabiston, C. M., Campbell, K. L., Ellard, S. L., . . . Caperchione, C. M. (2018). Acceptability and satisfaction of project MOVE: A pragmatic feasibility trial aimed at increasing physical activity in female breast cancer survivors. *Psycho-Oncology*, 27(4), 1251-1256. doi:doi:10.1002/pon.4662
- Qu, S. Q., & Dumay, J. (2011). The qualitative research interview. *Qualitative Research in Accounting & Management, 8*(3), 238-264. doi:doi:10.1108/11766091111162070
- Reis, A. D., Pereira, P. T. V. T., Diniz, R. R., de Castro Filha, J. G. L., dos Santos, A. M., Ramallo, B. T., . . . Garcia, J. B. S. (2018). Effect of exercise on pain and functional capacity in breast cancer patients. *Health and Quality of Life Outcomes*, 16(1), 58. doi:10.1186/s12955-018-0882-2
- Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (2013). *Qualitative research practice: A guide for social science students and researchers*: sage.
- Robinson, O. C. (2014). Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide. *Qualitative research in psychology*, 11(1), 25-41. doi:10.1080/14780887.2013.801543
- Rodriguez, A., & King, N. (2009). The lived experience of parenting a child with a lifelimiting condition: a focus on the mental health realm. *Palliat Support Care*, 7(1), 7-12. doi:10.1017/s1478951509000030
- Rogers, L. Q., Markwell, S. J., Verhulst, S., McAuley, E., & Courneya, K. S. (2009). Rural breast cancer survivors: exercise preferences and their determinants. *Psycho-Oncology*, 18(4), 412-421. doi:doi:10.1002/pon.1497
- Rubin, A., Babbie, E. R., Babbie, E., & Pa-pi, A.-e. (2001). *Research methods for social work* (4th ed.). Australia;Belmont, CA;: Wadsworth/Thomson Learning.
- Ryan, L. (2015). "Inside" and "Outside" of What or Where? Researching Migration Through Multi-Positionalities. *2015*, *16*(2). doi:10.17169/fqs-16.2.2333
- Sander, A. P., Wilson, J., Izzo, N., Mountford, S. A., & Hayes, K. W. (2012). Factors That Affect Decisions About Physical Activity and Exercise in Survivors of Breast Cancer: A Qualitative Study. *Physical Therapy*, *92*(4), 525-536. doi:10.2522/ptj.20110115
- Savvides, N., Al-Youssef, J., Colin, M., & Garrido, C. (2014). Journeys into Inner/Outer Space: Reflections on the Methodological Challenges of Negotiating Insider/Outsider Status in International Educational Research. *Research in Comparative and International Education, 9*(4), 412-425. doi:10.2304/rcie.2014.9.4.412
- Schmitz, K. H., DiSipio, T., Gordon, L. G., & Hayes, S. C. (2015). Adverse breast cancer treatment effects: the economic case for making rehabilitative programs standard of care. *Supportive Care in Cancer, 23*(6), 1807-1817. doi:10.1007/s00520-014-2539-y
- Shaw, J. A. (2016). Reflexivity and the "Acting Subject": Conceptualizing the Unit of Analysis in Qualitative Health Research. *Qualitative Health Research*, 26(13), 1735-1744. doi:10.1177/1049732316657813

- Shin, W.-k., Song, S., Jung, S.-Y., Lee, E., Kim, Z., Moon, H.-G., . . . Lee, J. E. (2017). The association between physical activity and health-related quality of life among breast cancer survivors. *Health and Quality of Life Outcomes*, 15(1), 132. doi:10.1186/s12955-017-0706-9
- Short, C. E., James, E. L., & Plotnikoff, R. C. (2013). How Social Cognitive Theory can help oncology-based health professionals promote physical activity among breast cancer survivors. *European Journal of Oncology Nursing*, 17(4), 482-489. doi:https://doi.org/10.1016/j.ejon.2012.10.009
- Smith-Turchyn, J., Richardson, J., Tozer, R., McNeely, M., & Thabane, L. (2016). Physical Activity and Breast Cancer: A Qualitative Study on the Barriers to and Facilitators of Exercise Promotion from the Perspective of Health Care Professionals. *Physiother Can*, 68(4), 383-390. doi:10.3138/ptc.2015-84
- Smith, Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: theory, method and research*. Los Angeles, [Calif.];London;: SAGE.
- Smith, J., & Osborn, M. (2003). Interpretative phenomenological analysis. In *Qualitative Psychology: A practical guide to research methods.* London: SAGE.
- Smith, J. A. (2017). Interpretative phenomenological analysis: Getting at lived experience. *The Journal of Positive Psychology*, *12*(3), 303-304. doi:10.1080/17439760.2016.1262622
- Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British journal of pain*, 9(1), 41-42. doi:10.1177/2049463714541642
- Smith, L., Croker, H., Fisher, A., Williams, K., Wardle, J., & Beeken, R. J. (2017). Cancer survivors' attitudes towards and knowledge of physical activity, sources of information, and barriers and facilitators of engagement: A qualitative study. *European journal of cancer care*, 26(4), e12641. doi:doi:10.1111/ecc.12641
- Soni-Sinha, U. (2008). Dynamics of the `field': multiple standpoints, narrative and shifting positionality in multisited research. *Qualitative Research*, 8(4), 515-537. doi:10.1177/1468794108093898
- Spellman, C., Craike, M., & Livingston, P. (2013). Knowledge, attitudes and practices of clinicians in promoting physical activity to prostate cancer survivors. *Health Education Journal*, 73(5), 566-575. doi:10.1177/0017896913508395
- Spinelli, E. (2005). *The interpreted world: An introduction to phenomenological psychology*: Sage.
- Stacey, F. G., James, E. L., Chapman, K., Courneya, K. S., & Lubans, D. R. (2015). A systematic review and meta-analysis of social cognitive theory-based physical activity and/or nutrition behavior change interventions for cancer survivors. *Journal* of Cancer Survivorship, 9(2), 305-338. doi:10.1007/s11764-014-0413-z
- Statistics, O. f. N., & England, P. H. (2017). *Index of cancer survival for Clinical Commissioning Groups in England: adults diagnosed 2000 to 2015 and followed up to* 2016. Retrieved from

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/con ditionsanddiseases/bulletins/indexofcancersurvivalforclinicalcommissioninggroupsi nengland/adultsdiagnosed2000to2015andfollowedupto2016

- Sternfeld, B., Weltzien, E., Quesenberry, C. P., Castillo, A. L., Kwan, M., Slattery, M. L., & Caan, B. J. (2009). Physical activity and risk of recurrence and mortality in breast cancer survivors: findings from the LACE study. *Cancer Epidemiology and Prevention Biomarkers*, 18(1), 87-95.
- Stevinson, C., Campbell, A., Cavill, N., & Foster, J. (2017). *Physical activity and cancer: A concise evidence review*. Retrieved from <u>https://www.macmillan.org.uk/ images/the-importance-physical-activity-for-</u> <u>people-living-with-and-beyond-cancer tcm9-290123.pdf</u>
- Stewart, M. A. (1984). What is a successful doctor-patient interview? a study of interactions and outcomes. Social Science & Medicine, 19(2), 167-175. doi:https://doi.org/10.1016/0277-9536(84)90284-3
- Street Jr, R. L., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient education and counseling*, 74(3), 295-301.
- Surbone, A., Annunziata, M. A., Santoro, A., Tirelli, U., & Tralongo, P. (2013). Cancer patients and survivors: changing words or changing culture? *Annals of Oncology*, 24(10), 2468-2471. doi:10.1093/annonc/mdt229
- Svenaeus, F. (2000). The body uncanny Further steps towards a phenomenology of illness. *Medicine, Health Care and Philosophy, 3*(2), 125-137. doi:10.1023/a:1009920011164
- Thomas, E., & Magilvy, J. K. (2011). Qualitative Rigor or Research Validity in Qualitative Research. *Journal for Specialists in Pediatric Nursing*, 16(2), 151-155. doi:10.1111/j.1744-6155.2011.00283.x
- Tighe, M., Molassiotis, A., Morris, J., & Richardson, J. (2011). Coping, meaning and symptom experience: a narrative approach to the overwhelming impacts of breast cancer in the first year following diagnosis. *Eur J Oncol Nurs*, *15*(3), 226-232. doi:10.1016/j.ejon.2011.03.004
- Todres, L., & Wheeler, S. (2001). The complementarity of phenomenology, hermeneutics and existentialism as a philosophical perspective for nursing research. *International Journal of Nursing Studies, 38*(1), 1-8.
- Tracy, S. J. (2010). Qualitative quality: Eight a"big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(10), 837-851. doi:10.1177/1077800410383121
- Trusson, D., Pilnick, A., & Roy, S. (2016). A new normal?: Women's experiences of biographical disruption and liminality following treatment for early stage breast cancer. Social Science & Medicine, 151, 121-129. doi:https://doi.org/10.1016/j.socscimed.2016.01.011

- Valle, R. S., Halling, S., & Valle, R. (1989). *Existential-phenomenological perspectives in psychology: exploring the breadth of human experience : with a special section on transpersonal psychology*. New York: Plenum Press.
- van der Spek, N., Vos, J., van Uden-Kraan, C. F., Breitbart, W., Tollenaar, R. A. E. M., Cuijpers, P., & Verdonck-de Leeuw, I. M. (2013). Meaning Making in Cancer Survivors: A Focus Group Study. *PLOS ONE*, 8(9), e76089. doi:10.1371/journal.pone.0076089
- Van Manen, M. (1990). Researching lived experience: human science for an action sensitive pedagogy. Albany, N.Y.: State University of New York Press.
- Veal, C. T., Hart, V., Lakoski, S. G., Hampton, J. M., Gangnon, R. E., Newcomb, P. A., . . . Sprague, B. L. (2017). Health-related behaviors and mortality outcomes in women diagnosed with ductal carcinoma in situ. *Journal of Cancer Survivorship*, 11(3), 320-328. doi:10.1007/s11764-016-0590-z
- Walsh, M., & Wigens, L. (2003). *Introduction to Research*. London: Cengage Learning EMEA.
- Wanzer, M. B., Booth-Butterfield, M., & Gruber, K. (2004). Perceptions of Health Care Providers' Communication: Relationships Between Patient-Centered Communication and Satisfaction. *Health Communication*, 16(3), 363-384. doi:10.1207/S15327027HC1603\_6
- Weed, M. (2005). "*Meta Interpretation": A Method for the Interpretive Synthesis of Qualitative Research.* Paper presented at the Forum Qualitative Sozialforschung/Forum: Qualitative Social Research.
- Weiner-Levy, N., & Abu Rabia Queder, S. (2012). Researching my people, researching the "other": Field experiences of two researchers along shifting positionalities. *Quality* and Quantity, 46(4), 1151-1166. doi:10.1007/s11135-012-9677-4
- Whitehead, S., & Lavelle, K. (2009). Older breast cancer survivors' views and preferences for physical activity. *Qual Health Res, 19*(7), 894-906. doi:10.1177/1049732309337523
- Williams, K. (2016). The New Normal. Retrieved from <u>https://www.lbbc.org/blog/new-normal</u>
- Williams, K., Beeken, R. J., Fisher, A., & Wardle, J. (2015). Health professionals' provision of lifestyle advice in the oncology context in the United Kingdom. *Eur J Cancer Care* (*Engl*), 24(4), 522-530. doi:10.1111/ecc.12305
- Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness*, 22(1), 40-67.
- Willig, C. (2008). *Introducing qualitative research in psychology: adventures in theory and method* (2nd ed.). Maidenhead: McGraw-Hill Open University Press.

