Understanding the experience of Pregnancy-Associated Breast Cancer (PABC)
– An interpretative phenomenological analysis

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Abstract

The psychological impact of breast cancer is well documented, but the experience of younger patients who are diagnosed whilst they are pregnant, is both physically and psychologically diverse from that of non-pregnant breast cancer patients, and this phenomenon has been little researched. Pregnancy-associated breast cancer (PABC) is rare but incidence rates are rising as women delay child-bearing. Currently no guidelines to psychological management exist, and practitioners’ competence in this area is challenged.

This unparalleled ‘insider’ study explores the experiences of women diagnosed with PABC, seeking to understand the features that make these unique to the condition and inform counselling psychology theory and practice.

The qualitative methodology used was Interpretative Phenomenological Analysis (IPA) and data was collected from 11 semi-structured interviews. Participants were 32-44 years old and from the UK. Major themes arising were: (1) experiencing a clash of priority between baby’s life and mother’s life, versus mother feeling in alliance with baby, (2) having perceptions of being physically and emotionally saved by the pregnancy and baby, and (3) experiencing a loss of being a mother.

This thesis argues that the experience of PABC involves distinct psychological challenges concerning: identity and behaviour as new ‘mother-patient’, maternal-infant attachment, coping and support, and impact on family life and relationships. Psychologists working in cancer care or perinatal care services will benefit from specialised education around PABC to proficiently help patients and families, and support healthcare professionals. For moderate to severe psychological presentations requiring management, findings suggest that emotion-focused, person-centred and cognitive behavioural therapies, including individual and family systemic approaches, are appropriate within a flexible structural format to accommodate illness and treatment effects, and especially parenting behaviour, wishes and responsibilities.

7
Introduction

Breast cancer is one of the most common types of cancer to occur during pregnancy (Azim et al, 2010; DiFronzo et al, 1996; Doger et al, 2011). Up to 300 of the approximately 10,000 women aged 20-49 years who are currently being diagnosed with breast cancer in the UK every year, are pregnant or have recently given birth, at the time of receiving their diagnosis (CRUK, 2016a). This number is likely to increase as more women tend to delay child-bearing till later in life (Azim et al, 2010; Doger et al, 2011; Kuerer et al, 1997; Voulgaris et al, 2011), and as breast cancer incidence rates continue to rise in the reproductive age groups (CRUK, 2016b).

Breast cancer is a challenging experience carrying physical, psychological and social consequences (Helms et al, 2008; Min et al, 2013). Breast cancer patients are frequently reported to experience emotional difficulties following diagnosis and treatment (Burgess et al, 2005; Hill et al, 2011). However, the number of pregnant cancer patients who are identified as clinically distressed is nearly 20% higher than that of non-pregnant breast cancer patients, and pregnancy is itself a time of heightened psychological vulnerability (Henry et al, 2012; Ives et al, 2012; Wylie and Bryce, 2016). Cancer during pregnancy presents unique and complex psychological and relational challenges with potential long-term consequences for patients and their families (Ferrere and Wendland, 2013; Wendland, 2009). Research shows that psychological practitioners’ and healthcare professionals’ knowledge about cancer experiences and knowledge-related psychological interventions can help patients’ coping and adjusting to life during cancer treatment and after (Andersen et al, 2008; Dean, 1989). Psychological ‘adjustment’ to cancer (Brennan, 2001) generates better outcomes for patients, better health and well-being, and higher quality of life and chance of survival (Andersen et al, 2008; Avis et al, 2005).

Little qualitative research has been carried out in the UK into the subjective experience of breast cancer diagnosed during pregnancy or soon after giving birth. Existing international and quantitative findings do not reveal the diversity of experiences, attitudes and coping mechanisms, which is necessary in order that appropriate and acceptable therapeutic interventions can be developed (McLeod, 2003). This thesis explores in-depth the qualitative experience of having breast cancer diagnosed whilst being pregnant or in the first year after giving birth, a condition known as Pregnancy-Associated Breast Cancer (PABC, or ‘pregnancy-related’, or ‘gestational’ breast cancer). The knowledge generated from this study will expand counselling psychologists’ and healthcare professionals’ (HCPs) understanding of the complex emotional conditions and needs of patients and their families, and is intended to function as a guide to future research.
Chapter 1  Literature Review

1.1  Breast cancer

Breast cancer incidence
The World Health Organisation (WHO) lists cancer as one of the leading causes of death in the world, and the disease can affect anyone regardless of gender, age, location and socioeconomic status (WHO, 2014a). Cancer of the breast is by far the most common cancer in women, and worldwide 1.7 million people are diagnosed with breast cancer each year (CRUK, 2014). Similarly to other cancers, breast cancer arises from the uncontrollable growth of abnormal cells in one location in the body, and typically the cells spread to tissue in other parts of the body, invading organs via the process of metastasis (WHO, 2014). Metastasis is the prime cause of death from cancer.

Breast cancer is the most common cancer in the UK, with overall incidence rates having risen by 72% since the mid-1970s (CRUK, 2014). Currently, one in eight women in the UK will be diagnosed with breast cancer at some time in their lives, and the disease is now the most frequent cause of cancer death in British women aged between 15-49 years.

Breast cancer incidence is strongly related to social and economic status, and rates are lower for more deprived women (NCIN, 2014). Likely explanations are that risk factors are more widespread amongst more affluent groups of women. A leading risk factor is a later first pregnancy, and this risk increases by 3% for each year older a woman is when first giving birth (CRUK, 2014). However, this association may be limited to non-genetically determined breast cancers (women who do not carry the breast cancer genes BRCA1 and BRCA2). Whilst breast cancer incidence is generally higher in more affluent groups, so is breast cancer survival (CRUK, 2014).

Nature of breast cancer and physical manifestations
The progression of a healthy cell into a cancerous one is caused by the interaction between a person’s genetic factors and external influences such as exposure to cancer-causing agents and/or high-risk behaviour (WHO, 2015). Initially, primary breast cancer (i.e. cancer which has not spread beyond the breast area) may manifest through the appearance of a lump, or tumour, located in the breast or in the armpit (or both) but the disease can also present via subtle changes in the breast tissue, such as changes in size and shape of the breast and/or the nipple, and
dimpling of the skin. Many women do not experience other symptoms.

Several types of primary breast cancer exist, with some more aggressive (i.e. more rapidly spreading) than others, and the disease is typically categorised in stages or grades at diagnosis. Invasive ductal carcinoma is the most common breast cancer and accounts for 90% of diagnoses (CRUK, 2014). Treatment for breast cancer depends on the nature of the individual presentation and is usually designed and applied by specialists working in medical and clinical oncology. In addition to chemotherapy and radiotherapy, most patients also have at least one of several types of surgery to remove cancerous tissue. A treatment process for a primary breast cancer might typically last 12 months or more depending on its effectiveness (Verywell, 2016).

Prognosis
Survival rates for all types of breast cancer have improved steadily over the last 40 years (CRUK, 2014), and a diagnosis of breast cancer can no longer be regarded as a conclusive death sentence. Eighty-five per cent of breast cancer patients can expect to survive beyond five years after diagnosis (CRUK, 2014). The main contributors to this steady rise in survival rates for all age groups and types of breast cancer since the 1970s are likely to be improved detection strategies combined with advances in treatment and specialised care provision (Giordano et al, 2004). A good prognosis for survival from breast cancer is generally linked to early diagnosis and the success of treatment (CRUK, 2016). It is also argued that a range of psychological factors, including a person’s style of coping (e.g. avoidance, control, emotion-focused coping) and attitude (e.g. hope and optimism, or a lack of it) might have a significant effect on recovery and long-term survival as well as psychological adjustment (Epping-Jordan et al, 1999; Groenvold et al, 2007; Watson et al, 1991). An early quantitative study by Funch and Marshall (1983) found that ‘subjective stress’ was strongly related to survival for breast cancer patients in younger age groups. More recently, findings from a meta-analytic study by Chida et al (2008) showed that stress-related psychosocial factors had an adverse effect on breast cancer incidence and survival, and thus experiencing stress may hamper the ability to physically ‘fight off’ the disease and result in a higher chance of mortality.

Psychosocial impact of breast cancer
Research carried out over the last few decades has confirmed that having breast cancer is a challenging experience for most women, which commonly extends beyond diagnosis and treatment, and encompasses physical, psychological and social consequences (Golant et al, 2003; Helms et al, 2008; NICE, 2009). As many as one third of breast cancer patients are reported to
experience psychosocial difficulties following diagnosis and treatment (Baker et al, 2013). This means that around 15,000 breast cancer patients in the UK per year experience significant and pro-longed psychological distress linked to their condition (although not all distress is categorised as severe).

Cancer patients are very likely to be emotionally vulnerable (Min et al, 2013; Singer et al, 2010). Facing illness and death, and being subjected to aggressive physical treatment over an extended period of time can cause psychological distress, trigger affective disorders and dramatically impact the person, her sense of identity and her social environment (Golant et al, 2003; Helms et al, 2008). These problems are often preceded or accompanied by feelings of helplessness, vulnerability, loss of control and loneliness/isolation (Reich et al, 2008). The most frequently reported psychological problems for breast cancer patients are depression and anxiety (Burgess et al, 2005; Shapiro et al, 2001), and the risk is increased if a woman has previously experienced these disorders (Hill et al, 2011).

Breast cancer patients are disposed to additional problems including excess worrying, social stigmas around disease and lowered self-esteem (Fobair et al, 2006; Hegel et al 2006). Much of the psychological impact is directly linked to the effects of cancer treatment. Radical surgery, hair loss, fatigue, weight fluctuation, lowered libido, menopausal symptoms and/or infertility, and cognitive impairments such as memory and concentration difficulties, in addition to common minor ailments (eg. colds and infections, digestion and colorectal problems, viruses) which often develop due to a weakened immune system, can all impact negatively on the overall quality of life and psychological well-being (Shapiro et al, 2001). A cancer patient in active treatment is unlikely to be physically and mentally able to perform the same care-giving role in a family that she may usually perform, and similarly, is unlikely to be able to work during much of the treatment period. This has psychological and social consequences and, besides economic difficulty, may involve specific forms of distress and feelings of inadequacy and failure that exacerbate the risk of depression and anxiety (Hill et al, 2011).

In Western society, the female breast is commonly perceived as a symbol of motherhood and nurturance, as well as of sexuality and womanhood (Pickler and Winterowd, 2003). Treatment of breast cancer frequently involves the surgical removal of part or whole of the breast, and in some cases both breasts. This procedure can have significant psychological impact on the body self-image of the patient, her sense of self as a female and her sexuality (Frost et al, 2000; Harmer, 2006). Losing a breast is a complex experience, and scars are openly regarded as unattractive and
unfeminine (Ogden and Lindridge, 2008). Many women experience some degree of identity confusion, and changes in the organisation of their self-image that involves femininity issues, intimacy and relationships concerns (Anllo, 2000). This can generate or intensify feelings of anxiety or depression during and after treatment, and in the long-term (Alfano and Rowland, 2006; Bender et al, 2005).

Fear and worry of the recurrence of cancer can also be a significant factor in experienced distress (Ferrans, 1994; Oh et al, 2004), and can affect social relationships and functioning. Between 27-58% of breast cancer patients experience some level of fear of recurrence, and this can persist long after treatment has ended (De Vries et al, 2014). Vickberg (2003) found that fear of recurrence was focused on the possibility of death, further treatment and the threat to health, more so than on identity and femininity issues, and that younger women demonstrated greater levels of fear. Researchers continue to investigate the factors that predict higher levels of distress experienced in connection with breast cancer. It has been found that a person’s age at diagnosis may be an influence on their levels of psychological distress. In particular, younger women (below 50 years) report higher levels of emotional distress than older women (Avis et al, 2005; Baucom et al, 2006; Bloom et al, 2004; Burgess et al, 2005; Thewes et al, 2004). See also below.

When investigating breast cancer’s psychosocial impact on patients, it is important to recognise that many patients undergo a positive adjustment to the illness and treatment, and that the experience can have an overall positive impact on the quality of life of an individual (Horgan et al, 2011). Research has found that some people are able to develop stronger appreciation of their lives and form better relationships with others as a result of their experience of having cancer (Andrykowski et al, 1993; Collins et al, 1990). Likewise, the levels of emotional distress that breast cancer patients experience throughout treatment and beyond are not the same for all, or the same throughout the individual experience, and there are factors that may significantly exacerbate or buffer the psychological impact. These factors may relate to the severity of the diagnosis, the nature of the treatment and the physical impact, coping style, the support network available and utilised, the phase of life the patient is in (including responsibilities and everyday roles), and the quality of life before diagnosis (Carver et al, 1993; Epping-Jordan, 1999; Sammarco, 2001; Stanton et al, 2002).

Studies have investigated the uptake of psychological support services amongst cancer patients of all types and ages, and surprisingly, some findings indicate that as many as half of patients in active treatment and after, who are identified as suffering significant psychological distress, do
not use the support offered to them (Merckaert et al, 2010; Nekolaichuk et al, 2011). The reasons for the low uptake are unclear but may concern the timing of psychological intervention in the cancer trajectory (Baker et al, 2013), attitude towards help seeking (McDowell et al, 2011) or the cooperation of oncologists and their recognition of patients’ emotional needs (Söllner et al, 2001).

The age factor in breast cancer incidence
Older age is a significant factor for higher incidence of breast cancer (CRUK, 2014). This may be explained by the fact that an elderly person has accumulated exposure to cancer-causing agents present in their environment, and that the cells of an elderly person are known to have a weakened ability to repair themselves, compared to the cells of a younger person. However, age at diagnosis has implications for survival, and breast cancer differs from other cancers in that older patients have consistently higher survival rates than younger patients. This may be as more aggressive types of breast cancer are usually diagnosed in younger, pre-menopausal women (CRUK, 2014).

Literature on the psychological impact of breast cancer is extensive, although more limited where younger women (<50 years) are concerned (Champion et al, 2014). This age group accounts for a fifth of the 50,000 women diagnosed in the UK every year, and research has found that the experience can be particularly distressing for patients diagnosed at below 50 years of age, with psychological adjustment harder to attain (Avis et al, 2005; Burgess et al, 2005; Howard-Anderson et al, 2012; Mosher and Danoff-Burg, 2006). Approximately 1200 younger women die from the disease in the UK each year, and a breast cancer diagnosis can be a significant stressor for both patient and family (CRUK, 2014; ONS, 2014).