- World Health Organization. (2018). Physical activity. Retrieved from <u>http://www.who.int/en/news-room/fact-sheets/detail/physical-activity</u>
- Wurz, A., St-Aubin, A., & Brunet, J. (2015). Breast cancer survivors' barriers and motives for participating in a group-based physical activity program offered in the community. *Supportive Care in Cancer*, 23(8), 2407-2416. doi:10.1007/s00520-014-2596-2
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15(2), 215-228. doi:10.1080/08870440008400302
- Zachariae, R., Pedersen, C. G., Jensen, A. B., Ehrnrooth, E., Rossen, P. B., & von der Maase, H. (2003). Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. *British Journal Of Cancer, 88*, 658. doi:10.1038/sj.bjc.6600798
- Zebrack, B. J. (2000). Cancer survivor identity and quality of life. *Cancer Pract, 8*(5), 238-242.
- Zhong, S., Jiang, T., Ma, T., Zhang, X., Tang, J., Chen, W., . . . Zhao, J. (2014). Association between physical activity and mortality in breast cancer: a meta-analysis of cohort studies. *European Journal of Epidemiology*, 29(6), 391-404. doi:10.1007/s10654-014-9916-1

# Appendices

# Appendix 1

Breast cancer survivors' perceptions of participating in a supervised exercise intervention: An exploratory review of the literature.

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**TITLE** Breast cancer survivors' perceptions of participating in a group-based exercise intervention: An exploratory review of the literature

**Background.** Despite the reported beneficial effects of PA (PA) during and after cancer diagnosis, research data suggests that the percentages of breast cancer survivors, who adhere to PA recommendations, are low. The aim of the review was to identify, analyse and provide a summary of qualitative literature findings, which explore breast cancer survivors' experiences of participating in an exercise/PA intervention after cancer treatment.

**Methods.** A systematic search was conducted using CINAHL, PsychINFO, PubMed and Scopus electronic databases to search for qualitative literature published from 2000-2016. A total of 6 studies which met the inclusion criteria were reviewed.

**Findings.** These were conducted in Australia, Canada, California, Denmark and Finland. Five of the studies used focus group interviews and one study used individual interviews to collect the data, three of the studies used a phenomenological approach to analyse the data, two of the other studies used thematic analysis and the final study used content analysis. In this review, thematic synthesis following Thomas and Harden's (2008) methods for qualitative research in systematic reviews was used to analyse the data. Seven descriptive themes were developed: control, focus, transitioning phase, regaining a sense of confidence, enhanced spirits, social support and safe environment.

#### Introduction

Breast cancer is the most common cancer in females; 53,696 women in the UK were diagnosed with new cases of invasive breast cancer in 2013 (Cancer Research UK, 2016) and nearly 1.7 million newly diagnosed cases worldwide in 2012 (World Cancer Research Fund International, 2015). Survival rates have been gradually improving, due to advances in treatments and early diagnosis, increasing the number of breast cancer survivors (Davies, 2012; & Whitehead & Lavelle, 2009). In 2010-2011, almost 87% survived breast cancer for five years or more, and almost 78% survived breast cancer for ten years or more, statistics represent females only in England and Wales (Cancer Research UK, 2016). Although, breast cancer survival rates are increasing cancer diagnosis and its treatments can lead to many significant, negative physical and psychological side effects (Spence, Heesch, & Brown, 2010; &, Pinto, Dunsiger & Waldemore, 2013). Consequently, these possible side effects have been identified to have an adverse impact on cancer survivors' overall quality of life (OQoL) (Milne, Guilfoyle, Gordon, Wallman & Courneya, 2007; & Ray & Verhoef, 2013). For the purpose of this review breast cancer survivors will be defined as "being 'free' from the disease, or after the completion of adjuvant treatment (Cancer.Net, 2013; National Coalition for Cancer Survivorship [NCCS], 2014 & Brunet, Sabiston & Meterissian, 2012). A number of quantitative studies indicate that regular participation in PA (PA) during 196

and after breast cancer treatment, may alleviate certain side effects of the treatment and lead to physical and psychological improvements such as; physical functioning, cardiovascular fitness and management of cancer related side effects (Loprinzi & Cardinal, 2011; & Wurz, St-Aubin & Brunet, 2015). Furthermore, research indicates that regular PA participation may increase OQoL amongst breast cancer survivors (Ferrer et al. 2010: & McNeely et al. 2006). The health improvements from regular participation in PA as mentioned above, may be associated with increased survival rates amongst breast cancer survivors and therefore, the decreased risk of breast cancer mortality (McNeeley et al. 2006). Findings from a meta-analysis conclude that there is an inverse relationship between PA and breast cancer related mortality and breast cancer recurrence. The summary effect size for breast cancer related mortality was 0.59, when higher levels of self-reported PA post diagnosis compared to lower levels of PA and 0.54 for those who meet PA recommended guidelines post diagnosis (Lahart, Metsios, Nevill & Carmichael, 2015). Thus, the importance of increasing PA participation levels amongst breast cancer survivors is emphasised, to achieve the maximum benefits of PA such as; increased OQoL and to decrease the risk of breast cancer mortality amongst this population.

The World Health Organization [WHO] (2015) defines PA as "any bodily movement produced by skeletal muscles that requires energy expenditure". Whereas exercise is defined as: "A subcategory of PA that is planned, structured repetitive and purposeful" (WHO, 2015). The PA guidelines for cancer survivors suggest that individuals should engage in 30-60 minutes of moderate intensity PA, at least 5 days per week, and strength or resistance training at least 2-3 days per week (American College of Sports Medicine, 2009, p.231). Despite the evidence suggesting that regular PA during and after treatment is beneficial for breast cancer survivors, previous research illustrates that the levels of PA amongst this population have been shown to decrease after diagnosis and treatment (Carmichael, Daley, Rea & Bowden, 2010). Additionally, results from an American national cross sectional survey, reported that only 37.1% of breast cancer survivors met the PA recommendations (Blanchard, Courneya & Stein, 2008). Moreover, qualitative studies have recognised that breast cancer survivors face significant challenges around PA and exercise after treatment, due to various factors, such as; pain, reduced range of movement, fatigue, fear of injury, low self-confidence, and lack of knowledge etc. (Bluethemann, Vernon, Pettee Gabriel, Murphy & Bartholomew, 2015; & Kampshoff et al. 2015). Thus, suggesting that these challenges faced by breast cancer survivors after treatment, may lead to additional barriers to PA participation. Although quantitative and qualitative research has been conducted within this field, and has contributed to the increased knowledge of; the benefits of PA for cancer survivors', their levels of PA, and factors which may influence their PA behaviour, it has been recognised that the synthesis of qualitative research findings exploring the individual, lived experiences of PA amongst cancer survivors is lacking in this field (Midtgaard et al. 2015). Midtgaard et al. conducted a meta-synthesis of qualitative research, which explored cancer survivors' experience of participation in exercise-based cancer rehabilitation. Although, the findings from this meta-synthesis may support implementation of future exercise based provision for cancer survivors, it is not based on and around breast cancer survivors specifically. Thus, an exploration of breast cancer survivors' individual 197

experiences of exercise and PA interventions, may be important to inform the implication and promotion of specific exercise and PA programmes, specifically for this population (Thomas & Harden, 2008). Therefore, the aims of this paper are to review and synthesise qualitative literature, which explores breast cancer survivors' experiences of participation in exercise-based rehabilitation interventions. The findings from this review may extend the understanding of breast cancer survivors' individual experiences of participating in an exercise-based intervention. Furthermore, the findings illustrate key factors which may support the implementation of future, clinical and rehabilitation exercise-based interventions for this population.

### Methods

A systematic review of qualitative research exploring breast cancer survivors' experiences of participating in exercise interventions was conducted. Searches were undertaken within four electronic databases: CINAHL, PubMED, PsychINFO and Scopus. Key words and search terms were: "PA", "exercise", "exercise therapy", "leisure activity", "breast cancer", "ductal cancer", "breast neoplasm", "Carcinoma, Lobular", "cancer survivors", "perception", "lived experience\*", and "life experience\*". The key words and search terms were modified, dependant on the database, to increase the search results. The inclusion criteria for selection involved: peer-reviewed, gualitative research methodology, English language, Scholarly articles published from 2000-2016. Articles were excluded if they focused solely on: any diseases/health conditions other than breast cancer, breast cancer populations before or undergoing treatment(s), child or adolescent populations (defined as <18 years of age), self-directed PA (not participated in an exercise intervention), and utilised quantitative or mixed methodological approaches. Articles were reviewed through examination of their title, abstract and full-text review based on the inclusion/exclusion criteria. All articles which met the inclusion criteria, were then assessed by two appraisers, based on their research quality through utilising the Critical Appraisal Skills Programme (CASP) checklist (2013). Following the full-text review and assessment of the results from the electronic database search, six articles met the inclusion criteria and were included in the review. Hand searches of the selected journals were also undertaken, to identify further articles. Following a review of the article titles, retrieved from the hand search, 13 new articles were identified and the abstracts were examined. No new articles meeting the inclusion criteria were identified, following the review of the titles and abstracts a PRISMA flow diagram of the study selection process can be found in Figure 1.

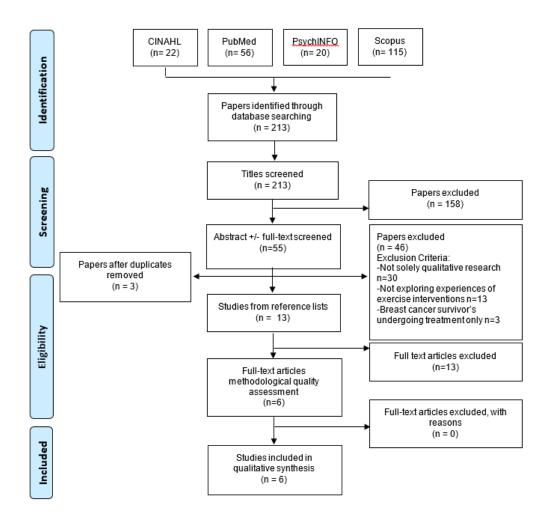


Figure 1. PRISMA diagram of study selection process.Data synthesis

A total of six studies were included in the review, these were individually analysed using thematic analysis as the appropriate method to analyse the qualitative studies (Thomas and Harden, 2008). The authors of the review followed a three stage process by Thomas and Harden (2008) to analyse the studies involved. The three stages involved:

- Line-by-line coding of the findings in relation to the meaning and content of each line. This is then continued throughout the rest of the article and 'initial codes' are developed. These concepts are translated between studies, and new codes are developed when necessary, as each study is coded.
- II. The emergence of 'descriptive themes', once initial codes have been identified they are then reviewed based on similarities and differences. Based on the review of codes they

are then grouped, new codes are created to 'capture the meaning of groups of initial codes', these are the descriptive themes.

III. The development of 'analytical themes', are developed from "going beyond the content of primary studies".

Results

Characteristics of included studies

The database search revealed a total of 213 articles, 207 were then excluded using the process mentioned in the methods section. After following the data extraction process, a total of six studies were included in this review (Figure 2).