Psychosocial issues associated with a diagnosis of breast cancer in younger women are known to include high prevalence of numerous types of psychological distress, ranging from negative body image changes, sexual functioning and relationship concerns, emotional and practical support provision, to depression, anxiety and existential crisis as well as concerns about early menopause and future child-bearing abilities (Baucom et al, 2006; Dunn and Steginga, 2000; Hollingworth et al, 2013; Avis et al, 2005). As younger women experience distinct psychosocial issues around having breast cancer, it follows that there are support needs for this group of patients particular to them. For example, issues around coming to terms with early menopause and the physiological aspects of this change, including infertility, may be important for support services to recognise and understand (Avis et al, 2004). Further problems commonly related to a patient’s age, such as missing work and specific everyday activities, fatigue and the sudden inability to carry
out the usual care-giving role in the family, add to the range of support needs that younger women will present to cancer services, and that these services will be required to accommodate in order to help control distress and manage the psychosocial impact of the disease (Wong-Kim et al, 2005). Intervention studies find that offering psychosocial counselling and peer group support to women diagnosed with breast cancer at a specific time, e.g. earlier (immediately after diagnosis or in the post-operative period) will have a greater positive effect in reducing distress than when the same support is offered at another time, and that even a few months can make a substantial difference to the outcome (Vos et al, 2006; Dunn et al, 1999).

It is important to recognise that not all younger women cope alike with the experience of breast cancer, and that there are psychological and social factors enabling some younger women to cope better than others. These individual differences may be especially salient in the diagnosis of breast cancer during pregnancy, when a woman is in particularly vulnerable circumstances, sometimes described as having to ‘fight for two’, and experiences that there is a relative lack of information about treatment options and prognosis, as well as a lack of training and experience in the healthcare professions (Henry et al, 2012).

1.2 Issues in pregnancy and early motherhood

The United Kingdom sees around 800,000 births per year (ONS, 2015; ISD Scotland, 2015). A full-term pregnancy lasts between 37-42 weeks (NHS, 2016d), and 5-10% of babies are born ‘preterm’ or ‘premature’, i.e. before 37 weeks of gestation, with many having associated medical issues, often caused by organ underdevelopment (WHO, 2007, cited in Behrman and Butler, 2007). In this study, the term ‘preterm’ is used throughout to indicate delivery before having reached full term.

Pregnancy is a radical transition from one physical and psychological state to another, and can be a highly challenging time (Lederman, 1996; Simpson et al, 2003). Most pregnant women experience common but relatively minor health problems such as nausea, constipation, backache and headache, low energy and sleep problems, as well as mood swings and worry (NHS, 2013). Complex problems range widely from fatigue, hypertension and cardiac conditions, to neurological conditions, autoimmune disorders, infections, pre-eclampsia and cancer (Pregnancy and Medicine Initiative, 2013). Pre-existing medical conditions may also affect the pregnancy directly or via the administration of medication (such as e.g. diabetes and HIV) (Wylie and Bryce, 2016).
‘Maternal-fetal conflict’

There are situations in perinatology (maternal-fetal medicine) where the health interests of the pregnant woman is deemed to conflict with those of the fetus, generally defined as ‘maternal-fetal conflicts’ (Fasouliotis and Schenker, 2000; Oduncu et al, 2003). In these situations, the mother may refuse treatment which is considered beneficial and important for her own health and for good fetal outcome, or she may make other choices (treatment-related or lifestyle) which doctors deem present a risk to herself and/or the fetus. The term ‘conflict’, and the application of a conflict-based model to the maternal-fetal relationship, has been disputed (Harris, 2000; Scott, 2007) as it designates the maternal-fetal relationship to be adversarial (Cummings and Mercurio, 2011; Steinbock, 2011), positioning the conflict in between the woman and the fetus, when this may be better placed between the pregnant woman and doctors (as a ‘maternal-doctor conflict’ (Oberman, 1999, p. 454)) ‘who believe they know best how to protect the fetus’ (Flagler et al, 1997, p. 1730). Cancer in pregnancy has been defined as a medical and bioethical dilemma where optimal maternal treatment and fetal well-being are posed as conflicting, and either the health of mother or the fetus must be compromised (Koren et al, 1996; Oduncu et al, 2003, Weisz et al, 2001).

Although a fetus is not considered to have equal moral status to its mother (Mahowald, 1992), and is not recognised by UK law to have a ‘legal personality’ (Scott, 2002, p.xxviii), there has been much progress in its clinical status, and a fetus is now in practice considered a patient ‘in its own right’ (Fasouliotis et al, 2000) with the pregnant woman part of a ‘two-patient obstetric model’ (Mattingly, 1992, p.13). However, in concordance with a fetus’ rights being largely demoted by the law, HCPs have traditionally, and are still legally obliged to, prioritise the promotion of the pregnant woman’s health above her child’s. HCPs must also fully respect the woman’s personal autonomy in making decisions about any medical intervention (Scott, 2002) regardless of how this may conflict with other professional obligations such as ‘non-maleficence’ and other professional and personal impulses. In practice, this is seldom clear-cut. However, coercing the patient into accepting certain treatments is never a permissible strategy (Pinkerton and Finnerty, 1996; Steinbock, 2011).

Maternal protective drive, bonding and attachment

Our understanding of the maternal instinct to protect an infant has been extensively researched within the field of sociology as part of modern constructions of motherhood, and in particular from feminist perspectives (Miller, 2007). Maternal protective drive or instinct, also recognised as maternal aggression, is in this study distinguished from the term ‘maternal drive’ (frequently
meaning the felt impulse of a woman to bear children) (Wiki, 2016). Maternal protective drive is understood as a woman’s innate inclination to carry out maternal behaviours such as sheltering, defending and protecting her child in order to optimise its health and survival (Epstein, 1987), and is based in the evolutionary neural ability to predict and recognise when one’s infant is in psychological distress (Noriuchi et al, 2008). Reron (1995) describes how the pregnant woman’s perception of the first fetal movement is a significant moment for the development of a maternal instinct and subsequent attachment.

As part of human reproduction, attachment is understood as the result of bonding, i.e. the forming of a ‘selective and enduring’ psychological bond between parent and child (Feldman et al, 1999, p.929), and serves the evolutionary purpose of infant survival (Stiefel, 1997). However, attachment style has also been widely found to be a significant factor in the way people respond to challenging life events, including pregnancy (Mikulincer and Florian, 1999). The definition of prenatal attachment (also maternal-fetal attachment (Mehran et al, 2013)) is the emotional bond, including emotions, perceptions and behaviours, which form between the pregnant mother and her unborn child (O’Leary and Thorwick, 2008; Pisoni et al 2014). Pisoni et al (2014) highlight the importance of prenatal attachment as predictor of the quality of the later relationship between parent and child, which, in turn, affects the child’s cognitive and emotional development. Gaffney (1986) investigated the association between components of maternal-fetal attachment (such as the giving of self, attributing characteristics to the fetus, role-taking, differentiation of self and interaction with fetus) and anxiety and concept of self.

Breast feeding
The meaning and purpose of breastfeeding exceeds that of providing nutrition, and is considered an important part of the bonding process between mother and infant (ScienceDaily, 2008). Public health discourses present breastfeeding as ‘vital to infant development and the mother-infant bond’ (Schmied and Lupton, 2001, p.234). Women’s qualitative experiences of breastfeeding are diverse, but the majority of professional accounts within medicine, nursing, midwifery, public health and public policy continually stress that ‘breast is best’ for infants, the mother, the economy and the environment (Sloan et al, 2006; Smith and Ingham, 2005). Although breastfeeding can be experienced as physically and emotionally exhausting, many women believe that breastfeeding is ‘natural’ and crucial to their relationship with their baby, and that breastfeeding represents ‘good’ mothering (Schmied and Lupton, 2001; Wall, 2001). Typical problems with breastfeeding, such as the mother’s perception of insufficient milk supply, can cause significant levels of maternal anxiety (Scott and Colin, 2002) and affect self-confidence and
the early motherhood experience (Burns et al, 2010).

Perinatal mental health

In 2016, The British Psychological Society (BPS) called for improved perinatal mental health services (BPS, 2016a). The BPS estimates that one in five women suffer from a mental health problem during pregnancy or in the first year after childbirth. Perinatal mental distress has been found to have negative effect on a woman’s function and on the development of her child (Bifulco et al, 2004; O’Hara et al, 2014; Rallis et al, 2014). Psychological conditions such as depression and anxiety are as prevalent in younger women during pregnancy as in non-pregnancy, and studies have found that exposure to high levels of psychological distress are associated with adverse obstetric, fetal and neonatal outcomes (complications, pain, preterm labour) and can negatively affect the well-being of the fetus, as well as the maternal identity development (Alder et al, 2007; Harrison, 2013). One on-going study has found that one in three first-time mothers suffers depressive symptoms which are linked to their baby’s birth, at least once from early pregnancy to four years post-partum (MCRI, 2014). These findings indicate that pregnancy can be a period with elevated emotional support needs for a woman. Specialised psychosocial monitoring and support may therefore be beneficial throughout pregnancy as well as in the post-partum period and the longer term, to manage distress and prevent psychological damage to mother and child and their fundamental relationship (Dennis, 2014; Ohoka et al, 2014).
1.3 Pregnancy-Associated Breast Cancer (PABC)

The implications of pregnancy-associated breast cancer relate to women of child-bearing age, and this age group is defined here as between 20-49 years of age (ONS, 2016). Healthcare professionals, including medical and clinical oncologists, obstetricians, nurses and midwives, but excluding counselling psychology practitioners, are hereafter termed HCPs.

PABC

Pregnancy-associated breast cancer (PABC), sometimes also called ‘gestational’ or ‘pregnancy-related’ breast cancer, is defined as the diagnosis of any type of breast cancer during pregnancy and up to one year post-partum (Doger et al, 2011, Azim et al, 2010, Voulgaris et al., 2011). Research shows that PABC is generally more advanced at diagnosis (Ulery et al, 2009), the cancer types are typically more aggressive, and the disease has statistically worse prognosis and a worse outcome than the diagnosis of breast cancer in non-pregnant women, although this last finding is debated (Amant, 2012a; Azim et al, 2012; McCready et al, 2014; Stamatakis et al, 2011). Because of the pregnancy, the condition occurs at an especially sensitive time for the diagnosed person, physically, emotionally and developmentally (Brennan, 2011; Stamatakis et al, 2011).

Complexity of treatment

PABC presents both therapeutic and ethical multidisciplinary challenges for clinicians and their patients (Córdoba et al, 2013). Treatment measures which balance optimal treatment for the pregnant woman with the minimization of harm to the developing foetus, are being increasingly researched (Albright et al, 2016; Becker, 2016; Oduncu et al, 2003), and a main goal of physicians is to offer pregnant women diagnosed with breast cancer the same or similar treatment and medical care to non-pregnant women (Becker, 2016; Paul, 2008; Morice et al, 2012). The Royal College of Obstetricians and Gynaecologists published their most recent clinical guidance for the treatment of breast cancer in pregnancy in March 2011 (RCOG, 2011). Here, they acknowledge the limited clinical recommendations and supporting evidence, and emphasise the importance of a multidisciplinary approach. Surgery and chemotherapy are generally deemed safe for the fetus after the first trimester (radiotherapy is not), and preterm delivery is now known to be unnecessary in most cases depending on individual diagnosis (Amant et al, 2015; Amant et al, 2012b; Guidroz et al, 2011; Sánchez Martínez and Ruiz Simón, 2010). Questions about the need to terminate the pregnancy seem less prevalent in recent literature (Molckovsky and Madarnas, 2008; NY Times, 2015) as termination is deemed to not improve maternal outcome (Amant et al, 2012; Cardonick et al, 2010; Rovera et al, 2013). However, some oncologists still advise pregnant
women to consider a ‘therapeutic abortion’ and terminate upon diagnosis (Amant et al, 2012; Mayer, 2000). Albright et al (2016) report that even though both surgery and chemotherapy have now been deemed safe to administer to a pregnant woman, ‘the majority of healthcare providers taking care of pregnant women with malignancy prefer preterm delivery despite the neonatal consequences’ (p.7). The authors also state that elected preterm delivery is performed in more than 70% of cases (across several cancer types, with maternal malignancy, as opposed to obstetrical indication, as the reason in over 76%)\(^1\). There is therefore some evidence that a majority of oncology HCPs encourage women diagnosed with cancer in pregnancy to allow an elected preterm delivery in order to simplify and maximise treatment, and minimize risk to the adult patient (Han et al, 2013). This may be understandable, as the main threat to both lives is cancer, and this must therefore be planned for and typically dealt with first. However, a preference for elected preterm delivery (or even termination) could also be ascribed to the rarity of PABC, and HCPs subsequent relative inexperience in treating the condition (Becker, 2016). Historically, therapeutic abortions after a cancer diagnosis were the norm, as pregnancy hormones were thought to aggravate the disease (Theriault and Litton, 2013). In the past, the fetus was not a patient, and is still legally a ‘non-person’, although as mentioned, it has obtained considerable more status as such in recent decades (as have the respect for, and encouragement of, the autonomy of the pregnant patient).

Psychosocial impact of PABC

Whilst there is ample research into the experience of parenting, motherhood and illness, existing literature on psychosocial aspects of PABC is extremely sparse. Most studies focus on the complexity of the medical physiological treatment of the cancer whilst minimizing effects on the fetus (Azim et al, 2010; Voulgaris et al, 2011). However, with rising incidence rates, wider attention is starting to be paid, and breast cancer during pregnancy has recently been considered a ‘hot topic’ amongst cancer specialists (The Royal Marsden, 2010) including practitioner psychologists. Most inquiry into cancer during parenthood has focused on the psychosocial impact on children, of their mother’s condition, as opposed to the mother’s experience (Bultmann et al, 2014; Gross, 2013; Krattenmacher et al, 2012; Turner, 2004; Wilson, 2007).