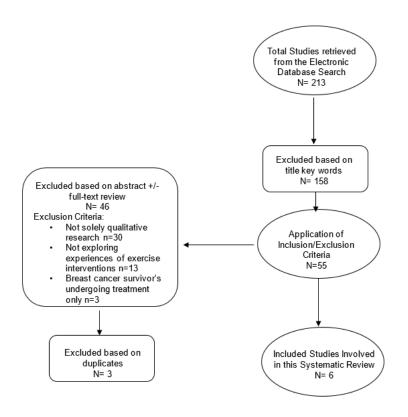


Figure 2 Flow diagram of the literature search

All the studies included in the review solely used qualitative methods to explore individual experiences of participation in an exercise-based rehabilitation intervention. However, the sample, location, aim, data collection and analysis methods varied across the studies (see Table 1 for characteristics of included studies). The majority of the participants in the studies were women (n=126) out of 143 participants, of these women 92 were breast cancer survivors (completed primary treatment). Three of

the studies involved breast cancer survivors only (Balneaves et al. 2014; Crane-Okada et al. 2012; & Luoma et al. 2014), while one study involved both breast cancer survivors and breast cancer patients undergoing treatment (Bulmer et al. 2012), and the other two remaining studies compromised of participants with other cancer diagnoses but, with breast cancer being the main diagnosis (Martin et al. 2015; & Midtgaard et al. 2011). The quotes used in the review were from breast cancer survivor participants only, most of the studies involved clearly stated which participants the quotes used where from. The most frequent method of data collection used was focus group

No	Author	Country and	Aim of the study	Methodological	Sample size and	Data collection and
		context for		perspective	demographics	analysis technique
		research				
1	Balneaves et al., 2014	Canada, offices of	Qualitatively describe the	Qualitative	9 women who had	Focus group interviews
		an unrelated	experiences of breast		completed the lifestyle	occurred 8 weeks after
		research	cancer survivors who took		intervention.	the participation in the
		programme	part in a successful 24			intervention for 80
			week lifestyle intervention			minutes. 2 women could
			aimed at weight loss.			not attend the date for the
						focus group completed a
						semi structured
						telephone interview.
						Thematic analysis was
						used to identify key
						themes, concepts and
						categories across
						transcripts.
2	Bulmer et al, 2012	San Francisco,	To provide an in depth		45 women ages 32-64	Individual in-depth
			description of women's		years. All included	interviews and email
			experiences with	Qualitative	participation in the	journals. All women
			exercising during and	research methods	IMPACT programme	completed at least one
			after their breast cancer		during or after breast	90 minute interview.

# Table 1. Characteristics of included studies

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	treatments. Particular	cancer treatment, a	
	their perceptions of th	e diagnosis of breast	
	benefits they experience	cancer within the	
	as a result of participatio	previous 2 years.	the study and
	in an individualised	,	corresponded with
	structure exercis	*Women who were	various stages in the
	programme (IMPACT).	completing hormonal	exercise programme.
		therapies were	
		considered to be post	
		treatment.	used to analyse the data
			and identify themes.
		Classified into 3	
		groups=	
		Timing of their	
		participation in the	
		programme: exercise	
		during treatment only	
		(n=9), exercise both	
		during and after	
		treatment (n=21), and	
		exercise post	
		treatment only (n=15).	

3	Crane-Okada et al.,	California	To examine participant	Qualitative	16 participants in the	Focus group discussions
	2012		perceptions of the effects	research methods	focus groups.	for 3 cohort groups.
			of a Mindful Movement			Specific open ended
			Programme (MMP)		51-90 (mean, 66.3)	questions. Each
			intervention on quality of		years, average 16	discussion lasted
			life and mindfulness		years since diagnosis.	approximately 90
			through focus groups.		Attended an average	minutes.
			MMP= 12 weekly 2 hour		of 10.4 MMP sessions.	
			sessions delivered to 3			Tape recordings of
			separate cohorts.			discussions were
						transcribed and reviewed
			Focus group discussion:			using content analysis.
			What did you find least			
			and most helpful from			
			MMP; how did the MMP			
			affect your everyday life?;			
			improvements to the MMP			
4	Luoma et al., 2014	Finland	To investigate how	Phenomenological	25 breast cancer	Focus group discussions,
			tailored exercise is	research method	survivors from the	consisted of semi-
			experienced by breast	chosen for data	breast cancer and	structured interviews.
			cancer survivors.	analysis methods	exercise study (open	Each woman participated
					prospective	in one of seven focus
					randomised controlled	groups, an average of

5	Martin et al., 2015	Australia	To examine the lived experiences of both breast and prostate cancer survivors participating in an 8 week exercise and counselling intervention, to determine how a multimodal intervention may be designed to optimally engage both populations.	Qualitative study with interpretative phenomenological analysis (IPA) used for analysis of the data	trial of physical exercise shortly after adjuvant treatment of breast cancer). Mean age=54 25 participants: Male n= 11 Female n =14, recruited through hospitals in Perth, Cancer Associations, and the Female General Practitioner Network. Participants had completed all planned surgery, chemotherapy, and/or radiotherapy.	four women in each group Phenomenological research method was chosen to analyse the data. Focus group interviews one week post- intervention. Semi- structured interview based on the participants overall experience of the intervention. Men and women participated in separate groups. IPA was used for data analysis, with an idiographic focus to identify any emerging themes.
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6	Midtgaard et al., 2008	Denmark	To describe the lived	A qualitative	23 cancer survivors:	Four semi-structured
			experiences of long term	exploratory		focus group interviews.
			PA maintenance in a	design, with a	Women n=17	Interviews lasted 60-90
			purposefully selected	descriptive	Mala a O	minutes.
			subsample of participants	phenomenological	Male n=6	
			recruited from the	approach	Breast cancer n=13	All interviews were audio
			Copenhagen PA after			taped and transcribed
			Cancer Treatment Study		Colon cancer n=2	following a four step
			(PACT).			editing
					Ovary cancer n=3	phenomenological
						analysis method. Sever
					Prostate cancer n=3	themes and overriding
					Testis cancer n=1	categories were
						identified.
					Hematological cancer	
					n=1	
					All had completed a	
					one year weekly	
					supervised	
					intervention PACT	
					study.	

		All participants	
		currently perform	
		regular PA, pre-illness	
		PA behaviour was low	
		(below 3hr/week).	

interviews n= 5 (Balneaves et al; Crane-Okada et al. 2012; Luoma et al. 2014; Martin et al. 2015; Midgtaard et al. 2011); however, Bulmer et al. (2012) used individual in-depth interviews and email journals.

#### Assessment of quality method

The methodological quality of the studies were assessed by the researcher and supervisory team, using the CASP checklist for qualitative research, as used in previous synthesis of qualitative research studies (Driscoll. 2015; & Midtgaard et al. 2015). The studies were scored on a low, medium and high rating. Two authors of this study independently reviewed the included studies (n=6) and assessed the methodological quality, following the CASP checklist tool. The authors then came together and discussed the scores, any agreement was resolved with a third author. Three out of the six studies scored a low quality rating (Balneaves et al. 2014; Crane-Okada et al, 2012; & Martin et al. 2015), one scored a medium level of quality (Luoma et al. 2014), and two scored a high level of quality (Bulmer et al. 2012 & Midtgaard et al. 2011). Most of the studies (n=5), did not clearly justify why the research design was most appropriate for the aims of the research and none of the studies considered or clearly addressed the relationship between research and participants.

#### Thematic synthesis

Each research paper was analysed independently following the stages of analysis, developed by Thomas & Harden (2008), as described above in the methods section. Firstly, each paper was read fully and analysed, 'line by line' coding was adopted to develop initial codes, these were then compared between each paper and new codes were developed throughout the analysis of the remaining papers. Once the first stage was complete, descriptive themes were then developed to 'capture the meaning of groups of initial codes', overall seven descriptive themes were developed. The descriptive themes were; *control, focus, transitioning phase, fear, regaining confidence, enhanced spirits, social support,* and *safe environment*. The most prominent themes found across the papers (n=6) were; *control (n=6), transitioning phase(n=4),* social *support (n=4) and safe environment (n=4)* these are the themes which appeared most in the studies.

#### Control

This descriptive theme involved initial codes; *control over cancer and recurrence of cancer, control over their bodies, health and fitness, and control over their emotions.* These initial codes were found across all of the included research papers (n=6). For many of the women in the studies, participation in the exercise intervention was an 'empowering' and 'motivating' factor, that helped them to either 'feel' in control (Midgtaard et al. 2011) or to take control, through being proactive to improve their physical self and their overall health (Balneaves et al 2014; & Bulmer et al. 2012).

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*Control over cancer itself and the chances of cancer recurrence.* For some women in the studies, participation in the exercise intervention helped them to 'regain a sense of control' over the chances of cancer recurrence (Balneaves et al. 2014; & Midgtaard et al. 2011). In Midgtaard et al. (2011) some participants perceived that through participating in regular PA, cancer recurrence 'is simply not a possibility' and it will not happen as long as they continue to stay active. Similarly, the women in Balneaves et al.'s study (2014) express that through leading a healthy lifestyle they are taking control over cancer itself *Control over their bodies, health and fitness.* Many of the women across the studies (n=4) associated improvements in their physical fitness with regaining control over their bodies and overall health. Regaining a sense of control through exercise participation led to increased adherence in the exercise interventions and further PA. Some of the women in Bulmer et al.'s (2012) study, described how exercise helped them to take control over their health and physical appearance of their bodies. Similarly, participants in Martin et al. (2015) and Balneaves et al.'s (2014) study expressed how exercise helped them to regain the feeling of 'being in control'.

*Control over pain and emotions.* Due to the side effects of cancer treatment, many of the women experienced long term treatment effects, such as; pain, physical limitations, emotional and psychological problems (Balneaves et al. 2014; Crane-Okada et al. 2012; Luoma et al. 2014). Many of the breast cancer survivors in Crane-Okada et al.'s (2012) expressed how the movement exercises involved in the intervention, helped them to control their management with the pain. Moreover, the breast cancer survivors in Bulmer et al.'s (2012) study describe how exercise helps them to deal with stress, and therefore regain control over their emotional health.

# Focus

This descriptive theme includes the sub themes; *Focus on the present, 'in the moment', and focus on themselves* and reflects on the participant's perceptions of how the exercise intervention allowed them to shift the *focus* away from breast cancer and its side effects of treatment and *focus* on themselves again.

Focus on the present, 'in the moment'. This initial code was only found in one study (Crane- Okada et al. 2012). The breast cancer survivors expressed that through their ability to be 'in the moment', they feel less stressed and worried, and therefore resulting in enhanced moods. Although, 'in the moment' was only identified in Crane-Okada et al.'s study (2012), it emerged as a main theme in the study. The majority of the breast cancer survivors perceived that a beneficial effect of the intervention was, the learned ability to 'focus on the present and slow down'. The emphasis on focus and 'in the moment' may be only present in this study, because of the concepts of the mindfulness and movement in the intervention.

*Focus on themselves.* Some of the participants in the studies described how their participation in exercise, through the interventions, allowed them to do something for themselves and gave them time for themselves (Bulmer et al. 2012; Crane-Okada et al. 2012; & Midtgaard et al. 2011). Midgtaard et al. (2011), describes how the participants maintenance in PA becomes a goal itself, as they perceive it to be rewarding because they are doing something for themselves.

#### Transitioning phase

This descriptive theme includes the initial codes *regaining a sense of 'normality', moving forwards and perceived self-identity.* These reflect upon the breast cancer survivors' individual experiences, perceptions of every-day life and what they portray as 'normal', and how they defined themselves after cancer diagnosis and treatment and throughout the exercise interventions.

*Regaining a sense of normality.* Throughout the studies many of the women express a desire to 'regain a sense of normality' in their lives. Since the cancer diagnosis and its treatment many of the women felt that 'normality' was lacking in their lives, particularly in social interactions (Balneaves et al. 2014, p. 2061). For most of the women in the studies (Balneaves et al. 2014; Bulmer et al. 2012; Luoma et al. 2014; & Martin et al. 2015), expressed that the exercise intervention helped them to *regain a sense of normality*. Some of the women discussed how they felt that they were not treated as an 'oddity' or as 'cancer patients', by the other participants in the exercise intervention and the exercise instructor (Luoma et al. 2014; & Martin et al. 2015). Whereas, other survivors express that the exercises intervention facilitated the opportunity to 'feeling more normal', through undertaking the exercises to improve their health (Balneaves et al. 2014; & Bulmer et al. 2012).

*Moving forwards*. Participation in the exercise intervention was described as way to *move forwards*, and beyond the cancer experience (Balneaves et al. 2014; & Bulmer et al. 2012). Balneaves et al. (2014), describes that the exercise intervention 'offered an opportunity to return to normal and move beyond cancer'. One particular participant in Balneaves et al.'s study (2014, p.2061), explicitly states that it is her 'mission' to put cancer and the implications alongside it behind her, and lead a healthy lifestyle to return to pre-diagnosis health levels. Similarly, breast cancer survivors in Bulmer et al.'s study (2012), explained how the exercise intervention was essential in their journey, from *moving forwards* from surviving cancer. In contrast, for some women in Luoma et al.'s study (2014, p.1197), the exercise group 'reminded them of cancer' and 'takes them back to cancer', opposed to *moving forwards* beyond cancer.

*Perceived self-identity*. Luoma et al. (2014) described how the women in the intervention had a 'desire to switch identity', the women expressed the need to being redefined as a healthy woman again, instead of being 'labelled' as a breast cancer patient or survivor. For several of the women in the studies, the exercise interventions played an essential role, allowing them to transition and redefine themselves as

'healthy' women (Balneaves et al. 2014; & Bulmer 2012). Whereas, one woman in Martin et al.'s study (2015), expressed her desire to eliminate a cancer stigma, "I don't want to say I'm a breast cancer survivor. I don't want to be known as that, I was to be me".

### Regaining a sense of confidence

This descriptive theme includes the subthemes of *increased self-confidence* and *increased confidence to express their thoughts.* Many of the women commented on how the exercise interventions helped them 'regain a sense of confidence', whether it was perceived physical ability, or mental toughness. The benefits experienced from participation in the exercise intervention, translated into '*regaining a sense of confidence*' again, as they felt a sense of accomplishment over the cancer treatment limitations (Balneaves et al. 2014; Bulmer et al. 2012; & Luoma et al. 2014).

*Increased self-confidence.* Some of the women described how exercise helped them to 'regain a sense of confidence', "I feel more confident" (Balneaves et al. 2014, p.2060), "I felt like I got extra confidence, actually" (Bulmer et al. 2012, p.778). Although many of the women experienced physical benefits from the exercise intervention, the women associated the physical benefits with increased self-confidence, "I felt a sense of confidence within myself, that was sort of based in the physical but it went beyond that". Furthermore, through increasing their PA levels the women felt in control and that they were 'doing something for themselves', in turn they *regained a sense of confidence*.

Increased confidence to express their thoughts. A female cancer survivor from Martin et al.'s study commented on how she feels more confident expressing her thoughts, because she has learnt to trust people quicker. This study involved an exercise intervention alongside supportive group psychotherapy, therefore the participants may have gained their confidence to express themselves through participating in the supportive psychotherapy groups.

# Enhanced spirits

This descriptive theme captures some of the women's feelings of 'lifted spirts' and being 'in a good place'. For some of the women, they expressed how they felt the exercise programme had *enhanced their spirits* (Bulmer et al. 2012, p. 778; & Luoma et al. 2014, p.1196). Feeling well and having the physical ability to do the exercises was transferred into feelings of enhanced spirits.

### Social support

This descriptive theme involved the initial codes of *shared experiences and understanding*, and *appreciation for the exercise instructor*. These initial codes captured the breast cancer survivors' experiences of social support received within different realms of the exercise intervention. *Social* 

*support* was one of the strongest themes throughout the research studies; the level of social support received throughout the exercise interventions influenced the breast cancer survivors' experiences.

Shared experiences and understanding. For many of the women in the studies, they described the exercise interventions involving other breast cancer survivors, as a benefit of the programme, the *social support* and understanding received by the other women in the exercise classes were valued and appreciated. A women in Balneaves et al's study (2014), expressed that there was an "understanding" amongst the women in the exercise group, which you wouldn't get if they attended a gym. Similarly, in Luoma et al.'s study (2014), a participant described how she felt that she did not need to explain to the other women in the exercise group, why she had short hair because they had similar experiences. The participant compared the *shared experiences* she had received from the women in the breast cancer survivors only exercise classes, to how she thought others from an "open exercise class", may notice her short hair and perceive her as a "lezzie". Accordingly, others felt that through sharing information and experiences amongst the group, acted as a source of "informal support" and a way of looking out for each other (Bulmer et al. 2012, p.782).

Appreciation of the exercise instructor. The structured exercises and delivery of the exercise intervention, were acknowledged as important factors for the participants (Balneaves et al.2014; Bulmer et al. 2012; & Luoma et al. 2014). The personality of the instructors were described as; "very motivating", "encouraging", "really accommodating", "nurturing" and "comforting" (Balneaves et al. 2014; & Bulmer et al. 2012), the positive relationships with the instructors were valued, thus increasing their adherence to the exercise classes (Bulmer et al. 2012).

#### Safe Environment

This descriptive theme involved the initial codes of *feeling safe* and *feeling comfortable*, these reflect the importance of the exercise environment for the women in the interventions, in regards to; the people involved, the types of activities involved and who was leading the exercise groups.

*Feeling safe.* Many of the women expressed the importance of having a "skilled instructor", who is knowledgeable of the implications to exercise, following breast cancer treatments (Luoma et al. 2014, p.1195; & Balneaves et al. 2014). This made the women *feel safe* and that "they could trust that the movements that they were asked to do were suitable for them" (Luoma et al. 2014, p.1195). Similarly, women in Balneaves et al.'s study (2014) perceived the exercise intervention as a "safe environment", as they felt more secure being supervised by an exercise instructor. One of the participants in Crane-Okada et al.'s study (2012), express how they *felt safe* and free, in relation to the instructor and the group setting of the intervention.

*Feeling comfortable.* A participant in Martin et al.'s study (2015), expressed how they wouldn't feel comfortable around other people, if they went to a gym. Thus, emphasising the importance of the people in grouped exercise interventions, having similar experiences and understandings.

#### Discussion

The findings provide an insight into breast cancer survivors' experiences of their participation in a groupbased exercise programme, then women in the studies emphasised that supervised, group-based exercise were an important influence to help 'regain a sense of control and normality' and 'moving forwards' beyond the breast cancer experience. Furthermore, it was perceived that exercising with other women, who have similar experiences, and having an exercise instructor, who was knowledgeable of their physical limitations, increased the breast cancer survivors' motivation to join and adhere to the exercise programme (Balneaves et al. 2014; Bulmer et al. 2012; Luoma et al. 2014; Martin et al. 2015). As a result of breast cancer treatment, physical limitations and changed appearances was a common issue amongst the breast cancer survivors in the exercise interventions. Thus, the women portrayed the exercise classes as; a "safe", "comfortable" and non-judgemental environment, and they felt that there was no need to explain their appearance or physical limitations; this may be due to a sense of shared understanding amongst the groups. These findings support those from Midtgaard et al. (2015) meta-synthesis of cancer survivors' experience of exercise-based cancer rehabilitation, which highlights the importance of exercising in a context where everyone has experienced breast cancer, and the altered appearance and physical limitations are understood. The role of the instructor was particularly valued in Crane-Okada et al.'s study (2012), the participants specifically appreciated the instructors "ability to create a sense of acceptance and freedom" and feeling "safe and free", compared to exercising with others who have a similar experience. Additionally, freedom was a main theme in Crane-Okada et al.'s study and was acknowledged as an aspect which enhanced the programme, the theme may only be apparent in this study because of the multi-dimensional approach of the intervention, which involved mindfulness and dance/movement therapy.

The group-based exercise intervention helped the women to 'regain a sense of normality and control' and 'move forwards' beyond the breast cancer experience, thus suggesting that exercise and lifestyle interventions would be very beneficial for breast cancer survivors transitioning from the 'treatment phase' to a 'survivor', should it be an integral part of breast cancer treatment/care. Many of the studies included in the review emphasised the beneficial effects that the exercise interventions had on the women's psychological health and well-being, which helped move them forwards and regain normalcy (Balneaves et al. 2014; Bulmer et al. 2012; Luoma et al. 2014; & Martin et al. 2015). Additionally, the physical benefits that the women experienced through their participation in the exercise interventions, rendered into feeling 'normal' and having more 'control', which ultimately increased their self-confidence;

"Its [exercise] going to generally make me feel better so that you see that sense of, you know, being in control of your life and I definitely feel that way, and I also feel that other people [do] as well. I feel more confident." (Balneaves et al. 2014, p.2060).

It appears that as the women began to experience physical improvements, their self-confidence increased and they began to feel like they were moving forwards to becoming healthy and 'themselves' again. Although many quantitative and qualitative studies have shown that the levels of PA participation amongst breast cancer survivors are low, and they have acknowledged that there are many challenges which they face with regards to PA, this review shows that the benefits experienced from the group-based exercise interventions, helped many of the women overcome the challenges of exercise and furthermore motivated them to adhere to the exercise interventions. Similarly, findings from a follow study of a two-armed, randomised control trial comparing a supervised group exercise program for breast cancer survivors, to a usual care group (Trinh et al. 2014), suggests that supervised group-based exercise have a positive effect on breast cancer survivors' motivation to engage and adhere in PA.

## Methodological considerations

To our knowledge, this is the only systematic review which explores only breast cancer survivors' perceptions of participating in a group-based exercise intervention. Throughout the documentation process of this systematic review there have been some difficulties with determining the methodological quality of the studies, due to the lack of information given by the authors, particularly in relation to research integrity and how the themes were developed. Despite this, the researchers included all of the studies regardless of their quality scores; the purpose of this is because all of the studies were relevant to the review aims (Thomas & Harden, 2008, p.8). There are some limitations which must be noted. The studies involved in the review were limited to English language only, thus it is possible that other studies might have been neglected. Additionally, the review included supervised exercise interventions were included in the criteria. Also, it is possible that other researchers may have different interpretations and findings within the review.

# Future research and implications for practice

Following this review, it is evident that qualitative studies exploring breast cancer survivors' experiences and perceptions of participating in a group-based exercise intervention are scarce, therefore there is a great need for further qualitative research, of high methodological quality. Additionally, further qualitative research exploring breast cancer survivor's PA in all contexts such as home based exercise and self-directed PA is suggested to increase understanding of breast cancer survivors' experiences of PA and exercise.