A recent quantitative study carried out by researchers involved in keeping a US registry of pregnant cancer patients (cancerandpregnancy.com), not only found that cancer diagnosed during pregnancy can have a long-term negative psychological impact, but also that the number of pregnant cancer patients who are identified as clinically distressed is nearly 20% higher than

\(^1\) For participants’ demographics, including weeks of gestation at diagnosis and at birth, see Chapter 2, Table 1.
that of non-pregnant cancer patients (Henry et al, 2012). Findings from this study also included identification of specific risk factors for long-term psychological distress for pregnant cancer patients. Indications were that women were at higher risk of experiencing long-term psychological distress if a) they had not had fertility treatment for the pregnancy, b) they had been advised to terminate the pregnancy, c) they had had a Caesarean section, d) they had had a pre-term birth, e) they had not produced enough milk to breast feed, f) they were experiencing a recurrence of the cancer, and g) they had had surgery after the birth (Henry et al, 2012, p. 448).

These risk factors were not explored qualitatively, but were described as markers for HCPs to use in making referrals for psychosocial support. The authors found that over 50 per cent of the women remained clinically distressed nearly four years after diagnosis. This compares to only 15 per cent of non-pregnant women remaining distressed at one year after their diagnosis (Burgess et al, 2005).

A recent qualitative study was conducted which investigated women’s experiences of PABC. In Australia, fifteen women were interviewed in a study carried out by a team of medics (Ives et al, 2012; Ives et al, 2005). The study used a grounded theory approach, and important findings included the identification of a very high and pervasive level of anxiety felt by the participants throughout their experience. Conflicting concerns about their own and their baby’s health, treatment effects disrupting normal maternal function, and the diversity and individuality of experiences were other noteworthy themes. Whilst the findings of this study are valuable, the study appeared to register the areas of concern, and did not explore participants’ experiences in depth, including what meaning these experiences held for individual participants. In addition, only four participants were pregnant at diagnosis. Data collection, in the form of interviews, was carried out by a breast cancer research nurse, and as medical professionals, the researchers appeared somewhat ‘distant’ from the data.

Pregnancy and cancer are major life-changing events for individuals and families (Brennan, 2004; Mercer, 2004). When they occur simultaneously we can expect emotional and psychosocial stressors to be greatly amplified (Harrison, 2013). Bylewski (2012) explains how being diagnosed during pregnancy is a confusing emotional experience, characterised by a paralyzing fear and panic. Speaking from clinical experience, psychologist Schover (2000) describes clients’ experience of cancer during pregnancy as a psychosocial as well as a medical crisis. In particular, the interruption of the normal process of adjusting emotionally and cognitively to pregnancy, and the unanticipated and sudden contrast between the focus on hope for the future versus confronting fears about death in the present, may lead to severe emotional turmoil and distress.
Schover also describes additional causes for distress as the ‘damaged’ expectation of a life enriched by a new baby, the child’s long-term healthy development, and fears about the impact on other children as well as about recurrence and future fertility. The notion and fear of termination itself can present the diagnosed woman with complex questions involving spirituality, ethics and personal values, and cause severe distress (Mayer, 2000). Paul (2008) suggests that the anger and bitterness about being betrayed by your own body at the most crucial time is a meaningful psychological issue, and that exposure to other expecting women and new mothers is extremely isolating for the PABC patient - ‘You’re the person nobody wants to be’ (online).

As a practitioner psychologist Brennan (2004 and 2011) suggests that coping with the uncertainty and the threat to motherhood and bonding are key issues for pregnant women with breast cancer. Also, conflicting emotions of joy, hope and positive expectation versus horror, fear and disillusionment are likely to cause high levels of stress and confusion. Zanetti-Dällenbach et al (2006) describe the inner conflict between a growing life and a threatened life, and how medical decisions can induce outer conflict between patients and HCPs, as everyone has different roles, perceptions and agendas. Bandyk and Gilmore (1995) present a list of perceived concerns for women who had chemotherapy for breast cancer whilst being pregnant, ranked in order of importance, with the first being ‘living to see my child grow up’, and others being about the long-term effects of treatment on the unborn child. The authors call for further research into concerns of pregnant women with breast cancer so that appropriate supportive interventions can be developed. The balance of medical treatment and the health of the unborn child seem to be a main worry for women who are pregnant with breast cancer. Dean (2007) emphasizes how the physical effects of the treatment can add to the stress of being a new mother, and that the psychological impact of having a mastectomy can disrupt the occasionally very fixed perceptions of being a mother (who breast feeds).

The few existing qualitative studies on PABC suggest that many, if not all, patients report that their experience has a positive as well as negative impact on their life, at diagnosis and throughout the period of treatment and afterwards, as life continues for them as individuals and as families (Ives et al, 2012; Schover, 2000; Zanetti-Dällenbach et al, 2006). Often, emotional resilience sets in to balance the felt devastation of the situation. Paul (2008) posits that patients feel that the pregnancy creates a necessity for living, and thereby an enhanced and essential motivation to survive, as well as a sense of a real and reciprocal protection between mother and fetus. Many women feel that the experience of having cancer makes them better and stronger individuals and better parents (Schover et al, 1999). Long-term survivors report that the
experience enables a degree of personal growth and development that is highly valued, and often makes the entire experience acceptable.

Other existing qualitative research on the topic of experiences of PABC is limited to case studies (e.g. Ferrere ad Wendland, 2013; Wendland, 2009), and can appear descriptive and unevidenced. Until now, no qualitative ‘insider’ research of the PABC experience has been conducted which present practitioners with sufficient details of the critical and distressing issues concealed in patients’ experience.

1.4 Support and counselling needs of patients and families

There is an evolving evidence base for the value of psychological intervention for people with cancer and their families (BPS, 2015; NICE, 2004). A range of individual models of therapy (e.g. psychotherapy, CBT, CAT, mindfulness, relaxation etc.), and group and couple/family models of therapy are now offered in many psycho-oncology services (NICE, 2004; Watson and Kissane, 2011). Omylinska-Thurston and Cooper (2014) have identified a range of helpful processes in psychological therapy for patients with primary cancers. These include talking about and expressing feelings to someone outside of one’s immediate social environment, forming a relationship with a non-judgemental therapist, normalisation of emotions through the therapist’s expert knowledge and experience, gaining an understanding of behaviour and coping patterns, relief through off-loading, problem-solving in the management of fear of recurrence, and cognitive behavioural techniques for identifying and challenging distressing thoughts, and activity scheduling. In another recent study, Bylewski (2012) emphasizes how psychotherapy can facilitate the development of coping strategies in several ways, such as being able to talk about your diagnosis with a HCP, help with communicating a diagnosis to other children and family members, and provide support in peer groups and for family members.

Some intervention studies have found that offering psychosocial counselling support to women diagnosed with breast cancer earlier (immediately after diagnosis) has a greater positive effect in reducing distress, than when the same support is offered later, and that a delay can make a significant difference to the outcome (Vos, et al, 2006). By contrast, other studies have found that earlier intervention does not mean better intervention, and that psychological and emotional needs and support should be carefully assessed and planned, as outcomes may depend on the stage of treatment (Baker et al, 2013). HCPs should have the ability and opportunity to identify early on in the patient’s cancer journey if someone is at risk of experiencing persistent
psychological distress (Henry et al, 2012). Detecting these patients early on, and assessing their individual psychosocial needs, may help treatment outcome and prevent, or treat, mental distress.

The National Institute for Health and Care Excellence (NICE) clinical guidelines recommend that people affected by cancer should be offered ‘a range of physical, emotional, spiritual and social support’ (NICE, 2004). The National Health Service (NHS) offers all cancer patients in the UK a cancer ‘Recovery Package’ adapted to the individual patient, and this can include psychological assessment and intervention by specialist psychology practitioners working within local psycho-oncology services (NHS, 2016). Routine screening for psychological problems is not commonplace, and most patients are referred to psycho-oncology services via their HCPs (MacMillan, 2011). These services offer direct clinical care for patients and their families to address distress, coping and adjustment, as well as involvement of oncology-HCPs through training and consultation (NICE, 2004). Training of HCPs is imperative, as immediate and upfront psychological support for patients in NICE’s four-level psychosocial care model (Figure 1 below) is provided by doctors, nurses, and allied health professionals at levels 1 and 2. Only at level 3 and 4 do specialist psychologists offer direct patient contact (Grassi and Watson, 2012; MacMillan, 2011).

Currently, guidance for practice at level 3 in the above-mentioned model (see Figure 1) suggest that cancer patients with mild to moderate needs receive psychological interventions such as ‘anxiety management and solution-focused therapy’ (NICE, 2004, p. 80) in response to worries, cancer-related impact on relationships, and spiritual and existential issues. Level 4 interventions, such as counselling and Cognitive Behavioural Therapy, are directed at patients’ more severe mental health problems, including affective disorders, personality disorders, psychosis and substance abuse. NICE calls for further research into which psychotherapeutic interventions are most effective, as ‘an eclectic mix’ (p. 83) of both individual and group interventions is currently applied, but recommend that these must be individually adapted, and the therapeutic approach directed by patient preference. Patients’ needs for ‘privacy and comfort’ (p.81) must be considered, and home visits facilitated where appropriate. Importantly, NICE asserts that information about psychological assessment and intervention should be formally shared within multidisciplinary teams and practitioners, to allow consideration of patients’ mental health issues, and impact of illness and treatment.
Figure 1. NICE recommended four-level model of professional psychological assessment and support for adults with cancer.

<table>
<thead>
<tr>
<th>Level</th>
<th>Group</th>
<th>Assessment</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>All health and social care professionals</td>
<td>Recognition of psychological needs</td>
<td>Effective information giving, compassionate communication and general psychological support</td>
</tr>
<tr>
<td>2</td>
<td>Health and social care professionals with additional expertise</td>
<td>Screening for psychological distress</td>
<td>Psychological techniques such as problem solving</td>
</tr>
<tr>
<td>3</td>
<td>Trained and accredited professionals</td>
<td>Assessed for psychological distress and diagnosis of some psychopathology</td>
<td>Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework</td>
</tr>
<tr>
<td>4</td>
<td>Mental health specialists</td>
<td>Diagnosis of psychopathology</td>
<td>Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)</td>
</tr>
</tbody>
</table>

Reproduced with free permission for educational purposes from NICE (2004) *Improving Supportive and Palliative Care for Adults with Cancer*, p. 78.
Cancer affects the patient and their family, however support services for families and carers are patchy, and needs often go unrecognized by HCPs (NICE, 2004). NICE recommends that family members and carers are involved in discussions about treatment, and that they are given access to information about support available to meet their own needs. This may include the offer of support groups, practical support (e.g. help with transport, maintaining the home, financial and workplace matters, and caring for dependent children) and family education programmes.

The NICE guidelines demonstrate that the support and counselling needs of breast cancer patients are increasingly acknowledged and understood in the healthcare professions. However, patients’ needs may in practice not always be met by an organised multidisciplinary healthcare team (Department of Health, 2007; NICE, 2002). A clinical nurse specialist may provide valued emotional support to cancer patients (Department of Health, 2011), but as a nurse, she/he may neither have the required training nor access to appropriate supervision support herself/himself (Brennan, 2004). Similarly, research has indicated that oncologists are not effective at identifying patients’ psychological distress, and that patients do often not believe it is a doctor’s role to help with emotional concerns (Söllner et al, 2001; Bogaarts et al, 2012). As a consequence many patients who need and want psychological support may not currently be referred.

In summary, breast cancer patients who are pregnant at diagnosis have particular psychological, social and informational needs. Understanding these needs can enable HCPs to develop the appropriate care, support and psychosocial interventions so that the quality of life of the patient and the family is positively maintained. This is important to help prevent the development of affective disorders, the potential disruption to the maternal bonding between mother and child, ruptures in the parental relationship, and problems with everyday coping. Published reports show that, in general, additional psychosocial support roles in cancer treatment are cost-effective, with savings being achieved in areas such as reduction in emergency beds, appointments and GP visits (Department of Health, 2011).

1.5 The current study

Insufficient research has been conducted into the qualitative experiences of pregnancy-associated breast cancer in the UK. Quantitative data does not explore the diversity of experiences, meanings and attitudes (McLeod, 2003), which are essential in order that appropriate and acceptable interventions may be developed. Knowledge and understanding of the experience of breast cancer diagnosed during pregnancy is of practical benefit to psychology practitioners
working with this group of clients, in building empathy for their clients, helping them to recognise the psychological impact, and address the particular needs which result from their condition (Ferrere and Wendland, 2013; Wendland, 2009). In addition, understanding the experience can help practitioners identify relevant theories and techniques in thinking about interventions to use in their work (Ives et al, 2016).

As an ‘insider’ study (see Chapter 2, section 2.9 and Appendix 11) with a counselling psychology perspective, the current research goes beyond the recording of themes, and dives deeper into the sense and meaning of the experience. Findings present an enhanced understanding of the phenomenon, the lived experience of the participants, and the wide range of relational factors involved in supporting women who experience breast cancer during pregnancy.

This qualitative study used semi-structured interviews to explore in-depth and create further understanding of the experiences of women in the UK who were diagnosed with breast cancer whilst they were pregnant. The value of this understanding lies in practitioners’ and HCPs’ ability and opportunity to identify early on the PABC patients who are at risk of experiencing persistent long-term psychological distress. In addition, there may also be important learning to derive from exploring what these vulnerable people make of their experience, and how they cope with the high level of anxiety and uncertainty they are facing. This information could help tailoring counselling approaches and psychological support to meet the needs of this growing population of women.

The objectives were:

- To explore the experiences of women who were diagnosed with breast cancer whilst they were pregnant, including factors that may make these experiences unique to the condition.
- To identify the challenges that women with PABC face in the long-term management of the psychological impact of the condition.
- To create a broad understanding of the experience of pregnancy-associated breast cancer to function as a guide for more focused future research into the psychological implications of the condition.
- To give a voice to this population of potential service users, and to make this narrative available to professional psychology practitioners, as well as other healthcare professionals working with PABC patients and their families.
Chapter 2    Methodology

2.1    Research design

Counselling psychology practice and research has helped promote the inclusion of qualitative inter-subjective accounts into an extended scientist-practitioner model of human psychology (Woolfe et al, 2010). This development has implications for both ontology and epistemology of recent qualitative research including the question of whether this research can now be considered a ‘scientific’ enterprise, carried out on the basis of observational, analytical and evaluative evidence (Corrie, 2010). With this in mind, the main motivation for the current research project was that of being relevant to counselling psychology practice, and of giving a voice to a growing population of women experiencing a rare but challenging phenomenon that has remained without presence in the counselling psychology literature.