Conclusion 214

The findings of this review provide an insight into breast cancer survivors' experiences of their participation in a group-based exercise programme, and may support the implementation of future, clinical and rehabilitation exercise-based interventions for this population. Previous research evidence shows that exercise interventions are safe and effective for breast cancer survivors during and after cancer treatment. Additionally, findings from this review and others, suggest that with the supervision of qualified professionals and exercising alongside other breast cancer survivors may increase their motivation to exercise and adhere to the exercise interventions. Subsequently, findings from this review may provide new knowledge and solutions to increase breast cancer survivors' participation and adherence in exercise and PA.

#### **Reference List**

American, Sports Medicine, Leonard A Kaminsky, Kimberly A. Bonzheim, PhD. Garber Carol Ewing, PhD Clem Stephen C, American College of Sports Medicine., and American College of Sports Medi... *ACSM's Resource Manual for Guidelines for Exercise Testing and Prescription*. 5th ed. Baltimore, MD: Lippincott Williams & Wilkins, US, 2009.

Balneaves, Lynda G., Cheri Van Patten, Tracy L. O. Truant, Mary T. Kelly, Sarah E. Neil, and Kristin L. Campbell. "Breast Cancer Survivors' Perspectives on a Weight Loss and PA Lifestyle Intervention." *Supportive Care in Cancer* March 15, 2014,. doi:10.1007/s00520-014-2185-4.

Blanchard, C. M., K. S. Courneya, and K. Stein. "Cancer Survivors' Adherence to Lifestyle Behavior Recommendations and Associations with Health-Related Quality of Life: Results from the American Cancer Society's SCS-II." *Journal of Clinical Oncology* 26, no. 13 (April 29, 2008): 2198–2204. doi:10.1200/jco.2007.14.6217.

Bluethmann, Shirley M., Sally W. Vernon, Kelley Pettee Gabriel, Caitlin C. Murphy, and L. Kay Bartholomew. "Taking the Next Step: A Systematic Review and Meta-Analysis of PA and Behavior Change Interventions in Recent Post-Treatment Breast Cancer Survivors." *Breast Cancer Research and Treatment* 149, no. 2 (January 2015): 331–42. doi:10.1007/s10549-014-3255-5.

Brunet, J., C. M. Sabiston, and S. Meterissian. "PA and Breast Cancer Survivorship: Evidence-Based Recommendations." *American Journal of Lifestyle Medicine* 6, no. 3 (December 1, 2011): 224–40. doi:10.1177/1559827611421460.

Bulmer, Sandra Minor, Jeremy Howell, Louise Ackerman, and Regan Fedric. "Women's Perceived Benefits of Exercise During and After Breast Cancer Treatment." *Women & Health* 52, no. 8 (November 2012): 771–87. doi:10.1080/03630242.2012.725707.

Cancer. Net. "About Survivorship." October 15, 2015. Accessed April 18, 2016. http://www.cancer.net/survivorship/about-survivorship.

Cancer Research UK. "Breast Cancer Incidence (invasive) Statistics." April 13, 2016. Accessed April 18, 2016. http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer/incidence-invasive.

Cancer Research UK. "Breast Cancer Statistics." March 8, 2016. Accessed April 8, 2016. http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer#heading-Three.

Carmichael, A. R., A. J. Daley, D. W. Rea, and S. J. Bowden. "PA and Breast Cancer Outcome: A Brief Review of Evidence, Current Practice and Future Direction." *European Journal of Surgical Oncology (EJSO)* 36, no. 12 (December 2010): 1139–48. doi:10.1016/j.ejso.2010.09.011.

Crane-Okada, Rebecca, Holly Kiger, Nancy L. R. Anderson, Rose Mary Carroll-Johnson, Fred Sugerman, Shauna L. Shapiro, and Wendy Wyman-McGinty. "Participant Perceptions of a Mindful Movement Program for Older Women with Breast Cancer." *Cancer Nursing* 35, no. 3 (2012): E1–E10. doi:10.1097/ncc.0b013e31822539c5.

Davies, Eleri Lloyd. "Breast Cancer." *Medicine* 40, no. 1 (January 2012): 5–9. doi:10.1016/j.mpmed.2011.09.010.

Driscoll, Susan D. "Barriers and Facilitators to Cervical Cancer Screening in High Incidence Populations: A Synthesis of Qualitative Evidence." *Women & Health* 56, no. 4 (October 23, 2015): 448–67. doi:10.1080/03630242.2015.1101742.

Ferrer, Rebecca A., Tania B. Huedo-Medina, Blair T. Johnson, Stacey Ryan, and Linda S. Pescatello. "Exercise Interventions for Cancer Survivors: A Meta-Analysis of Quality of Life Outcomes." *Annals of Behavioral Medicine* 41, no. 1 (October 8, 2010): 32–47. doi:10.1007/s12160-010-9225-1.

G, Smith, Savanna and Chagpar B Anees. "Adherence to PA Guidelines in Breast Cancer Survivors." *The American Surgeon* 76, no. 9 (September 1, 2010): 962–65. Accessed April 19, 2016. http://www.ingentaconnect.com/content/sesc/tas/2010/00000076/00000009/art00029.

Irwin, M. L., A. W. Smith, A. McTiernan, R. Ballard-Barbash, K. Cronin, F. D. Gilliland, R. N. Baumgartner, K. B. Baumgartner, and L. Bernstein. "Influence of Pre- and Postdiagnosis PA on Mortality in Breast Cancer Survivors: The Health, Eating, Activity, and Lifestyle Study." *Journal of Clinical Oncology* 26, no. 24 (August 18, 2008): 3958–64. doi:10.1200/jco.2007.15.9822.

Kampshoff, Caroline S., Mai J. M. Chinapaw, Johannes Brug, Jos W. R. Twisk, Goof Schep, Marten R. Nijziel, Willem van Mechelen, and Laurien M. Buffart. "Randomized Controlled Trial of the Effects of High Intensity and Low-to-Moderate Intensity Exercise on Physical Fitness and Fatigue in Cancer Survivors: Results of the Resistance and Endurance Exercise After ChemoTherapy (REACT) Study." *BMC Medicine* 13, no. 1 (October 29, 2015). doi:10.1186/s12916-015-0513-2.

Lahart, Ian Matthew, George S. Metsios, Alan Michael Nevill, and Amtul Razzaq Carmichael. "PA, Risk of Death and Recurrence in Breast Cancer Survivors: A Systematic Review and Meta-Analysis of Epidemiological Studies." *Acta Oncologica* 54, no. 5 (May 2015): 635–54. doi:10.3109/0284186x.2014.998275.

Loprinzi, Paul D. and Bradley J. Cardinal. "Effects of PA on Common Side Effects of Breast Cancer Treatment." *Breast Cancer* 19, no. 1 (July 2, 2011): 4–10. doi:10.1007/s12282-011-0292-3.

Luoma, ML, L Hakamies-Blomqvist, C Blomqvist, R Nikander, M Gustavsson-Lilius, and T Saarto. "Experiences of Breast Cancer Survivors Participating in a Tailored Exercise Intervention -a Qualitative Study." *Anticancer research.* 34, no. 3 (March 7, 2014): 1193–99. Accessed April 20, 2016. http://www.ncbi.nlm.nih.gov/pubmed/24596359.

Martin, Eric, Caroline Bulsara, Claudio Battaglini, Beth Hands, and Fiona L. Naumann. "Breast and Prostate Cancer Survivor Responses to Group Exercise and Supportive Group Psychotherapy." *Journal of Psychosocial Oncology* 33, no. 6 (August 28, 2015): 620–34. doi:10.1080/07347332.2015.1082166.

McNeely, M. L. "Effects of Exercise on Breast Cancer Patients and Survivors: A Systematic Review and Meta-Analysis." *Canadian Medical Association Journal* 175, no. 1 (July 4, 2006): 34–41. doi:10.1503/cmaj.051073.

Midtgaard, Julie, Nanna Maria Hammer, Christina Andersen, Anders Larsen, Ditte-Marie Bruun, and Mary Jarden. "Cancer Survivors' Experience of Exercise-Based Cancer Rehabilitation – a Meta-Synthesis of Qualitative Research." *Acta Oncologica* 54, no. 5 (March 9, 2015): 609–17. doi:10.3109/0284186x.2014.995777.

Midtgaard, Julie, Kasper Røssell, Jesper Frank Christensen, Jacob Uth, Lis Adamsen, and Mikael Rørth. "Demonstration and Manifestation of Self-Determination and Illness Resistance—A Qualitative

Study of Long-Term Maintenance of PA in Posttreatment Cancer Survivors." *Supportive Care in Cancer* 20, no. 9 (November 15, 2011): 1999–2008. doi:10.1007/s00520-011-1304-8.

Milne, Helen M., Andrew Guilfoyle, Sandy Gordon, Karen E. Wallman, and Kerry S. Courneya. "Personal Accounts of Exercise and Quality of Life from the Perspective of Breast Cancer Survivors." *Quality of Life Research* 16, no. 9 (August 24, 2007): 1473–81. doi:10.1007/s11136-007-9251-z.

National, the. "The NCCS Definition of a 'cancer survivor." July 24, 2014. Accessed April 18, 2016. http://www.canceradvocacy.org/news/defining-cancer-survivorship/.

Pinto, Bernardine M., Shira Dunsiger, and Marissa Waldemore. "PA and Psychosocial Benefits Among Breast Cancer Patients." *Psycho-Oncology* March 2013,: n/a–n/a. doi:10.1002/pon.3272.

Ray, Heather A and Marja J Verhoef. "Dragon Boat Racing and Health-Related Quality of Life of Breast Cancer Survivors: A Mixed Methods Evaluation." *BMC Complementary and Alternative Medicine* 13, no. 1 (2013): 205. doi:10.1186/1472-6882-13-205.

Spence, Rosalind R., Kristiann C. Heesch, and Wendy J. Brown. "Exercise and Cancer Rehabilitation: A Systematic Review." *Cancer Treatment Reviews* 36, no. 2 (April 2010): 185–94. doi:10.1016/j.ctrv.2009.11.003.

Stevinson, Clare. The Importance of PA for People Living with and Beyond Cancer a Concise EvidenceReview.n.p.,2012.http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/Physicalactivityevidencereview.pdf.

Thomas, James and Angela Harden. "Methods for the Thematic Synthesis of Qualitative Research in Systematic Reviews." *BMC Medical Research Methodology* 8, no. 1 (2008): 45. doi:10.1186/1471-2288-8-45.

Trinh, Linda, Nanette Mutrie, Anna M. Campbell, Jennifer J. Crawford, and Kerry S. Courneya. "Effects of Supervised Exercise on Motivational Outcomes in Breast Cancer Survivors at 5-Year Follow-up." *European Journal of Oncology Nursing* 18, no. 6 (December 2014): 557–63. doi:10.1016/j.ejon.2014.07.004.

Whitehead, S. and K. Lavelle. "Older Breast Cancer Survivors' Views and Preferences for PA." *Qualitative Health Research* 19, no. 7 (May 15, 2009): 894–906. doi:10.1177/1049732309337523.

WHO. "PA." June 19, 2015. Accessed April 8, 2016. http://www.who.int/dietphysicalactivity/pa/en/.

World cancer research fund international. "World Cancer Research Fund International." January 16, 2015. Accessed April 18, 2016. http://www.wcrf.org/int/cancer-facts-figures/data-specific-cancers/breast-cancer-statistics.

Wurz, Amanda, Anik St-Aubin, and Jennifer Brunet. "Breast Cancer Survivors' Barriers and Motives for Participating in a Group-Based PA Program Offered in the Community." *Supportive Care in Cancer* 23, no. 8 (January 22, 2015): 2407–16. doi:10.1007/s00520-014-2596-2.

## Email confirmation for University ethical approval

Reply Reply All Forward 👻 - 🏭 - 🍙 🌧 🍅 🗙 🏰 🐟 🗇	•
Your Amended SREP Application - Leanne Livsey (PhD Candidate) - APPROVED - An exploration of breast cancer survivors lived experiences of physical activity (SREP/2015/108)	at in
To: Cc:	
14 Decem	per 2015 14:56
• To help protect your privacy, some content in this message has been blocked. If you're sure this message is from a trusted sender and you want to re-enable the blocked features, click here.	
Dear Leanne,	
Rachel has confirmed that you have addressed the necessary issues and full ethical approval has now been given.	
With best wishes for the success of your research project.	
Regards,	
School of Human and Health Sciences Research Office (HHRG/11)	



## Title of Research Project: An exploration of breast cancer survivors' experiences of PA.

It is important that you read, understand and sign the consent form. Yo entirely voluntary and you are not obliged in any way to participate, i	
please contact your researcher.	
I have been fully informed of the nature and aims of this research	

I consent to taking part in the research study	
I understand that I have the right to withdraw from the research at any point through until publication without giving any reason for withdrawal	out the research, up □
I give permission for my words to be quoted (by use of pseudonym)	
I understand that the information collected will be kept in secure conditions for a period of five years at the University of Huddersfield	
I understand that no person other than the researcher/s and facilitator/s will have access to the information provided.	
I understand that my identity will be protected by the use of pseudonym in the	

report and that there will be no written information, which could lead to me being identified, will be included in any report.

If you are satisfied that you understand the information and are happy to take part in this project please put a tick in the box aligned to each sentence and print and sign below.

Signature of Participant:	Signature of Researcher:
Print:	Print:
Date:	Date:

(one copy to be retained by Participant / one copy to be retained by Researcher)

## An exploration of breast cancer survivor's experiences of physical activity.

#### **INFORMATION SHEET**

You are being invited to take part in this study; 'An exploration of breast cancer survivor's experiences of physical activity'. Before you decide to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with me if you wish. Please do not hesitate to ask if there is anything that is not clear or if you would like more information.

#### What is the study about?

The main purpose of this study is to explore breast cancer survivor's experiences of physical activity. With the secondary aim to explore health care professional's perspectives and experiences of promoting physical activity to breast cancer survivors.

#### Why I have been approached?

You have been asked to participate in the research to explore your experiences and perceptions of physical activity after breast cancer treatment.

#### Do I have to take part?

It is your decision whether or not you take part. If you decide to take part you will be asked to sign a consent form, and you will be free to withdraw at any time throughout the research, up unitIl publication and without giving a reason. A decision to withdraw at any time up until publication, or a decision not to take part, will not effect you and will not involve a penelty or loss of benefits towards you.

## What will I need to do?

If you agree to take part in the research, you will be asked to sign a consent form to provide written evidence of your willingness and understandings of participating in the study, you will be expected to participate in an individual, 45-90 minutes, audiotaped, semi-structured interview which will be guided by the research questions and/or purposes.

## Will my identity be disclosed?

All information disclosed within the interview will be kept confidential, except where legal obligations would necessitate disclosure by the researchers to appropriate personnel.

## What will happen to the information?

All information collected from you during this research will be kept secure and any identifying material, such as names will be removed in order to ensure anonymity. It is anticipated that the research may, at some point, be published in a journal or report. However, should this happen, your anonymity will be ensured, although it may be necessary to use your words in the presentation of the findings and your permission for this is included in the consent form.

## Who can I contact for further information?

If you require any further information about the research, please contact me or my supervisor on:

Name: Leanne Livsey

Main Supervisor: Dr Kiara Lewis

E-mail: <u>u1171934@hud.ac.uk</u>

Email: kiara.lewis@hud.ac.uk

Telephone: 01484 473218

#### Interview Guide

#### Interview guide for breast cancer survivor sample

Background and diagnosis:

- 1. Could you give me brief history of your diagnosis and treatment?
  - Can you tell me more? How does/did that make you feel? How did it effect you?
- 2. Did you get any side effects from the treatment?
  - How did they effect you? How long did they last? How severe was they? Are you still experiencing side effects/consequences of the cancer/treatment?

## PA:

- 3. Describe what PA means to you?
  - Can you expand on that?
- 4. How would you describe your PA levels since treatment?-Prompts and probes if needed for more information
- 5. How do you feel about participating in PA and/or exercise?
  - What are your experiences of PA prior/since treatment?

Information and advice received from health care professionals:

- 6. What are your experiences/perceptions of PA advice from professionals involved in your cancer treatment pathway?
  - What advice were you given? By whom? In what form? When?
- 7. How did the advice you received/found affect your PA participation and/or levels of PA?

- What specifically had an impact?

NB. For each area of questioning an attempt will be made to facilitate participant's reflection of their lived experiences.

Evidence of initial analysis

Reassurance that is right. MA: Ok I'll give it you all, if you want it. Ermm right I ... erm my 21 "Erms+Errs Used to fullo breast cancer was found erm during a routine ... erm 22 sugnies pause mammogram examination in ermm... March 2013 errr I had a 23 Nerves or strug biopsy, shortly after that I had a recall and had to go to Leeds 24 to describe his err no I didn't, I had to go to Bradford St Luke's. Errr where I had expensence of a 25 difficult time ermm several biopsies taken ... err the week following that I er 26 RUICKLY COM Kerself, wants i Who to be correct had a diagnosis errmm that I had breast cancer... And that the 27 28 only solution because of where it was and what type of cancer onlytreatment the believes i we it was ermm I didn't have a lump, I had calcification I had two 29 spots of calcification err one was non-cancerous the other was the only thing with 30 ermm and unfortunately it was err well behind the nipple and so 31 unfortunate? would she have it was errmm there was no other solution, other than a full 32 wanted hoped A Just a Lumpecton mastectomy, ermm I was then sent to to Calderdale err for a 33 Maybe the felt the she took control of the diagnosis becc the carried at the 34 consultation with err Mrs Waterworth who ermm ... put me under her care and I had my first operation, the mastectomy in ermm 35 pperoltion ? 36 May... of 2013. Unfortunately ermm I had some ermm spreading wash convol into the lymph nodes and so I had to in errm three weeks after 37 the mastectomy I had to have a second operation to remove word I discribe the 38 Maybe because of t The May have just forgotten how to u ermm the rest of my lymp... lymph nodes 39 01 LE: right 40 MA: errr after that ... I ermm was sent for a bone scan and errr relieved of 41 The News CT scan to see if there had been any spread anywhere err 42 whether there was any secondary's [secondary cancer] err 43 - UNEVE CONTROLOGIE QUITE FORMENS WAS SOOMS CONT UNOS OFFICESSI (fortunately at that ermm at the least they weren't any. Errr so I 44 then had because of the type of cancer that I had, errr and it was 45 invasive and err I think it was grade 3... ermm I had to have 46 cancer 2

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Idiographic analysis

Maggie Transcript analysis

#### 1.0 Cancer in/took control

Throughout the transcript Maggie describes the effects of her cancer treatment and how it had changed her life in many ways. She describes her treatment as a *"controlled regime"* which restricted her from doing almost anything, and how the physical consequences of her treatment affected her. The subthemes are: *"controlled regime"*, *physically restricted*, and lost *sense of self*. These subthemes highlight how cancer had taken control over her in many ways.

## 1.1 "Controlled Regime"

Whilst undergoing treatment for breast cancer, Maggie explicitly reports feeling "*restricted*", and unable to do things, which she would usually have done before her diagnosis, such as going away or going out:

MA: err so it was erm life had been pretty restricted, we couldn't ermm... we couldn't just think "oh we'd like to go away for a few days" because it was ermm trying to arrange a few days when you didn't think you might be having to have treatment and then I think with also having had two infections, during that time I was a little bit nervous about being too far away [from the hospital]

Maggie creates the sense of being a prisoner to her treatment, as she is confined to *"controlled regime"*, which "restricted" her from doing anything. The language Maggie uses within these extracts, suggest how her everyday life was focused around her treatment schedules, and almost put on hold until she had completed her treatment. Note how she uses the first person plural "we", here, she is referring to herself and her husband, further highlighting how being controlled by a strict treatment regime had not only affected her but her husband also. She then continues to highlight how restricted her treatment regime was by giving further description and insight:

MA: what I had to do after every treatment err the district nurse used to have to come ermm everyday between a certain time, for 5-7 days, depending on how many they [district nurses] thought I needed and she had to give me ermm an injection in my stomach to help keep my blood count up.

The repetition of "every" within this extract emphasises how often she received treatment and how it had restricted her "everyday" life. It appears as though she is tired of the repetitive nature of the

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treatment and almost bored of being confined by this *"controlled regime"*. In addition to this, Maggie then goes onto describe another form of treatment which she received. However, the sense of her being controlled by the treatment is portrayed slightly differently, as the treatment was attached to her chest and intruding her body:

MA: it was awkward for when you, when you had your clothes on and bathing because [pause] ermmm you could either have them just hanging loose, which I was a little bit wary of because I thought they may get pulled or tugged [pause] errmm so I liked to to have mine [catheter] sort of ermm coiled up and then they [breast care nurses] put plasters across it to keep it [pause] err sealed on your chest er but they they're [catheter] not actually water tight, so you [have] to be careful while bathing. Errr so because like I say, because of that I had to go back [to the hospital] then every week, because even though when you're not having your treatment they need to flush the line out to keep it free of ermm infection orr...

Again, there is a sense of annoyance here throughout the extract, as she explains how the catheter causes disruption for simple everyday tasks, such as bathing and clothing. Maintaining the cleanliness of the catheter also restricts her life, as she reports the need to go to the hospital every week, this appears to be a burden for her, although it is beneficial for her health in the long run. There is a sense of internal conflict towards her treatment here, as she seems disgruntled and controlled almost by the restrictive treatment procedures and regime. However, on the other hand, as a result of the treatment being attached to her, she seems to form an attachment with the catheter, in a literal and metaphorical sense. She takes ownership and control over the catheter: *"I liked to to have mine"*, the use of possessive pronoun *"mine"* and verb *"liked"*, implies a sense of attachment and satisfaction. Perhaps she felt a sense of control and attachment here, as she was in control of the catheter which was attached to her own body, rather than the chemotherapy invading her body from an external source.

Her attitude changes when she describes completing treatment and the removal of her catheter:

MA: I had my last Herceptin infusion erm at the end of September and I had then a week later, I had the tube removed from my chest. So then I felt as though I were a a free agent again, you know as sort of like ermm a bit more freedom.

The repetitive theme of becoming *"free"* once she had the catheter removed, highlights the sense of being a prisoner to her treatment, and she was no longer controlled by a treatment regime. The notion of *"freedom"*, creates the image of her detaching herself from the catheter and regaining control as she is handed back her "normal" body again. Of which she is now able to do things without the physical restriction of the catheter and the restriction from the *"controlled treatment regime"*.