The current research project used a qualitative methodology to explore participants’ accounts of their experiences of having breast cancer diagnosed whilst being pregnant or immediately after giving birth. The qualitative design was intended to enable an in-depth exploration of individual participants’ lived experience including their understanding and meaning-making of the phenomenon being investigated. Thus, the study was interested in original accounts of personal experiences. Interpretative phenomenological analysis (IPA) was considered the most appropriate methodology, as this method is an effective approach when a) the topic is under-researched, b) when there is novelty and complexity, and c) when there are issues relating to identity and sense-making (Smith and Osborn, 2015). In addition, IPA is considered particularly suitable for investigating experiences of illness (Smith, 2011; Smith et al, 1997), and for giving a voice to a specific group of individuals, which was part of the aim of this research. Due to the limited volume of existing research on the topic, the study was intended to have the additional function of guide for future research.

Ontology, Epistemology and IPA

IPA is an analytical method based on the principles of the philosophy known as Phenomenology (Smith et al, 2009). Phenomenology is concerned with people’s view of the world and their lived experiences, as explored from an ‘insider’s’ perspective (Smith et al, 1997) (see also section 2.9). The IPA approach is concerned with the cognitive, linguistic and affective aspects of what people say, and how they might assign meaning to their experiences (Smith and Osborn, 2015). IPA considers the participant to be the expert on the experienced phenomenon, and the participant is
encouraged to use their own words in the creation of a detailed description of the understanding and felt sense of the experience (Reid et al, 2005). IPA will allow for the expression of the individuality of each case as well as the shared experiences, and create a subjective but transparent account of the phenomenon (Lawthom and Tindall, 2011). This is important to counselling psychology as most professionals working with cancer patients have leaned towards a biomedical and behavioural model, which neglects the importance of the subjective experience of the patient and engages little with them in understanding their inner world (McLeod, 2005). By employing this method to explore the phenomenon of breast cancer during pregnancy, it was expected that the results would reveal diverse psychological experiences. The method is congruent with the practice of counselling psychology itself, where respectful inquiry and intersubjective understanding form the basis of any therapeutic treatment and intervention designed to help an individual make meaning of, and adjust to, adverse experiences (Barua and Das, 2014; Smith, 2004; Woolfe et al, 2010).

As a counselling psychology study, one motivation for this research was the improvement of the psychological experience for the patient and her family of having breast cancer whilst being pregnant. In order to help develop and tailor the best counselling approaches and psychological support, the phenomenon of PABC should be understood from a counselling perspective, with a focus on the facilitation of change through therapeutic dialogue. The result of a phenomenological interpretation becomes a narrative of participants’ experiences, and as such the epistemology is that of a socially constructed understanding (rather than an explanation) of the topic investigated (Smythe and Murray, 2000). IPA involves the ‘double hermeneutic’, a situation where the researcher is interpreting the participants’ own interpretation of the experience in a dual role, similar to that of a counsellor who shows empathy at the same time as she questions the understanding (Smith et al, 2009).

### 2.2 Role of the researcher in the IPA research process

IPA becomes phenomenological through the detailed exploration of participants’ ‘lifeworld’, i.e. the ways they perceive and make sense of their personal and social world (Smith and Osborn, 2015; Husserl, 1970, cited in Langdridge, 2007). The researcher is the medium through which an understanding of this lifeworld is generated, and the researcher adds the interpretative element to the approach in an interactive process (Willig, 2008). Access to the participants’ lifeworld is, however, essentially complicated by the researcher’s own experiences, assumptions and preconceptions (Heidegger, 1962), and this must be explicitly examined and acknowledged in the
outcome of the research activity (Smith and Osborn, 2015). This study can be described as ‘insider’ research in that the researcher herself experienced having breast cancer during pregnancy, and thus belongs to the population being studied herself. As such, she has direct personal involvement and connection with the research setting (Rooney, 2005) and multiple commonalities with the participants (Adam, 2012; Chavez, 2008). See also section 2.9 and Appendix 11).

Reflexivity, defined as an ‘explicit evaluation of the self’ (Shaw, 2010, p.234), is central to ‘insider’ research where it enhances validity of interpretations (O’Connor, 2004) through the awareness and understanding of the researcher’s subjectivities and bias in relation to the topic researched (Hall and Stevens, 1991). Reflexivity discourages presumptions and encourages the researcher to seek clarification directly from the participants (O’Connor, 2004). This makes for a solid connection to the method of IPA which aims to obtain an ‘insider’s perspective’ (Larkin, Watts and Clifton, 2006). Reflexivity in IPA is important to manage potential problems in interpretation (Clancy, 2013) such as influences that affect data analysis and other parts of the research process.

To meet the requirement of examining and acknowledging the researcher’s ‘insider’ status and its effect on the outcome, this study contains reflections on positionality (section 2.9 and Appendix 11).

2.3 Rationale for chosen methodology

At the design stage for this project several considerations about approach and methodology were made in relation to the research question.

Using a qualitative rather than a quantitative method
This study aimed to explore and understand the experiences of women who were diagnosed with breast cancer whilst they were pregnant. The aim was to build insight into the phenomenon of pregnancy-associated breast cancer (PABC), which would be contributory to the field of counselling psychology as well as a wider audience including healthcare professionals (HCPs). The literature on the subjective experience of PABC is sparse, and so far, predominantly authored by physicians. It is expected that this unique study will fulfil the objective of adding significantly to this literature whilst functioning as a directional basis for future research. For this purpose, the study required flexibility in its search for meanings, perspectives and understandings, and in its approach to the findings. Qualitative methodology offers this flexibility, and is sensitive to a high
level of diversity in the data set. Quantitative data is not often suited nor designed to reveal the diversity of people’s experiences, attitudes and their individual coping mechanisms (Avis et al, 2004). The voices of the population investigated are individual and highly knowledgeable about their first-hand experience of the phenomenon in question. Therefore, an idiographic rather than a nomothetic approach was required.

Rationale for choosing IPA

Whilst it was apparent that a qualitative methodology was most useful for exploring the complexity of the experience of PABC, the exact type of qualitative method was deliberated. Specific methods within qualitative research will produce specific types of data. Braun and Clarke (2006) advise that the researcher identifies the type of data required to answer the research question, and balances this with the theoretical framework and method in an explicit decision making process.

Two alternative and well established qualitative methods were considered before settling on IPA, namely grounded theory (GT) and thematic analysis (TA). Grounded theory shares much of its terminology and systematic data analysis procedure with IPA (Charmaz, 2014; Smith, 2015). Grounded theory ‘lite’ (Braun and Clarke, 2006) was used in the pilot study (Appendix 12), where the time frame was tight, and data could rapidly be collected from multiple sources. However, whilst GT is suitable for the generating of an original substantive theory of the social processes taking place in the context of a phenomenon, IPA specifically addresses people’s everyday experience of reality in order to facilitate in-depth understanding of the phenomenon (Langdridge, 2007; Willig, 2012). This matched the aims of this study and was why IPA was chosen over GT.

Another method considered was that of TA, which is flexible and can produce similar end results to IPA (Larkin, Watts and Clifton, 2006). However, as a technique, TA was considered insufficient for the methodological framework, and offering little guidance on how to determine ontological and epistemological underpinnings, theoretical framework, sampling and data collection. Whilst TA looks for patterned meaning across participants’ data, IPA has a dual focus on the unique experience of individual participants, as well as patterned of meaning across participants. With a relatively large sample, the concern was that using TA, results would be further from the actual data, more descriptive and less interpretative than preferred (Braun and Clarke, 2006).

2.4 Data collection

In light of the researcher’s previously utilized data collection method for the pilot study (see
below), consideration was given to several data collection methods. It was clear that in order to meet the objective of understanding participants’ lived experience, the data collection method needed to be flexible, facilitate understanding and allow for clarification. Semi-structured individual interviews were chosen as the appropriate method (Smith and Osborn, 2015), as these are deemed suitable for exploratory aims and under-researched topics (Smith et al, 2009). Eatough and Smith (2008) describe semi-structured interviews as the exemplary method of data collection for IPA studies, and as face-to-face meetings, they typically aid the building of a trusting rapport between participant and researcher.

Focus groups may have been a viable alternative for data collection, and this was considered, but ruled out on the basis of practical logistical difficulties of locating and recruiting participants who would be able to get together for a group. Other potentially problems would include group dynamics where some participants may exert influence over others, and conformity and inhibition of expression may impede disclosure (Wooten and Reed, 2000).

Piloting
The researcher conducted earlier research (Rodsten and Jenkinson, 2013) on the topic of the psychological impact of PABC but used a different qualitative method, namely Grounded Theory, as described by Charmaz (2006). This was a smaller-scale feasibility study, where open-ended questionnaires were completed online by six women who self-identified as having had breast cancer whilst being pregnant. Participants were selected from a purposive sample and recruited through a range of websites relating to cancer and motherhood, as well as Facebook. Grounded theory ‘lite’ (Braun and Clarke, 2006) was chosen as method of data analysis due to the under-researched nature of the topic and the perceived difficulty in recruiting participants directly. This method does not require as stern a theoretical commitment as Grounded Theory ‘proper’, and is therefore appropriate for a study with a very limited time frame such. The method was suitable for generating an original substantive theory on the basis of data type, and on a topic where no such theory had previously been published. The data confirmed that having breast cancer whilst being pregnant generated unique experiences, and had a profound and personal psychological impact on the lives of the participants and their families. From the data, a theory was developed of how these women constructed their experience in a sequential manner (see Appendix 12).

The Research instruments
A topic guide and interview schedule (Appendix 6) was developed based on the literature and findings from the researcher’s pilot research, on the research question and on the specific areas
which the researcher wished to explore with the participants, such as relational themes at the time of diagnosis and after.

The schedule listed a number of broad open-ended questions and prompts, which was used to elicit narratives concerning:

- What were participants’ experience and understanding of their individual concerns during the first year following diagnosis?
- What were participants’ experience of the impact on the relationship with their newborn baby, their close family, amongst friends and in their local community?
- What were participants’ perceptions of the uniqueness of the situation in which they found themselves?

The interview schedule was used as a basis for conversation and not applied prescriptively. It was designed to assist participants to communicate salient aspects of their experience without being suggestive, and was adapted and tailored as each interview progressed, including adding closed questions to clarify and construct coherency in the data (Booth and Booth, 1996).

The other research instrument used in data collection consisted of a basic demographical information page designed to record details including current age, time since diagnosis, PABC pregnancy number and total number of children, gestation at diagnosis and at giving birth, parental relationship changes, details of treatment and current health, self-reported social class and self-reported ethnic origin (see Table 1).

2.5 Participants

Sampling
The study focused on women, aged 18+ years and living in the UK only, in order to maximise the likelihood that participants had shared experiences. The sample was as homogenous as possible and presented a perspective of British women’s experiences of PABC. It was expected that a minimum of eight women who had personal experience of being diagnosed with PABC would be recruited for this study. However, it was anticipated that around 10 interviews would be conducted, allowing for follow-up on particular issues and providing clarifications where required. For professional doctorates, Smith et al (2009) recommend between four and ten interviews (with an equal or lower number of participants) as a maximum when using IPA, so that the analysis can be given time and scope for appropriate reflection and dialogue.
Inclusion criteria
Participants were women living in the UK who self-reported as having been diagnosed with breast cancer whilst they were pregnant, or within one year of giving birth. Participants were typically two-to-five years post diagnosis. The aim was to ensure that participants had had time to recover from their illness and from treatment effects, and that they had had opportunity to reflect on their experience. Cancer patients can be reluctant to acknowledge and address emotional aspects of their experience when recently diagnosed (Baker et al, 2013). Participants were all over eighteen years of age.

Exclusion criteria
Participants who were still in active treatment for primary breast cancer were excluded. This was due to the risk of being psychologically too vulnerable with regards to addressing prognosis and recovery in the short term. It was also considered that they would be too immersed in survival and physical treatment issues, and therefore not having yet made much meaning of their overall experience of PABC (Baker et al, 2013). Participants who did not speak or understand English were excluded, as no translation services were offered.

Recruitment
Participants were selected from a purposive sample for their personal experience of having breast cancer diagnosed whilst being pregnant or within a year of giving birth. Women who self-identified as having experienced PABC but were no longer in active treatment were invited to take part via letter (Appendices 2 and 3) or via online promotion, in accordance with the inclusion and exclusion criteria. Participants invited by letter had either participated in the pilot study and agreed to future contact, or they were located through recent feature articles concerning their experience of PABC in public media.

Recruitment of most participants took place through online channels including the online chat forum of the charity Breast Cancer Care, and directly via the charity Mummy’s Star. Permission to promote the study and to recruit was sought and received from both Breast Cancer Care and Mummy’s Star administrators who were informed of the aim, purpose and format of the project. The study had its own Facebook page (Pregnant With Cancer UK), Twitter account (https://twitter.com/JMRodsten) and blog (http://jmrodsten.wordpress.com) for promotional and recruitment purposes, and information about the project and participation was available there, as well as upon request. The feasibility of recruiting sufficient participants using this method had previously been demonstrated via the pilot study where six women who agreed to
take part in an online survey were recruited over a three-month period.

Potential participants expressed their interest in the project by emailing the researcher. The researcher then provided information about the purpose, aim and format of the study, explaining the interview procedure, and assessed initially for competence to give valid consent. An interview date and time was then agreed, and confirmation and further information was emailed back.