#### 1.2 Physically restricted as a consequence of treatment side effects

Before her diagnosis, Maggie describes herself as being *"quite physically active"*, as she attended a *"keep fit"* exercise class regularly. However, due to the restrictions of her breast cancer treatment and the side effects she had experienced from treatment, her fitness and PA levels declined:

MA: errmm [I] just tried to potter about and do the best I could, until the last week, where I felt as though "oh yes that's nice I'm coming round again", and errm "I feel more like it, I've more energy, I can get up you know, I can go for a walk, I'll do this, I'll do I'll do that" and then you start all over again

MA: the middle of the three weeks ermm used to be quite bad, some days I just erm I'd have to force myself to get up. Err but I always did get up I always did something.

In the first extract Maggie, is explaining how her energy levels changed throughout having chemotherapy. Her energy levels were interpreted as a visual representation of the motions of a rollercoaster ride, which increases and dips continuously, thus affecting her physical ability. Her voice reflects the image created of the rollercoaster, as her pitch increased highlighting feelings of being more energetic, and her voice dims as she states "*and then you start all over again*". Implying a sense of slight annoyance towards her uncontrollable fluctuations of energy and how this affected her mood and physical ability. Additionally, as a consequence of treatment, her range of movement and physical abilities was affected further:

MA: right at the beginning [of treatment] err when I was, especially when ermm I was having the chemotherapy erm and the other treatment, there were times when I couldn't erm get onto the floor. Err if I was gunna' [going to] have to bend down er get down, I would of had to lean on that table, go on my knees and gently ease myself down

In this extract, Maggie describes how her treatments had impacted on her physical ability to do simple tasks, which she could do before her treatments. The visual description of relying on the table for a physical aid, creates the image her body being fragile and weak as a consequence of the treatment. Further on, she continues to describe other physical restrictions which she had experienced as a result of her treatments:

MA: I ended up with a frozen shoulder, on the left side because of the second operation, I'd not been able to get enough exercise in from the first one [operation], to the second one [operation]. erm and I ended up having to have quite extensive radiotherapy with that side

MA: ermm and it was more when I had more movement, that I felt more like doing the exercises anyway. Err when they became easier, so erm ehh and that is not restrictive but it's time consuming Although Maggie, does not explicitly describe the impact of having a frozen shoulder on her physical ability, she does imply that it was a result of receiving "extensive radiotherapy". Furthermore, in the following extract, she continues to describe how the restriction of her movement had prevented her from undertaking exercises, which she was given by the breast care nurses. The consequences of her treatments restricted her physical ability and therefore, highlights the sense of the treatment controlling her.

#### 1.3 Lost sense of self- rebirth

The theme of lost sense of self is again a consequence of treatment, which Maggie experiences due to changes in her physical appearance and body image.

Unfortunately, Maggie lost her hair as a result of her chemotherapy treatments, leaving her feeling *"devastated"* and losing her sense of self:

MA: I think the worst bit about the chemotherapy was the hair loss... in fact I think that was (laughs) the worst bit of the lot [pause] well what [pause] devastated I think the word is, you know, you know it can happen [hair loss], you're always like to think it might not happen [pause] ermm and and unfortunately erm mine wasn't gradual err I'd wash my hair and I did what I shouldn't of done, I rolled it and put it in the towel, I didn't comb it out straight away. When I'd took the towel off, the hair came away with it most of it. Which is is quite a shock [pause] erm it's ermm it's coming to terms with the fact that [pause] this isn't [pause] ermm it made my view to me ermm I didn't think I was the same person, it was like coming to terms and getting to know a new person.

Note how she corrects herself at the start of this extract, to emphasise how badly her hair loss had affected her. Although she is describing the event as a traumatic experience, she laughs, implying that she is possibly protecting herself from her true feelings and emotions towards this. There is a sense of betrayal by her own body and the treatment, as she discusses how she thought it wouldn't happen to her, perhaps leading to feelings of "shock" and "devastation". The language she uses here to describe her change in appearance implies a sense of difficulty with accepting this physical transformation, "I didn't think I was the same person, it was like coming to terms and getting to know a new person". The sense of being a different "new person", creates the image of her being reborn and leaving her "old" self behind, furthermore, she also creates the image of rebuilding a relationship with herself, as she is a stranger to her "new" sense of self.

Additionally, the sense of rebirth is continued when she describes her experience of having a mastectomy. She creates two different identities for herself; one being, "the old me" which was how she identified herself before the operation and the other being, "the new me" which she describes herself as being after the operation, implying that she was reborn when she had the operation: 229

MA: I knew the day that I went for the operation I was me, the old me and I knew when I came round the day after, I would be a different me because my body would be different. And it's it's erm it takes, or it took me quite a long time to come to terms and accept the new me [pause] because the body image is affected because I'd not had a reconstruction, so I am lob sided, I am you know [pause] I am only half of what I was.

The language she uses within this extract to describe herself, again creates the sense of rebirth, the idea of her going into the operation as *"the old me"* and awakening from the operation as *"the new me"*, suggests confusion and difficulty with accepting her new sense of self. This sense of awakening is symbolic for being reborn, as she wakes up from the operation in a *"new"* and different body, one which she does not associate her former self with. The language she uses to describe her physical appearance after the operation *"lob sided"* and her description of her sense of self in the final sentence of the extract also suggest conflict within herself and identity issues. She creates the idea of her breasts being a symbol of her identity, and once she had one breast removed, without the reconstruction, she felt that she had lost her sense of self also. Note how she repeatedly stumbles on her words when describing her attitude towards her *"new"* self, this is perhaps a reflection of how she found it difficult to accept her new identity.

Maggie continues to discuss how the experience of having the mastectomy had affected her not only physically but psychologically too:

MA: ermm I err [pause] tended to [pause] find that it affected me [pause] erm psychologically, emotionally. Erm you lose your confidence because I'm not an over confident person and I never have been, but your confidence seems to go with it as well. So part from building your physical strength up, you've got to then to start build your erm emotional strength with it err to try and you know, find a happy medium.

Here, she associates losing her confidence, with losing her hair and breast as a result of the treatments. Again, she highlights the theme of rebirth, as she describes rebuilding strength and confidence, implying that the treatment had taken that from her also and as a result she has reborn into this *"new"* person, claiming her strength and confidence back. The theme of the treatments being in control is central to her experiences throughout these extracts.

#### 2.0 Regaining control

Throughout the interview there is a sense of Maggie regaining or taking control over her cancer diagnosis and treatment experiences. This theme is split into two subthemes of: *"just getting on with it"*/ *stoical acceptance* and *exercising to gain control*.

#### 2.1 "Just getting on with it"- stoical acceptance

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Throughout the interview Maggie explains how she *"just got on with it"*, referring to her experiences of breast cancer diagnosis, treatments and consequences of treatments.

MA: when it's happening to you [diagnosis and treatment], you just get on with it and somebody once said to me "oh oh you, you really have been through it" and I thought "oh oh well I must of been if she thinks so". Ermm but I didn't you know [didn't think she has been through it?], while it's happening, yes you can feel a bit sorry for you [yourself] on days when you think "oh no I've got to have another injection, she's coming to give me another one".

It seems reasonable to suggest that the term "*just getting on with it*" can be interpreted as, a sense of stoical acceptance of the negative/unfortunate experiences which she had to face during her journey. Perhaps she did not want to sit around and dwell on these or feel sorry for herself, as she did not want to let these control her, she just wanted to "*get on with it*". She then continues to describe this sense of "*just getting on with it*" further:

MA: but erm... while it's, while it's happening you just do it. I think you do it in a haze [pause] in some, in some, I think it's just that you know it's got to be done, you just get up, you go, you do it and get on with it. You don't always, you don't always think about [it] till [until] afterwards.

It is apparent that Maggie perhaps accepted the unfortunate consequences of treatment, as they were unavoidable and part of the recovery process. It appears that her main focus and concern was *"getting on with it"*, referring to her diagnosis and cancer, to ultimately cure her cancer, allowing her to move on and get on with the rest of her life. As a result, she is regaining the control over her life and emotions with adopting a stoical attitude towards her experiences.

#### 2.2 Exercise to gain control

When Maggie is describing what PA means to her, she often refers to PA as a means to improve her health and physical abilities. This theme is split into two subthemes, which reflect Maggie's reasons for doing PA. The first subtheme is: *Regaining physical movement and strength by exercising* and *doing PA to control health and reduce the risk of illness and disease*.

#### 2.2.1 Regaining physical movement and strength through exercise

In the extracts below, Maggie describes how exercising has helped her to regain her physical abilities. She highlights this further by explaining how her movement has improved since before her diagnosis and treatment: MA: I now have full movement in that arm [points at left arm] and I can only put it down to the fact that erm I've exercised every week, sometimes twice a week erm in in the gym [exercise class] and I think, I think the weights have helped with that?

And,

MA: yeah so erm I do know that erm it's given me errr more physical ere [pause] being able to give me more physical movement, in some of my joints and I can also get up and down off the floor better than I could before, so I know that's helped.

It is reasonable to suggest that Maggie sees exercising as a tool which improves her physical abilities, as she repeats the word *"helped"*, referring to exercise. Her physical abilities were something which her treatment had impeded, therefore, it could be possible that she engages in regular exercises to revert the effects of her treatment and regain control of her physical abilities through enhancing these.

#### 2.2.2 Undertaking PA to control health and reduce the risk of illness and disease.

Improving her health to *"fight off illness"* appears to be a significant focus for Maggie when participating in PA. This specific focus could provide PA with a purpose and therefore, motivate Maggie to participate in regular PA:

MA: I can understand and see the logic in the fact that, to fight off illness of any kind your body needs to be in a fairly fit state.

It appears that Maggie may have gathered information of the benefits of being healthy and physically fit on illness and disease risks. Her statement *"I can understand"* implies that she has acquired this knowledge from elsewhere, rather than suggesting that it is her own beliefs. Therefore, she may act in agreement with this through participating in regular PA, to ensure that her body is fit and able. In addition to this, she begins to explain how her PA levels have increased after completing her treatment, compared to before her diagnosis:

LE: and now you say your PA level is similar to what it was?

MA: I would say it's more now

MA: than before I was diagnosed [pause] yeahh and some of that and some of it is psychological knowing the fact that erm all being under the err the impression that that ermm to err keep [pause] illness and disease at at bay you need to have a fit body and a good immune errr system, which of course when you've had this and an treatment err your immune system ermm gets fairly [pause] battered about ermm like I say, I have the thyroid problem which affects my immune system anyway so I feel that I perhaps need it more because ermm that's impeding my immunity and I want to keep my body fit, to counteract whatever that that the thyroid takes away from ma my erm ability to fight.

In the extracts above, she is highlighting the focus of being *"fit"* to prevent or fight illness, as a purpose for increasing her PA levels. The phrase *"psychological knowing"*, suggests that she is preventing thoughts and worries of health, knowing that she is helping to improve her health through exercising. This is highlighted further in the extract below:

MA: Ermm I think it's helps with the mind ermm if I'm, if im a bit anxious sometimes, you know [pause] I can feel less anxious when I've done it, I think it helps erm to keep my mind on an even field.