Participant demographic information
The current study collected eleven interviews from the equivalent number of participants, and this was ample for the researcher to explore and compare accounts without being overwhelmed by the amount of data present (Smith et al, 2009). A table of participants’ relevant demographic information is presented below. All names have been changed in accordance with participants’ limitations of consent in order to preserve anonymity.
Table 1. Participants’ demographic information

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Time since diagnosis</th>
<th>PAEC pregnancy no. / total no. of children</th>
<th>WEEKS of gestation @ diagnosis / when giving birth</th>
<th>Healthy baby at birth?</th>
<th>Marital changes since diagnosis</th>
<th>General health Self-reported</th>
<th>Social class Self-reported</th>
<th>Social class</th>
<th>Ethnic origin/race Self-reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Katie</td>
<td>44</td>
<td>11 yrs 8 mths</td>
<td>2/2</td>
<td>16/32</td>
<td>Yes</td>
<td>None</td>
<td>Good</td>
<td>High working / Low middle class</td>
<td></td>
<td>White British</td>
</tr>
<tr>
<td>Lorna</td>
<td>38</td>
<td>2 yrs 9 mths</td>
<td>1/1</td>
<td>30/34</td>
<td>None</td>
<td>Partial loss of hearing</td>
<td>Stable 2ndary BC</td>
<td>Middle class</td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Chrissy</td>
<td>37</td>
<td>2 yrs 2 mths</td>
<td>3/3</td>
<td>28/35</td>
<td>Yes</td>
<td>None</td>
<td>Stable 2ndary BC</td>
<td>Working class</td>
<td>British</td>
<td></td>
</tr>
<tr>
<td>Jane</td>
<td>38</td>
<td>4 yrs 11 mths</td>
<td>2/2</td>
<td>22/34</td>
<td>Yes</td>
<td>None</td>
<td>Good</td>
<td>Working class</td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Nadine</td>
<td>32</td>
<td>4 yrs</td>
<td>1/1</td>
<td>-/40</td>
<td>Yes</td>
<td>None</td>
<td>Stable 2ndary BC</td>
<td>Don’t know</td>
<td>White</td>
<td>Don’t know</td>
</tr>
<tr>
<td>Corinne</td>
<td>48</td>
<td>12 yrs 6 mths</td>
<td>2/2</td>
<td>5/40</td>
<td>Yes</td>
<td>None</td>
<td>Good</td>
<td>Don’t know</td>
<td>White English</td>
<td></td>
</tr>
<tr>
<td>Rebecca</td>
<td>37</td>
<td>7 mths</td>
<td>2/2</td>
<td>-/40</td>
<td>Yes</td>
<td>None</td>
<td>Good</td>
<td>Middle class</td>
<td>Welsh</td>
<td></td>
</tr>
<tr>
<td>Anna</td>
<td>38</td>
<td>11 mths</td>
<td>2/3 (twins)</td>
<td>24/35</td>
<td>Yes</td>
<td>None</td>
<td>Good</td>
<td>Middle class</td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Daisy</td>
<td>33</td>
<td>5 yrs 9 mths</td>
<td>2/3</td>
<td>12/33</td>
<td>Yes</td>
<td>None</td>
<td>Good</td>
<td>Working class</td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Rita</td>
<td>37</td>
<td>1 yr 6 mths</td>
<td>4/4</td>
<td>11/40</td>
<td>Yes</td>
<td>None</td>
<td>Good</td>
<td>Middle class</td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Linda</td>
<td>33</td>
<td>4 yrs 9 mths</td>
<td>1/1 (pregn.)</td>
<td>30/35</td>
<td>Yes</td>
<td>None</td>
<td>Very good</td>
<td>Working class</td>
<td>White</td>
<td></td>
</tr>
</tbody>
</table>
2.6 Procedure

Ethical considerations

Ethical approval
Ethical approval for this study was sought from the University of the West of England Faculty Research Ethics Committee (FREC). No NHS approval was required as recruitment was direct and private, and no data collection took place through NHS channels. The study was granted ethical approval on 2nd April 2014 subject to conditions being observed (Appendix 1), including minor changes to the participant information sheet (Appendix 4) and suggestions for interview location.

Consent process

Informed consent
A respect for consent sets standards of respect for the relationship between researcher and participant (The Research Ethics Guidebook, 2016). Valid consent requires that research subjects are informed fully about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks may be involved. In addition, participants must participate voluntarily, free from any coercion (BPS, 2016). All participants were over 18 years and self-selected to take part. On initial contact, the researcher engaged with participants in communication about the study, sensitively enquiring about the participant’s relevant personal circumstances and explaining the study’s overall aims and format. This communication was a first assessment of the participant’s competence to consent, and involved informal assessment of ability to understand and decide, being sufficiently informed and having the autonomy to make a decision to take part (or not), and depended on the researcher’s judgment (The Research Ethics Guidebook, 2016). The suitable participants were then emailed a participant information sheet (Appendix 4). Upon meeting for interview, participants were again assessed face-to-face for competence. This involved the researcher assessing cues and body language of the individual, using simple language when providing information, and allowing the participant time to process this information and to ask questions. Strategies for determining competence were a high level of engagement (appearing eager to tell their story, and talking about the purpose of taking part), and affirmative non-verbal responses such as eye contact and nodding. A consent form was then discussed and signed by the participant who retained a copy (Appendix 5).

Right to withdraw
Participants were informed about their rights to withdraw when meeting the researcher at
interview, including rights to withdraw specific parts of their data should they wish to do so. The Participant Information Sheet contained details of participants’ right to withdraw their participation from the study, including the limitations of withdrawal.

Confidentiality
Participants were informed (via the Participant Information Sheet and upon meeting at interview) that all data would be anonymised and kept confidential. The limitations, including the sharing of data in anonymised form with supervisors, were explained to participants by the researcher.

Interview process
All eleven interviews were conducted by the researcher, eight of these in the participant’s homes, two in a hotel meeting room, and one in the home of a friend of the participant. Upon meeting, the participants were thanked for agreeing to take part, and asked about receiving the Participant Information Sheet. The aim and format of the study were explained, and the participant assessed according to the inclusion/exclusion criteria. The participants were then given opportunity to ask questions. The digital audio recorder was started, and the interview commenced.

Participants were asked to provide basic demographic information at each interview (Table 1). Participants were then asked mainly open-ended questions in order to obtain detailed individual accounts of their experiences. The duration of the interviews ranged from approximately one to two hours. Upon ending the interview, the participant was thanked for their participation, and given the opportunity to provide further comments and ask questions.

Risks and risk management
The risks involved in carrying out this study were assessed as relatively low. However, conducting qualitative research has “considerable potential of inducing negative psychological states” (Hadjistavropoulos and Smythe, 2001, p.163), and it was recognised that there was a risk of the participants suffering emotional distress as a result of talking in detail about their autobiographical experience. Much qualitative research essentially works with an open-ended methodology as new questions and issues emerge during the data collection process. This presents the potential risk that content will come up which the researcher and the participant have not been preparing to talk about, including sensitive information and details of traumatic experiences. Smythe and Murray (2000) highlight the narrative ownership, i.e. who has control over the interpretation and presentation of data, as an ethical issue for which measures should be taken. Participants may experience an emotional impact of having their story reinterpreted and
filtered by the researcher, and feel that this undermines their authority over their own story (Hadjistavropoulos and Smythe, 2001). The researcher made it clear to participants that the final outcome would be the researcher’s understanding of the narrative. After interview, the researcher signposted the participant to their General Practitioner and to the support organisations listed on the Participant Information Sheet, should the participant feel any persisting negative emotional effect by having taken part in the interview.

As with the participants, there is a risk that the ‘insider’ researcher can experience emotional distress during the data collection, and in addition, during the analysis and writing up stages of a research project. With extensive explicit reflecting on one’s own experience, there may be a sense of exposure and, in contrast to participants, the researcher is unable to anonymise herself. ‘Just as our personhood affects the analysis, so, too, the analysis affects our personhood’ (Dwyer and Buckle, 2009, p. 61). This risk was managed through continuous reflection in the form of research journaling, and debrief (formally in the form of research supervision, and informally in the form of sharing experiences with others including therapists and peers). Risks concerning validity of the findings and ‘role confusion’ in ‘insider’ research (Asselin, 2003, p.102) are discussed in the reflexive section 2.9 below and Appendix 11.

Finally, there was a risk of ‘leaking’ of data, or the public availability of participant’s narratives, as the study is disseminated, which could make possible the identification of participants and/or third parties, and this risk is discussed under Data Protection below.

To protect participants and to minimize the risks above, the following measures were taken.

- Risks and risk management strategies were identified and discussed in supervision from design stage and throughout the course of conducting the study.
- Planning protection strategies for the confidentiality of participants and for any third parties mentioned in interviews (see Data Protection below).
- Making participants aware of risks prior to and throughout the data collection stage, including the possibility of having negative emotional responses to the content.
- Planning the use of the researcher’s special competencies as a therapist (including having mental health first aid training) and monitoring participants’ emotional balance during interview.
- Explaining to participants that although they were considered the ‘expert’ on their own experience, their narrative would eventually be presented from the researcher’s
understanding and perspective.

• Debriefing participants following interview and keeping an ‘open’ communication channel in order to allow for questions, comments and suggestions.

• Offering participants accurate information about sources of support in the event they experience pro-longed emotional distress following interview.

• Taking steps to debrief to recognise and explore any emotions that may affect the researcher’s judgement, and affect the researcher personally, including sharing ideas, findings and other aspects of the study with others (e.g. peers and supervisors). This is deemed an effective strategy to overcome own emotional experiences in research (Dickson-Swift et al, 2007).

• Attending personal therapy and keeping an up-to-date personal journal to enhance critical thinking about the research.

Transcription
All interviews were transcribed verbatim. In line with considerations of confidentiality, personal names were replaced with pseudonyms, and place names were replaced with indication of type of place (e.g. a hospital) or blanked out. Non-verbal expressions or body language were not recorded consistently in the transcripts, however occasionally, expressions such as crying or laughing were noted.

Data Protection
Recordings and transcribed data were kept in secure storage according to guidelines of The Data Protection Act (1998). All data records, including all types of research notes, transcribed interviews and audio recordings were stored in password-protected files on a personal computer, or in a locked cupboard, in line with UWE ethical approval requirements, and were only accessible to the researcher. Personal names were replaced with pseudonyms whilst place names were replaced or blanked out in all transcriptions. Participants were reassured that all identifiable information would be removed to safeguard their anonymity.

2.7 Data analysis

Analysis of the data was based on the six steps for Interpretative Phenomenological Analysis (IPA) as suggested by Smith, Flowers and Larkin (2009). The authors encourage researchers to apply extensive interpretation to the data, to dig deep for meanings, and to ‘use themselves to help make sense of the participant’ (Smith, Flowers and Larkin, 2009, p.90). With a larger sample it is
suggested that "group-level analysis" (i.e. shared experiences/recurrent themes) is applied to the data, and that the written up narrative becomes a summarizing account of recurrent themes (Smith, Flowers and Larkin, 2009, p.114).

Initially, the researcher read and re-read the transcript, immersing herself in the data in order to recall the atmosphere of the interview and engage with early patterns in the life story. With an organised approach, the researcher worked extensively on a single interview transcript at a time, applying a method which started with the specific experience and progressed to the more general throughout the individual participant’s data set.

Comments were made in the right hand side of the page including exploratory comments, interesting observations and preliminary interpretations. Inevitably, some interpretation was already being applied here, because although no parts of the data set was intentionally selected or ignored, noticing particular expressions and issues over others must be considered an act of interpretation in itself (Willig, 2012).

Next step led into an initial but comprehensive examination of the content, language and meanings used in the interview, producing all-encompassing and unfocussed annotations, notes and comments, and this step served as a way to become increasingly familiar with the whole data set. The challenge at this stage was to identify present-in-the-data associations within the individual data set, as Smith, Flowers and Larkin (2009) stress that it is important that the interpretation remained grounded in the account, and anchored to the participant’s own words.

At this stage, the researcher decided to carry on the data analysis within the software programme for qualitative data analysis, NVivo (QSR International, 2016), and imported the interview data into this programme for continued electronic processing (Appendix 7). Following this, analysis involved organising and interpreting the data to develop the emergent themes using the software procedure. The data of each interview was coded into emergent themes and scrutinized for thematic similarities. As each transcript was coded, it was treated on its own terms, and this work was carried out with awareness of minimizing the influence of earlier data on in order for the subsequent analysis to be idiographic.

Once all data sets were coded into themes, the next step involved identifying similarities and connections between these themes in a mapping manner whilst remaining mindful of the unique characteristics and content of each separate participant. Themes were described and listed
together as the researcher searched for the connections between them, and clusters of themes were created in an analytical order, with some themes suggested as potential super-ordinate themes with assigned sub-themes. Because the super-ordinate themes signified a higher level of abstraction from the data, and a more psychological understanding of occurrences, they were checked against the transcript, and hence close contact between researcher and transcript was maintained (Smith and Osborn, 2015). The two supervisors attached to the project were consulted to check the identified themes with the interview data, and a preliminary agreement on findings was reached.

Lastly, a table of the main super-ordinate themes and sub-themes was created that effectively captured the participants’ experiences (see Table 2). Here, prominence was given to themes deemed to be unique to PABC and less likely to occur in (non-pregnant) people’s experiences of breast cancer in general. Thus, the chosen themes concerned experiences around the pregnancy, the newborn baby, and the role and identity of being a parent, in all of the contexts revealed in the data. Themes involving well-known and more common (non-PABC) breast cancer experiences were organised within NVivo and kept for inclusion in a table in the appendices (Appendix 9). Any general and occasional themes were bracketed off if they did not seem to be evidenced in the data. Participants were contacted via email and presented with a brief overview of the findings, and invited to comment (Appendix 10). Some participants acknowledged, but none queried, the findings.

The selected themes were developed into a coherent narrative account of participants’ shared experiences ready for review by supervisors and subsequent inclusion in the thesis write up. All themes were illustrated and evidenced through verbatim extracts from the original interview transcripts.

Willig (2012) asks where ‘data analysis’ ends, and ‘interpretation’ begins. Any level of interpretation has an impact on the people involved and it is necessary to ensure that interpretations are as ethical as possible, so that they do not damage the participants and people like them in the general population (Willig, 2012). However, IPA looks for a dual understanding, which is both grounded in participant experience (empathic-descriptive) and goes deeper into hermeneutic description that may differ from the participant’s experience (critical-hermeneutic) and includes pre-existing theoretical perspectives (Willig, 2012).
2.8 Quality and validity considerations in qualitative research

The quality and validity of the analysis in this study was established by applying the guidelines of assessing qualitative research as described by Lucy Yardley (2015). Yardley sets out four broad criteria, and Smith et al (2015) describe how these are met through an IPA study. The principles are a) sensitivity to context, b) commitment and rigour, c) transparency and coherence and d) impact and importance. The application of the guidelines to this study is described further in Appendix 8.

2.9 Considerations on positionality

‘There’s no enunciation without positionality. You have to position yourself somewhere in order to say anything at all’ (Hall, 1990, cited in Bourke, 2014, p. 3).

In qualitative research, the researcher is the main data collection instrument, and the researcher’s socio-cultural background and subjectivity will affect the research process in a similar way to how the participant’s background affects the data (Bourke, 2014). IPA works with a ‘double hermeneutic’ where the researcher endeavours to understand the participant’s own understanding of the phenomenon (Smith et al, 2009). The research is therefore a shared space where both parties’ identities, as expressed through their perceptions, impact on the quality of the work. Positionality thus represents a space in which objectivism and subjectivism meet (Freire, 2000, cited in Bourke, 2014). Pure objectivity can be strived for, but never achieved, and it is therefore essential to acknowledge our subjectivity.