The sense of exercising as a tool to help manage her worries of health related problems is emphasised here. When questioned about what anxieties she had, she confirmed that they were health related anxieties. Therefore, there is a sense that exercise offers a purpose, as she believes it helps manage her anxieties and possible fears of illness, as she feels that exercise will decrease her chances of illness and help "fight" it. Again, this highlights the theme of exercising to gain control, as she is using exercise as a tool to take control over her physical health and psychological health. Furthermore, she is regaining her control back from the treatment, as she is improving her PA levels and abilities compared to before she was diagnosed.

#### 3.0 Significant influences/motivators of the breast cancer specific exercise class

Within the interview, Maggie describes how the different aspects of the exercise class motivate her to participate in regular PA, and how it differs from other forms of exercise classes. Therefore, this theme is split into two subthemes which reflect the most significant factors of the exercise class for Maggie. The first subtheme is: *appreciation of exercising within a group setting, with other women who have similar experiences* and the second subtheme is *recognition and appreciation of support from the exercise professional.* 

# 3.1 Appreciation of exercising within a group setting, with other women who have similar experiences

Maggie describes how exercising with other women, who have similar experiences offered her a *"greater incentive"* to participate in the exercise class:

MA: erm I probably wouldn't of bothered doing it you know. I might of perhaps eventually gone back to the exercise class that I went to once a week but erm that would then, be with people who had not had my experience. And I find they both [exercise class and exercising

with other breast cancer survivors], that they both go together well because we all do talk to each other about [pause] you know odd things, that erm that crop up and one of us could say "oh I've got so and so" or "I've got a pain here, oh I've got that". I'm glad you know and it sort of erm it's a mind easer.

#### And,

MA: So erm I think the two combined, the fact that err yes it's a gym and we're having exercise and there are people there who have had a like experience, it's it's erm it it gives you, ME a greater incentive to actually errr want to be in that group, rather than in in another group.

In the extracts above, Maggie appears to be apprehensive about re-joining the exercise class which she did before her diagnosis because it is not targeted at women who have had breast cancer. Again, this sense of new identity is brought to light here, as she almost disassociates herself from women who have not had breast cancer and therefore, defines herself as someone who has experienced breast cancer. The sense of belonging and shared understanding is highlighted within the extracts, through sharing similar experiences from breast cancer and treatment with the other women. Maggie highlights the reliance for a social network, for shared support and sense of belonging amongst women with similar experiences in the extract below:

MA: I think you find yourself... it they say "it's the loneliest time of your life", it is. Because unless you are surrounded or can be with people who are, or have had the same experience, no matter how hard somebody else tries, I don't er they don't understand.

Notice how she starts the extract in first person and then continues in third person, as though she is repeating what other people have said. This makes the statement impersonal and almost implies that she doesn't want to admit that she felt lonely. However, she then agrees with the statement and the reliance on shared understanding and support from other with a similar experience is heightened here. As she explained in a previous extract, these shared experiences act as *"a mind easier"*, as they are focused on health and side effects of treatment. As stated before she worries about health problems, which causes anxiety, therefore, it could be possible that she worries less knowing that other people experience similar things.

Alongside exercising with other women with similar experiences, Maggie highlights the importance of the exercises being somewhat specific for her, since her diagnosis and treatments:

MA: I went to bums and tums and I didn't, I didn't feel as though I could go back to that... I wanted to go back to some physical ermm exercise aft after, soon as I felt as though I could do. But I didn't feel as though I could go back to that because they did alot of erm things

where you had to take your weight on your arms and they [breast care nurses?] always warn you about not putting too much weight on you erm because of erm lymphedema or whatever it is. Yeah so I sort of shied ahh away from that.

Again, she shows her apprehension about returning to the exercise class she did prior to her diagnosis. Perhaps she feels guilty for not returning to the class, or perhaps she feels the need to justify her reasoning for not returning. However, her apprehension is focused around the exercises involved in the class and the safety aspects of them. It appears as though she is scared of causing further damage or complications to her physical ability, through participating in a class which isn't specifically for women who have had breast cancer. It could be possible that she doubted the physical ability of her own body or the knowledge of the instructor, in terms of exercising after breast cancer. The language she uses with regards to being advised about exercise *"they always warn you about"*, creates the image of her being cautioned about possible danger, "they" implies vagueness and depersonalises the subjects, similar to a caution sign. As a result, the "warning" prevented her from returning to the exercise class.

#### 3.2 Recognition and appreciation of support from the exercise professional

The sense of support is heightened further throughout the interview, as Maggie expresses her appreciation for having a knowledgeable exercise instructor, who shows an interest in her.

MA: I like the you know, the fact that we were being monitored for it err to start with, like in the pod. Err it makes you feel as though somebody is taking some er perhaps a greater interest in what's what's happening to you and errmm and gives you that little bit of motivation to be... better.

And,

MA: It was just as though somebody err was taking some interest in what had happened to you, ermm and they wanted to... help you, try and help yourself to make a difference.

The repetition of *"somebody taking some interest"* emphasises her appreciation for the support from the exercise professional and implies that she felt abandoned by other professionals previously throughout her breast cancer journey. Again, it highlights the image of her being "alone" throughout her journey and the reliance for support is important to her. It seems that she is not only motivated by improving her health and fitness, for her own benefits as mentioned previously. However, she is motivated to improve for the acknowledgement from the exercise professional perhaps she feels the need to improve because of the personal support she is receiving from them.

Furthermore, she highlights the differences of the exercise class compared to other exercise classes. Again, she appears to associate the exercises and instructor as providing safety and preventing physical damage:

MA: the things that we do are different to what I would do in a keep fit class because we have the advantage of the weights and erm and the the equipment on occasions

MA: when your body's been through something like that, ermm there are sort of yes. You know what, yourself if you are doing an exercise and it's hurting then, then yeah, then yeah. Let's leave it errr a little but erm if you've got somebody with some experience and knowledge, then they you know, they can say to you straight away "oh I wouldn't do that one".

MA: whereas you, you can, if you're doing it yourself, you can go into it and probably do more damage, than having somebody stop you straight away say "well I wouldn't do that for a while I'd ermm you know lets". [pause] Like when we [are] doing the floor exercises when when I, er if it makes me feel err sickly, you'll say "well don't do [that]... you do this one".

Throughout the extracts above, there is a repetitive theme of appreciation for the instruction of a knowledgeable exercise instructor specifically for breast cancer. This appears to create a sense of safety for Maggie, as she relies on this supervision to prevent her from doing exercises incorrectly or exercises which are not suitable for her. Again, she mentions changes in her body's abilities as a result of her cancer, creating the image of her body being fragile, and so implying that she worries about her body's capabilities since her treatment and fears of causing any more damage. It could be possible that she did not receive enough advice and information prior to attending the exercise class, therefore, she does not feel knowledgeable or confident to undertake exercises on her own, or within another exercise setting which is not specific for breast cancer.

#### 4.0 Experiences of receiving PA advice

As stated previously, Maggie appears to be unknowledgeable of what exercises are safe and appropriate for her, this could be a result of not receiving enough, if any advice. When asked about her experiences of receiving any PA advice from health care professionals and if she received any, Maggie simply replies with *"no":* 

MA: No in a word (laughs) apart from the only, the only erm the only thing as I mentioned early was, when we had the operation you're given a leaflet with exercises in erm which you have to go away and do yourself.

MA: so unless your fairly well motivated ermm its just how much you do anyway erm there were erm yes er because I was still going into ermm the hospital and had ermm access to their leaflets errr that there were leaflets out about organised walks within the area, ermm I never went on one I did keep saying I would do and I didn't do. Err but apart from that until I went on the moving forward programme.

Her laugh is implied as a mask to hide her disappointment with the lack of information and guidance she perhaps expected to receive from the health care professionals. The language and tone of her voice which she uses at the end of the first extract, further heightens her feelings of disappointment as she suggests a sense of disapproval with the non-existent supervision or instruction given alongside the leaflet. Perhaps she expected the health care professional to demonstrate how to do the exercises and give personal instructions for additionally information and support. She then continues to describe which sources of information she received, emphasising the lack of advice from health care professionals:

MA: erm but apart from that, that is the only time I can remember anything being erm promoted towards physical erm exercise.

Although, Maggie did not receive personal information regarding PA from the health care professionals, she was invited to the Moving Forward course from the breast care nurses. This course covers a variety of topics one being exercise, therefore, this could be a possible reason why some health care professionals do not give personal advice themselves. However, as implied by Maggie, the experience of advice from health care professionals may influence one's PA levels and act as a motivator or a hindrance.

Development of the themes (Phase One)



#### NHS Ethical Approval

HHR 2/04 Human and Health Research Building Queensgate Campus University of Huddersfield Huddersfield HD1 3DH

#### Dear Ms Livesy

#### ID:1292

#### 192 Title Breast cancer survivors' experiences of physical activity

The Research and Development department has consid<u>ered the following documents in support of the</u> application for approval to undertake your PhD study of NHS Foundation Trust under your academic supervisor [

Document	Version	Dated
Research Protocol	1	16-11-15
Interview Guide for Health Care Professionals	1	16-11-15
Information Sheet	2	14-12-15
University of Huddersfield SREP approval [Email]		14-12-15

Your study now has R&D approval on the understanding and provision that you will adhere to the following conditions:

#### That the research should:

- Comply with the requirements of The Research Governance Framework for Health and Social Care (2<sup>nd</sup> DH 2005);
- Comply with regulatory requirements and legislation relating to: Clinical Trials, Data Protection, Health and Safety, Trust Caldicott Guidelines, and the use of Human Tissue for research purposes;
- Be conducted in accordance with: ICH Good Clinical Practice and/or the MRC guidelines for good clinical practice (as appropriate);
- Not commence until it has received written approval from a UKECA recognised Research Ethics Committee (REC) and that any REC imposed conditions of that approval are implemented:

#### Chairman: Andrew Haigh Chief Executive: Owen Williams



#### You must also:

- Request written approval for any change to the approved protocol/study documents that you
  or the Chief Investigator wish to implement;
- Ensure that all study personnel, not employed by Calderdale and Huddersfield NHS Foundation Trust, hold either an honorary contract with the Trust or a letter of access issued by the Trust, before they have access to any facilities, patients, staff, their data, tissue or organs;
- · Complete the Research Governance interim and final reports as requested;
- Submit monthly recruitment and screening data to R&D (if applicable).
- · Comply with our audit and monitoring procedures as required.

Yours sincerely

#### Interview guide for health care professionals:

Background information

5. How long have you been a health care professional involved in the breast cancer treatment pathway for?

-Role within the NHS

- Prior related experience?

Physical activity:

6. What are your perceptions of advising physical activity to patients following breast cancer treatment?

-do you see this as part of your role?

-if not why? Whose role (if anyone's) is it?

- would you view breast cancer patients differently from other cancer patients with regard to advising physical activity? Why/why not?

- 7. What are your experiences of giving physical activity advice to patients following breast cancer treatment?
  - Have you given any advice?
  - If yes: Facilitators? What types? To whom?
  - Please describe an example of a case where you gave such advice.
    - How did you feel in this case? How does that compare to others?
  - If no: Why not? Barriers.
- 8. How do you feel about giving advice and information regarding physical activity to those who have completed breast cancer treatment?
  - Facilitators?
  - Barriers?

NB. For each area of questioning an attempt will be made to facilitate participant's reflection of their lived experiences.

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#### Initial template

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