This research project was an ‘insider’ study in more than one respect. The researcher experienced first hand the phenomenon under investigation, fulfilled the criteria for taking part as a participant in the study, and thus theoretically ‘belonged’ to the sample population. In addition, the method of IPA is designed and intended to create an insider’s perspective (Smith and Osborn, 2015), and the researcher was therefore required to position herself within the life world of the participant. This duality required some internal addressing, including considering how it would be possible to step back from the insider position to interpret the data more broadly, i.e. as an ‘outsider’ taking an ‘insider’s perspective (Ritchie et al, 2009).

Appendix 11 contains reflection on the insider positionality applied in this study, specifically in relation to access and data collection, shared knowledge, relationship with participants, analysis, emotional impact and personal stake.
Analysis of the data set identified the participants’ experience of PABC through three super-ordinate themes with a number of sub-themes emerging within each super-ordinate theme (see Table 2). The following three chapters will present a descriptive overview of each super-ordinate theme and its sub-themes combined with some analytical discussion. The findings are then interpreted and discussed further in Chapter 6. These findings chapters present extracted features of participants’ experiences, and draw attention to commonalities and divergences in narratives. As such, it is not an exhaustive analysis of the whole data volume. Upon choosing features of experiences, prominence was given to experiences that were judged to be unique or particularly salient to PABC. Features of more general and well-documented breast cancer experiences, which were also identified in the data set, are presented in Appendix 9.

Direct quotations from interview transcripts are italicized and used to evidence and illustrate findings. The following keys are used to indicate changes in the flow of talking and/or tailing off, where sections of data have been removed to save space, and where names have been blanked.

**Key**

... Indicates a break in the flow of talking and/or tailing off.
[...] Indicates places where sections of less relevant data have been removed to save space.
[sobs] Indicates non-verbal expression deemed significant to the meaning of what is said.
[my husband] With or without pronoun. Replaces a name and/or indicates the person talked about.
[older child] or [other child] Indicates children that were born from pregnancies other than the PABC pregnancy.
[PABC baby] or [baby] or [PABC child] Indicates the child born from the PABC pregnancy.

HCPs Healthcare professionals: all professionals working in either cancer care or obstetrics, i.e. medical consultants incl. oncologists, radiographers and nurses, obstetricians, midwives and obstetric nurses. Counselling psychologists are not included in the description ‘HCPs’, but are named separately.

The super-ordinate themes and sub-themes are summarized and shown in Table 2 below.
Table 2. Main Findings: Super-ordinate themes and sub-themes

<table>
<thead>
<tr>
<th>Super-ordinate theme</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Whose life comes first?</strong></td>
<td></td>
</tr>
<tr>
<td>1a. ‘I’m not putting [my baby] in danger’</td>
<td>A maternal protective drive</td>
</tr>
<tr>
<td>1b. ‘I let them fight it out’</td>
<td>The experience of a conflict between obstetrics and oncology</td>
</tr>
<tr>
<td><strong>2. My baby saved me</strong></td>
<td></td>
</tr>
<tr>
<td>2a. ‘I could have been dead a long time ago’</td>
<td>Coping and surviving in a physical sense</td>
</tr>
<tr>
<td>2b. ‘You have to keep going for this baby’</td>
<td>Coping psychologically by keeping a focus</td>
</tr>
<tr>
<td>2c. ‘As much normality as I could squeeze in’</td>
<td>Seeking family normality</td>
</tr>
<tr>
<td><strong>3. The loss of being a mother</strong></td>
<td></td>
</tr>
<tr>
<td>3a. ‘We didn’t go to any baby groups’</td>
<td>Loss of new mother-infant engagement and behaviour</td>
</tr>
<tr>
<td>3b. ‘That year should have been all lovely’</td>
<td>Bonding and attachment - disrupted by circumstances</td>
</tr>
<tr>
<td>3c. ‘I think I kind of withdrew from him’</td>
<td>Protective distancing myself from baby (and from others)</td>
</tr>
</tbody>
</table>
Super-ordinate Theme 1: Whose life comes first?

A significant aspect of the PABC experience as recounted by most participants takes place around the moment of receiving the diagnosis of breast cancer. Out of the eleven participants, eight were aware that they were pregnant at diagnosis. The women describe how they felt themselves thrown into a sudden psychological and physical dilemma involving their own survival and the survival of their unborn child. This is experienced as an existential struggle about whose life comes first and whose health and well-being warrants priority above the other: the mother-cancer patient needing urgent treatment, or the unborn baby needing more time to grow and develop naturally in the womb. Cancer treatment is here generally perceived by participants as a threat to the health and well-being of the baby (having treatment whilst baby is still in the womb or electing baby to be born preterm). Conversely, remaining pregnant and delaying treatment out of concern for the baby is perceived as a threat to the survival of the mother-cancer patient.

Maternal-fetal alliance

The majority of participants do not hesitate to think of the survival and well-being of their baby before their own, and thereby put their baby first. There may be varying explanations for this, including the participants’ felt maternal obligations, a denial of the situation and the risk to themselves, and strong feelings of guilt for the sudden ‘disruption’ to life as it was until that moment (including the baby’s natural development during what was a normal pregnancy) through falling ill and needing treatment. At the same time, it seems that participants regard themselves to be in an alliance with their baby against the adversity of the disease and treatment, a maternal-fetal alliance. This notion is also discussed in Super-ordinate themes 2 and 3. The sense of being engaged in a maternal-fetal alliance contrasts sharply with how HCPs may consider PABC likely to give rise to a maternal-fetal conflict, where the well-being of the mother conflicts with the well-being of the fetus. This is discussed further in Chapter 6.

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2 One participant received diagnosis shortly before discovering she was pregnant, and two participants were diagnosed shortly after giving birth. See Chapter 2, Table 1.
Sub-theme 1a. ‘I’m not putting [my baby] in danger’: A maternal protective drive

For the participants, the dilemma of ‘whose life comes first’ seems to emerge upon diagnosis, partly through communication from HCPs, and partly from within the participants themselves. It is experienced as a direct confrontation between the mother’s own life and the life of her child. As mentioned, women diagnosed with PABC are not required by medical protocol to terminate their pregnancy in order for cancer treatment to start, or for treatment to be effective. Several participants in this study were asked to make the choice of whether to continue their pregnancy or not, and some HCPs advised or suggested termination. At this point, despite the obvious difference, having a selective preterm delivery or a termination seem equally upsetting and devastating to participants. Thus, the question promptly arises for the participants as a momentous existential and evolutionary question, which they feel compelled to answer immediately and resolutely. Whose health, and indeed whose life, comes first in the here and now? This question seems to activate a maternal protective drive in the participants, and all but Corinne (diagnosed before knowing she was pregnant) and Rebecca/Nadine (diagnosed shortly after giving birth) express little hesitation in prioritising their child over themselves.

*I just right away said, ‘Well, I’m not having the baby before, kind of, 35, 37 weeks, because I’m not putting it in danger.’ I would rather just carry on with my pregnancy and deal with it after. They said then, ‘Well, you’d be putting your life at risk to do that,’ so I said, ‘Okay.’* Chrissy

For Chrissy and Daisy, as for others, the dilemma of ‘whose life comes first’ presents itself as an ‘us-and-them’ oppositional conflict where they as individual mothers stand alone between the world of desolation (breast cancer, cancer treatment, and at times, the HCPs) and their baby. As mothers, they immediately rise to the threat they perceive in the moment and act to protect their unborn child, ignoring the potential cost.

*And my first question was ‘What about my baby?’ Because I’d already said to [my husband], I’d said, ‘If it’s bad news they’re not touching my baby, nothing is happening to my baby.’ I don’t even know why I said it or… it was just ‘They’re not touching my baby.’* Daisy

There is a sense of denial in the moment about the potentially heavy cost to their own life by postponing treatment and putting baby first and above themselves. The women are making rapid decisions from the basis of their maternal protective urge in the here and now and with a sole focus on the immediate situation.
In Katie’s case, as in others, there are additional factors to activate her maternal instincts. Prior to being diagnosed, and as she has felt the baby move in her womb, Katie already feels she has a bond with her unborn child. Terminating her pregnancy therefore seems too stark and abhorrent an action, and one that she as a mother can proactively choose not to take. She ignores the potential consequences, maintains a sense of control, and chooses what is by far the ‘easier’ option, i.e. protecting the baby, with the option of terminating the pregnancy readily dismissed.

*I was straight away ‘No’. It didn’t even cross my mind, it was just basically ‘No I’m not having one’, I’d felt her move and I couldn’t. It would never cross my mind to get a termination.* Katie

Katie’s stance of ‘straight away no’ seems like a response to felt external pressure, perhaps via treatment options presented to her by HCPs, and the dilemma seems instantly addressed by Katie taking charge herself.

For Chrissy and Daisy, as for the majority of the participants, thinking of the baby first seems to come naturally and automatically, and their statements relay the straightforwardness of their reaction at initial diagnosis.

*I think having a newborn baby and being pregnant, initially, at first when they told me I had cancer, my first thought was, ‘What about my baby?’ I didn’t care about myself, I just wanted to think about the baby.* Chrissy

[…] *I would imagine that’s most people’s first thought, isn’t it? Is my baby going to be alright?* Daisy

Corinna feels slightly differently about the dilemma and seems less impulsive than the others in choosing the baby above herself. She is conscious that her maternal protective instinct is a surprise to her. Corinna was diagnosed before knowing that she was pregnant, and in that sense, she was a ‘cancer patient’ before a prospective ‘new mother’.

[…] *so when I then found out I was pregnant, you know, I was sort of surprised myself in a way at how strong my urge was to do everything I could to preserve the baby’s life almost above my own which, I suppose, that part is what surprised me, because even though obviously I didn’t want to die, it was almost like if I was going to risk my own chance, I would do it to save the baby.* Corinna

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3 Super-ordinate theme 3 presents findings in relation to role and identity as a mother and cancer patient.
The question of ‘whose life comes first’ becomes more complex as the women who have older children⁴ feel an additional impulse to prioritise their own survival and health in order to be there for them. The women may instinctively question whether their primary identity in this situation is that of ‘a patient’ or ‘a mother’ or a ‘new mother’. In addition to any feelings of wanting to survive for one’s own sake, for egoistical reasons, and the fear that the prospect of death evokes, their own survival represents the ‘survival’ of their other children, and in the prevailing situation it is up against the perceived survival of the PABC baby.

*I just thought, ‘I can’t leave [older child]’ you know, and then because I was 22 weeks, obviously the cut-off time for termination is 24 weeks, so it was then the decision of do you terminate the pregnancy and go aggressive and then, you know, cut my boobs off. I said to [husband] ‘We need to terminate the pregnancy’, you know, all I could think of was [older child].* Jane

*I was more scared that my kids would be without a mummy, not so much [PABC baby] because I felt he was a baby and he wouldn’t have that connection with me yet so he wouldn’t know any different.* Rebecca

*I’m thinking about [older child] who is only one year old and I’m sort of worried that I’m going to die and he’s not going to remember me, that was my… I think one of my main concerns that how long will I live for? What age will he be when I die?* Corinne

Like most of the participants, Linda does not hesitate to put her baby first, but for her there are particular concerns about her child being unsafe and vulnerable whilst in her womb, and she feels better able to protect him and care for him once he is born.

*The entire focus was on the baby. It was all about the baby, getting the baby out safely, making sure that he was okay…. I wasn’t thinking about myself and I wasn’t worrying about what else was going on. It was ‘Got to get this baby out.’* Linda

It is as if Linda experiences a lack of control whilst her son is in her womb which is threatening, and she trusts her own maternal protective abilities more to care for him appropriately once he is outside, even though this means giving birth preterm. Similarly, for Corinne (treated with chemotherapy whilst pregnant, 13 years ago), the sense of her baby being unsafe during treatment is significant, and brings with it considerable feelings of fear, guilt and shame⁵ towards her unborn child.

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⁴ Eight of the eleven participants. See also Table 1.
⁵ See also Super-ordinate theme 3.
Yeah, because I felt very uncomfortable about having chemotherapy, really uncomfortable, I felt very ashamed of it almost because I thought how can I be allowing this... for me, it felt like poison being put into my body when I've got a little baby in there. Corinne

The feelings of guilt at what the women might be ‘doing’ to their baby by becoming ill and needing to give birth preterm to have treatment is also reflected in Anna’s account.

[...] with a caesarean, the poor little baby’s just sat in there completely unsuspecting, and then suddenly...ripped out...and you just, well I just feel very, very guilty about that. She’s absolutely perfect, there’s nothing wrong with her, but I still feel, I don’t know what... she wasn’t ready to come out... Anna

For Corinne, the guilt she feels extends beyond having to have treatment and into her lifestyle and typical behaviour.6

Yeah, I felt guilty, I felt bad, I thought ‘Oh I mustn’t [eat unhealthy foods] ... and I couldn’t do it, I didn’t have strong enough willpower and there was like this battle of wills... Corinne

The feelings of guilt that are a significant part of the experience and which occur after giving birth, also form part of Super-ordinate theme 3, and are discussed in further detail in Chapter 5.

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6 Corinne was unknowingly 5 weeks along in her pregnancy when she was diagnosed, and by the time she gave birth at full gestation she had completed all of her cancer treatment.
Sub-theme 1b. ‘I let them fight it out’: The experience of a conflict between obstetrics and oncology

There are contradictions in the participants’ accounts of their experience of their own life versus the life of their baby, and some of these contradictions reveal the complexity of the dilemma for the pregnant women.

_I did obviously want her as healthy as I could, but obviously I had to think of myself as well._ Katie

The problematic experience of the shifting focus on mother and baby which is presented in Sub-theme 1a is mirrored in the medical domain, and particularly in the treatment planning involving different types of HCPs, as well as the patient herself. Upon diagnosis, the participants experience a struggle in the coordination of care from obstetrics and oncology as represented by the different types of HCPs involved. Typically, the participant’s oncologist pushes for early or immediate elective delivery of the baby (or offers/suggests a termination of pregnancy) so that cancer treatment is simplified, with no need to consider the effect of treatment on the unborn child. In contrast, the obstetrician (usually in accordance with the mother’s inclinations, see Sub-theme 1a) seeks to delay delivery in order to protect the well-being and development of the unborn child. There is a clash of medical ethics, and a question of who is the (more important) patient – what HCPs might term a classic maternal-fetal conflict. For some participants, the explicitness of this clash leads to confusion and distress, at a time when they are most vulnerable, many feeling helpless and powerless, and looking to authoritative medical professionals for guidance, help and support.

Linda copes with the situation by focusing on the well-being of her child, and as such indirectly sides with the obstetrician linking in with Sub-theme 1a of putting her baby first.

[...] they wanted me to give birth early because they wanted to start chemo as soon as possible, but there was a lot of to and fro between the oncologist and the obstetrician because obviously the obstetrician wanted to keep the baby in as long as possible, and the oncologist wanted to start chemo straightway. [...] [for me] the entire focus was on the baby...I wasn’t thinking about myself... Linda

_The oncologist was wanting me to have her at 32 weeks... so they basically argued between them when we were going to have her. One wanted her to come early, and it was almost like trying to think of the best for the baby and me, and the other one was trying to think of the best for the cancer and me, so they had differences of opinion._ Katie
For Katie, the conflict between obstetrician and oncologist does not seem to present distress, but is more a burden, which she seems content to not have to carry. She expresses her powerlessness as she and the baby are positioned between the two types of HCPs, and yet maintains that, like the obstetrician, she would choose her baby’s well-being before her own.

*I just put myself in their hands... I think I went more with the side of the obstetrician than the cancer doctor. I just thought ‘They can argue all they want but there is nothing I can do to change it really’. I just let them fight it out between them.* Katie

For Anna, who has worries about the development of her baby, the conflict is distressing in particular as it leaves her feeling helpless and unable to do right by her baby. The conflict is further enhanced by the sense that oncology and its consultants are ‘above’ obstetrics, that they work at a higher level in medicine, saving lives from cancer, and address more important and serious health questions, than do obstetricians when these are involved in a typical uncomplicated pregnancy and birth. Participants seem to experience being caught in this power play.

*So there was discussion between the obstetrician and the oncologist as to when to deliver the baby. I’d said [that I wanted to give birth] 18th March, that’s what the obstetrician had in their notes, and then the oncologist said “No, the 11th”, so when I went to see the obstetrician that got confirmed, it was going to be the 11th, and I wasn’t... it was not something I could choose unfortunately.* Anna

The explicit conflict between medical specialties as played out by the different consultants, exacerbates the participants’ stressful experience of being forced to choose between their own well-being and that of their baby. The maternal-fetal alliance which they feel protects both their child and themselves is severely threatened. In most participants’ cases, actual termination of the pregnancy is discussed only briefly with their oncologists, but regardless of how determined to protect their pregnancy/baby the participants feel, the threat is persistent and the discussion itself is upsetting to them.

* [...] [the oncologist] gave the indication [a termination] would be okay, that it was something we could do. That was such a shock, I suppose in my own mind there was just no way I was going to terminate the pregnancy...maybe that was crazy, and my husband was less sure, he was like ‘Well, we need to find out if it makes things worse for you or for the baby’. *Rita

7 See Chapter 6: Discussion of Sub-theme 1b.
The surgeon wanted me to have a termination, but [...] I was like ‘No, no I can’t do that’. Katie

Linda feels overwhelmed at the complexity of her treatment plan, and at the indecision of her HCPs.

[...] so we were still sort of waiting for a date that they wanted to have this baby, but at the same time it’s still in your mind that I could wake up from the surgery with a baby being handed to me. And that was at seven months. Linda

Again, she copes with this situation by focusing exclusively on her pregnancy and baby rather than her own illness, and thereby downplays the significance of the potential threat to her own life.

I wasn’t even thinking about [my survival]. It was a case of this was very inconvenient at this time and I don’t have time for this nonsense, I think more than anything [...] it was a case of get rid of it, take it off, don’t want it there and sort of move on from there. Linda

For most participants, having treatment (i.e. chemotherapy and surgery) means not being able to breastfeed for any amount of time, or for as long as they would wish. This issue is significant and brings with it feelings of sadness and guilt, and is discussed in further detail in Super-ordinate theme 3 in Chapter 5.
Super-ordinate Theme 2: My baby saved me

Throughout their accounts there is a sense that participants feel that the pregnancy and the baby somehow help the mother cope practically and emotionally with both illness and treatment, and contributes to her survival and recovery of the disease. This supports the notion that mother and baby are in a maternal-fetal alliance (see also Super-ordinate theme 1). In some accounts, this sense is stronger still, and participants relay how they feel that they coped and survived only because they were pregnant and had a baby to give birth to, and to be a mother to, throughout the difficult times and until recovery.

The notion of pregnancy and baby serving as rescue mechanism for the ill mother holds both physical and psychological functions for the participants, and both types of functions are operating from the time of diagnosis and giving birth, and throughout having treatment during the baby’s first year of life. The physical functions concern the pregnancy initially alerting the participant to the cancer during regular pregnancy consultations with doctors, as well as drawing attention to less distinct cancer symptoms, which may otherwise have gone unnoticed for longer. After giving birth, the physical presence of a newborn functions as instigator for the mother to attempt to remain active in the daily care of the baby (this is also described in Sub-theme 3c) and the maintenance of a normal family life. The emotional functions are more complex, and concern the mother’s motivation to cope and survive, being given purpose and having positive distraction from overwhelming negative emotions, and a meaning-making function of life as a cancer patient where the ‘bad’ is balanced with some ‘good’. The perception of the baby as a rescue for the ill mother brings sense and meaning to the unfortunate timing of the two events, and the clash of pregnancy and cancer therefore happens for a (valid and good) reason. This notion is discussed further in Chapter 6. The experience of ‘baby as rescue’ is presented in the following two sub-themes.
Sub-theme 2a. ‘I could have been dead a long time ago’: Coping and surviving in a physical sense

Some participants feel that had it not been for the pregnancy, they would not have discovered or investigated the physical symptoms that led to their diagnosis. They feel they owe it to their baby that the illness was detected, and this implicates the pregnancy and baby greatly in the mother’s continuing psychological adjustment to her disease, where there exists a perception of being almost lucky that they were pregnant when the cancer occurred. The participants seem to make sense of the timing of their diagnosis, the fact that their cancer diagnosis happens during pregnancy, by conferring a great deal of value to the circumstance of being pregnant when diagnosed with cancer.

*I do feel emotionally like how lucky I am that I could have him, and my husband has said ‘if it wasn’t for him we wouldn’t have found out so early’, because I wouldn’t have gone to the doctors to say I was pregnant, and I wouldn’t have said ‘I’ve still got these lumps’. Yeah, in that way he was part of the whole finding out and making treatment possible.* Rita

Nadine and others mirror this sense that being pregnant at diagnosis was key to an earlier detection of the cancer, and that being pregnant was therefore indirectly central to their survival.

*Yes, having him has probably sped up the growth […], but I see that as a good thing because if I hadn’t had him, I wouldn’t have got the MRSA and they wouldn’t have found it.* Nadine

*If I hadn’t been carrying the extra [pregnancy] weight, I might not have had that pain, it could have been so far on then that actually it’d spread to my liver, my lung, my brain, whatever, and then I could have been dead a long time ago.* Nadine

This experience has conflicting features within individual participants’ accounts. In addition to the notion of finding out about the cancer because of the pregnancy/baby, most participants also feel that the pregnancy masked the cancer symptoms, and thereby delayed diagnosis and treatment. Nearly all participants describe how, at initial consultation with their GP, they were misdiagnosed, as the doctor attributed symptoms (a tumour or breast changes) to their pregnancy. The misdiagnosis is experienced as a positive occurrence, as an earlier diagnosis may have brought with it perceptibly negative consequences, such as facing a termination of the pregnancy or having chemotherapy whilst still being pregnant.
I had that inverted nipple for a few months, which looking back was crazy not to do anything about it sooner. But at the same time I kind of see it as a blessing that I didn’t, because it would have panicked me to have to have chemo during pregnancy. Rebecca

The idea that the pregnancy masked the cancer symptoms links in with Sub-theme 1a as the pregnancy and baby feels more important to the participants than the detection and treatment of their disease. With participants ignoring their cancer symptoms, consciously or not, the pregnancy and baby is allowed to remain undisturbed and progress naturally, and this brings feelings of relief.

Katie describes the experience of being misdiagnosed, with cancer symptoms being attributed to the pregnancy, and how this enables her to carry on with her pregnancy and have her much-wanted baby.

I always think if they hadn’t made that mistake and had diagnosed it pretty early, then I would have had an abortion before I would have felt her. So I am glad that they made that mistake because I got a baby at the end of it. Katie

There are further meanings in the notion of the physical rescue functions of pregnancy/baby. These seem to help participants make sense of the devastating timing of cancer and pregnancy colliding. Corinne, who had all of her treatment whilst being pregnant, feels that the pregnancy gave her body a physical boost in the management of her chemotherapy treatment.

I think in a way, and other people have said it that have had treatment when they were pregnant, [being pregnant]'s almost an advantage, it’s almost like your body puts in this extra, kicks into extra power to deal with it. Corinne

For Daisy and others, the maternal drive to care in the usual way for your children seems to function both as protection for the older children (against any anxiety and distress accompanying the mother’s illness and the effects of treatment) and to help the mothers themselves to remain physical and strong.

[...] while you are in it, we kept busy, went to restaurants, we went to town, we did kiddie things like go to the park, and we did cope on a daily basis because I was desperate to protect my kids from all of this. I didn’t want them to feel my anxiety. Rebecca

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8 Theme: Relationships within the core family. See Appendix 9 for a table of themes identified in the data but not included in the main thesis.
So the children, I think just in terms of physically being busy all the time with them meant that through chemotherapy, although you felt rubbish you wanted to get out of bed, you got up and you want to take them to school... but I think if you didn’t have that focus on the children [...] there would be not that much motivation to get out of bed. Daisy

The physical requirement to get out of bed to help run and care for the family seems to be a significant factor in the overall coping physically for the participants.

[…] even on a bad day I had to get out of bed. I was obviously more tired after having chemo, but I think being a mum of two under two you would be tired anyway. Rebecca

The attitudes of the participants that they wanted to (and did) keep as physically active as possible links in with the theme of striving for family normality as a coping mechanism and is discussed further in the Sub-theme 2c.
Sub-theme 2b. ‘You have to keep going for this baby’: Coping psychologically by keeping a focus

The notion of the baby helping its mother to cope and survive extends from having physical functions into psychological functions. The baby helps fulfill the mother’s need to be a mother, with what this entails of identity formation and pursuing maternal instinct and behaviour. As a rescue mechanism, the baby is helping the mother to fulfill her needs, and these are arguably about the mother rather than the baby (with a shift from Super-ordinate theme 1, where the baby’s needs are at the centre). As the mother’s personal needs, these do not necessarily come from an egotistical position, as often a main ‘problem’ with dying is the guilt arising from the perception that it causes pain and suffering to loved ones. Sub-theme 3a describes the participants’ experience around the loss of their ‘new mother’ identity in closer detail.

I’m not scared of dying. It’s just the people that are left behind and what effect it has on them, and that’s still the main thing because I just can’t bear the thought of the girls not having their mum. I’m not saying I’m Super-Mum or anything like that, but they need you. Anna

The participants convey how their baby rescues them from the illness by helping them cope and survive psychologically, specifically in two ways. Firstly, the baby provides motivation for the participants to recover and survive due to the baby’s practical needs for maternal protection, care and attention. Secondly, the baby acts as a distraction by providing a positive focus that means not having to constantly face the illness and its potentially fatal and distressing consequences. Across these important functions, the participants express experiencing a craving for family normality in their lives which, when obtained, helps apply some sense of control and order to what may otherwise seem a chaotic and uncertain situation. The participants relay how the baby’s existence is what enables the establishing of that family normality. Some participants go as far as expressing that were it not for the baby, they feel they would not have survived their cancer. The concept of seeking family normality is presented separately in Sub-theme 2c.

Motivation

For Katie, having something ‘to aim for’ is important for her motivation to recover and survive. Being pregnant requires and enables her to have an optimistic attitude, which she feels is vital for recovery and for treatment to be effective.

I think the pregnancy made me more focused that we were going to get through it. I think that is why I wasn’t feeling sorry for myself, because I just wanted a healthy baby at the end of it, to me that was the priority, and I was secondary. Katie
I just think it does give you something to get better for. More focus definitely. I think a lot of your treatment is to do with your mind. If you’ve got a positive ‘We can do this…’. Yeah, you’ve got to survive. If you’re in your fifties, you’re single, then you could just fade away. If you’ve got a young family you have to get better. Katie

For Chrissy, there is the additional incentive to physically look after yourself as the vehicle that the baby needs for its own survival and healthy development. She describes the symbiosis of the mother/baby duo where she, as the mother, will worry about (i.e. protect) her child at the same time as the child will motivate the mother to recover. The baby helps save her by making her keep physically ‘healthy’ and thereby fight the disease more efficiently.

Yes, there’s an extra reason to really fight it, you’ve grown this baby in your belly, you want it to come out and be healthy... and even just to look after yourself, because I was pregnant, you want to take three healthy meals a day, you want to take sleep and get up as normal. Whereas I think if I hadn’t been pregnant, I maybe would have just been like, I don’t want to eat anything and lie about and... but, yes I had a wee drive and so it kept me going, because I needed the baby to be healthy, couldn’t just give up, because of the baby... it was really scary, because you are trying to worry about the life inside you, it’s also on a positive note, the life inside you keeps you going. Chrissy

Similarly, Jane and others convey how it feels helpful that they are forced to ‘get out bed’, and this phrase comes to symbolize how participants manage their lives throughout the earlier period after diagnosis during the physically demanding treatment.

I think because I had [older child] and this one on the way there wasn’t an option to lie in bed and...probably there was more positives, because you had to get up, you know, you just had to, whereas I’m not convinced that... had that not been the situation, I would have probably just laid in my bed for six months until it was over, you know, I don’t know. Jane

Keeping themselves busy with everyday tasks and child care brings all-important positive experiences and helps to keep the mood stable by way of not allowing participants to dwell unhelpfully on their illness. Chrissy expresses how her baby saves her from the ‘doom and gloom’ that other female cancer patients, who do not have a newborn, might experience during treatment. Again, there is a sense of being lucky for having been pregnant and/or having a newborn during the experience of breast cancer.
Definitely, when I spoke to some of the other girls [being treated for cancer] who didn’t have children, or their children were about school age, you know, they were all, kind of, doom and gloom and [...] they were very like, ‘I just get in my bed and I stay there until I feel better,’ kind of, down in the dumps. Chrissy

Finally, for Nadine and others, having a baby is a crucial motivational factor in feeling disposed to ‘fight’ her cancer illness, rather than psychologically giving up before time.

[…] but the effect that it has on the baby, on your relationship with the baby, I think that’s where it comes into it. I think, you know, you’re more likely to want to fight it and not go within yourself and think, I’m not going to do this, I can’t do this, so I think you’re going to be more likely to fight for it. Nadine

Distraction and Focus

The focus on the pregnancy and the baby above the cancer links to Sub-theme 1a where participants say they focus on their baby above themselves. Placing focus on the baby seems to help participants cope with the illness and treatment as well as a multitude of difficult emotions such as fear of death and recurrence, anger and sadness (see also Appendix 9). The baby serves as a practical distraction and allows the participant as far as possible to ‘pretend’ or ‘act’ that everything is normal, and to deny the threat and severity of their condition. This brings an effective temporary relief from physical and psychological distress. Although it seems helpful and easier for participants to try to get on with their usual life in the present and not ‘dwell’ on their fears, simply having to ‘get on with life’ is naturally also a typical part of being parents to young children, where everyday life is busy, and there is little time nor inclination to stop and reflect deeply on life, including your existence and mortality, to any substantial degree.

However, with the distraction that the baby brings, outside of this ‘everyday young family’ life, reality can at times suddenly hit home, as it does for Jane, who experiences moments of overwhelming emotional distress at night.

[…] and with the baby comes night feeds, and yes… those are the hours of the morning when you’re sitting lying in bed, feeding your baby and just looking at her and thinking… tears rolling down my face… it sounds dramatic, but just feeding her and thinking, ‘Okay, I need to do this, I need to do this.’ Jane

Linda feels a strong attachment to her baby in both a very physical and psychological way, and openly expresses the need for her child to be her distraction and rescue throughout the difficult
times.

I think I didn't hand him to other people as much as I probably would have if I hadn't been going through that, because he was my absolute focus and he was a complete distraction. And he was so incredibly beautiful that I just didn't want him away from me. Linda

For Rita, it is clear that having the baby to focus on is what enables her to adjust to life after her treatment, a period of time that is typically emotionally challenging for many cancer patients.9

So, after the treatment finished I think with the pregnancy, although there was the extra stress of what might happen to him, to the baby,10 in some ways it gives you a focus, and I imagine if you don’t have that you’d have the treatment and then it finishes, you’re left with a bit of a void, whereas I think at least we had him to focus on, you know... they’re still so little, your life’s so busy, that I found it almost better that I didn’t have the time, I was more worried about him. Rita

Having the distraction of the baby is helpful as participants experience that they can avoid the risk of ‘dwelling’ on their suffering and their mortality, and also includes not having to confront their fears and worries. During the earlier stages after diagnosis and treatment, participants experience a need for this distraction, for something to help take them away from the reality of what they are going through. That need is fulfilled by the pregnancy and the baby.

A lot of people say to me, ‘Oh, you poor thing with two kids as well.’ For me, thank goodness for them, because I think I would have dwelled much more if I didn’t have kids. Rebecca

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9 Theme: After treatment. See Appendix 9 for a table of themes identified in the data but not included in the main thesis.
10 Theme: Impact on baby. See Appendix 9 for a table of themes identified in the data but not included in the main thesis.
Sub-theme 2c. ‘As much normality as I could squeeze in’: Seeking family normality

The pregnancy and baby as physical and psychological rescue mechanism extends into the fulfillment of participants’ yearning to maintain a ‘normal’ family life. Having a newborn and/or being a parent to young children makes the participants desire to (and also partly forces them to) create some normality, i.e. a routine in carrying out everyday tasks, of family life. Obtaining a sense of normality has multiple advantageous functions for the mother herself and for the family as a whole, and these functions relate to a sense of protection and coping (including developing and maintaining an identity as a new mother equal to, or above, that of a cancer patient).

*Everybody would stop me and go ‘How old is your baby?’ and all that, and I absolutely loved that, and it was just the normality, but no, I think [the worst thing about cancer] was the huge disruption to our life.*

Nadine

Nadine, who was diagnosed with secondary cancer whilst pregnant with her first child, seems clear that taking her son out for a walk and interacting with other people helps her create a sought-after sense of normality during a time where she feels her life is being ‘wrongly’ disrupted. She seems to feel it a privilege to carry out what might be regarded as typical new parent behaviour (this is described further in Sub-theme 3a), and it serves as an important relief from her treatment obligations and worries about coping and survival.

Similarly, for Linda, there is a strong urge to focus on the family unit, and for as much as it is possible, pretend that life is ‘normal’ (i.e. cancer free) in order to have the space and opportunity to form an identity as a mother and bond with her newly born child. In order to do this, she feels she needs protection from any outside intrusion (e.g. HCPs and concerned family and friends), and she imagines this protection as a bubble around the family.

*I think I just wanted as much normality as I could possibly squeeze into the two weeks before they started chemo. I basically just wanted everybody else to fade into the background, and my little family, my little bubble, just have a couple of weeks where things would be normal.*

Linda

Daisy also talks about her core family as existing within a protective bubble. This seems helpful for coping with the demands the participants are experiencing from the healthcare side of their situation (the illness and treatment process), which feels like a threat, not just to the participants but to the core family itself.
It’s just the kind of here and now in your little bubble, your immediate family, you know, making sure that the children are okay and sorted and protected\textsuperscript{11}, and you and your... you know, it’s really... it’s very strange...

Daisy

Having some level of family normality seems to be critical to the well-being of the participants. Normality brings a balance to disruption. It also brings respite and lets the participants suspend worries about their disease and its consequences momentarily, and enjoy time together as a family. As such, it brings relief and lets the mother settle into the role and become accustomed to being a mother, in the way she had expected to be able to do at this stage in her life. Normality also lessens guilt feelings because it lessens the sense of disruption to the family\textsuperscript{12}. It creates a sense of managing to look after and care for the other children, by attempting to make sure life is as stable as possible and they are not too affected by the situation. Notably, the PABC baby is a significant factor in achieving this normality.

\textsuperscript{11} Theme: Protecting others. See Appendix 9 for a table of themes identified in the data but not included in the main thesis.

\textsuperscript{12} See also Super-ordinate theme 3.
Throughout the early period of treatment and parenthood, there is clearly awareness, guilt and felt distress about life not being ‘normal’ in the way the participants would have wanted and had envisaged at this point in time. But having (and taking) the opportunity to pretend that it is (or perhaps to temporarily suspend the reality of being ill with cancer) brings emotional benefits to participants and impacts positively on their feelings about their ability to parent their children.

*So I had those three weeks with him breastfeeding, which was really nice... and made me feel like he was just like the others... yeah, it sort of made it the focus was not the cancer any more, it was just normal, getting into the baby.* Rita

Family normality is experienced by the participants as being critically important for everyone in the family. It is particularly helpful for the participants in terms of coping with the distress of the diagnosis and throughout treatment, whilst being allowed the opportunity to form and maintain a
maternal identity and role. The baby’s role is vital in the successful achievement of this because it encourages (and in most cases, forces) the participant’s involvement in everyday routine care-taking behaviour.
Chapter 5  Findings Part 3

Super-ordinate Theme 3: The loss of being a mother

The theme ‘loss of being a mother’ is the main finding of this study and central to all the participants’ accounts of their experience of PABC. The previously presented Super-ordinate themes 1 and 2 contain elements of the experience of loss across both the perceived balance of mother’s versus child’s life, and the mother being saved by the baby. This chapter focuses on the experience of loss across three sub-themes.

All the women who took part in the study relay how they struggled to come to terms with a pervasive sense of an irreparable loss. For all participants, the sense of loss brings with it deep-rooted feelings of pain and guilt, and an urge to compensate their child who they feel has also experienced a loss. For the mother, the experience concerns the loss of time, ability and opportunity to engage with the pregnancy and the baby, to bond and be a mother-infant twosome in the way it was imagined, and the way it is typically perceived as being the norm and the definition of motherhood in Western culture.

Yeah, you just feel like a lot's been taken away from you, that this isn't how it's meant to be, this isn't what you planned. Linda

The following three sub-themes present participants’ experience of loss over three areas of motherhood, however, there is considerable overlap between these, and they are presented separately mainly to explore specific aspects of the experience. Sub-theme 3a concerns the perceived loss of new mother-infant engagement and behaviour, i.e. experiencing being prevented from doing and being what they believe they would normally have done and been as a mother, had they not been diagnosed with cancer. This includes activities (e.g. walking with baby, going to groups) and interaction (e.g. breast feeding), involving their new baby, and family life as it was supposed to be, including having more children. The mothers convey how having cancer treatment is physically preventing them from forming an identity as their new baby’s mother, or at least, as they had envisaged it, due to the blocking of typical parenting activities and behaviour. Sub-theme 3b. overlaps the preceding sub-theme, but focuses on the experience that the typical and desired attachment process and outcome between mother and new baby is disrupted by the illness and treatment. The participants’ accounts describe the loss of being able to, and being allowed to, express themselves physically and emotionally towards their baby.
Sub-theme 3c. presents participants’ experience of withdrawing emotionally from their baby and from others, due to the fear of loss of their own life or their baby’s, in order to protect themselves and their family. This behaviour triggers persistent feelings of pain and guilt. The participants relay how, since recovering from their illness, they try continuously to make good and resolve the loss through an intense nurturing of their relationship with their PABC child, including constructing this as a ‘special’ relationship.
Sub-theme 3a. ‘**We didn’t go to any baby groups**: Loss of new mother-infant engagement and behaviour

**Loss of opportunity for new mother-infant engagement and behaviour**

Participants report how being diagnosed and starting treatment feels like being hit with a ‘sledgehammer’ (Daisy and Anna). The ensuing time period is taken up with numerous practical and physical obligations relating to being treated for the expectant and new mothers (see Table 1 for participant demographics). What might otherwise have been a period of ‘settling in’ as a family and getting used to the idea and the practical reality of having a new baby, is disrupted and filled by hospital appointments, scans and consultations, treatment and monitoring. In addition to the practical requirements of treatment, a mix of distressing emotions such as fear, worry, anger and guilt take over the participants’ emotional lives, and thereby temporarily oust the ability and opportunity to engage emotionally with each other as a ‘normal’ family.

*I wanted to be the first person to give him his bath and to put him in his new clothes and do all that sort of stuff, but actually we got so wrapped up in medical issues and being in and out of hospital and worrying about that, he did sort of... the new baby experience took a real back seat.*

Nadine

Being physically prevented from doing mother-baby activities together is experienced by the participants as a painful loss, thwarting the opportunity of forming a naturally close relationship between mother and child.

[...] *I think just the massive disruption, you know, we should have been going out with our baby in a pram and you know, going for walks and just enjoying that thing as a family and actually we just weren’t at all, we were in the hospital.* Nadine

*So it was just so hard, it was absolutely exhausting. Like I say, we didn’t bond. We didn’t go to any baby groups. We didn’t do sort of baby massage or, you know, any of the things that I would have done that I did with [older child], because I was just too poorly.* Daisy

[...] *and I maybe couldn’t... well, I didn’t go to like, you know, with my other two boys I went to mummy and baby singing classes and things like that with them, but I didn’t do things like that with [baby] and looking back now, I get upset about that.* Chrissy

Daisy, whose son is in the hospital neonatal unit for a while, expresses how she is physically and emotionally prevented from caring for her baby, and how the baby does not feel as her baby to be a mother to, leaving her feeling that she is not her son’s mother.
that’s kind of like an ownership... sort of, like a barrier [...], and you don’t feel like you own that baby to begin with when you first go into special care, it’s like it’s not your baby and you’re not allowed to touch that baby because you don’t know how to care for that baby around its wires and its tubes... Daisy

Chrissy describes how it feels painful to think about what her cancer illness has taken from her child, even though she acknowledges that her son may not know any different. She also seems to feel blame towards herself for the dearth of mother-infant activities and behaviour.

I felt quite bad, looking back... the new baby pram, I think, I hardly used that. My other boys, I was out walking miles with them, but with [baby] I wasn’t really, you know, we just had wee walks and it was different to what it would normally be like, that’s why I get upset now. He doesn’t remember, he wouldn’t know, but I remember it. Chrissy

Loss of breastfeeding

Breastfeeding, for most participants, appears to represent the ultimate contact between mother and baby, and breastfeeding is cited as ‘the one thing’ that the participants feel compelled to do for (and with) their child. Breastfeeding during PABC is experienced as being taken away from the participants, by the illness and by having to have treatment. For some, it is described as the most adverse aspect of the entire PABC experience.

There is a sense of loss of control in being disallowed to breast feed, and consequently disallowed to engage with and care for their baby.

the fact that I couldn’t feed her for very long. That was the worst thing for me really... I mean I know it’s out of my control and I had to get the lump sorted [...] and it’s still difficult. Anna

The participants express how important breastfeeding feels to them, and how devastating it is that breastfeeding must be secondary to treatment. Breastfeeding then seems to become a representation of the many maternal behaviours participants feel are needed and desired to obtain a maternal-infant relationship, and the hindrance of breastfeeding a symbol of the lack of control for the mother, who is desperately trying to connect physically and emotionally with her baby. Lorna feels that a basic right as a mother has been taken away from her and she expresses anger about this loss.

that’s was my right, that was my right as a woman to be able to breastfeed my child and you know, I didn’t have that, it was all taken from me... Lorna
For Anna, there are feelings of guilt\textsuperscript{13} that they have not fulfilled her maternal obligations to breastfeeding, exacerbated by breastfeeding being heavily promoted through official healthcare advice.

\textit{[the advice to breast feed] is drummed into you [...] every time you go and get them weighed, they ask you how they’re fed and each time I felt bad saying “bottle”, each time. Anna}

Nadine expresses the pain of losing what she feels is the privilege of breastfeeding her son, that somehow she is excluded from caring for her son. She feels that consequently she has lost some of her status not just as the mother of her new baby but also as a woman ‘who can do this stuff’.

\textit{What really upset me was I had to stop breastfeeding [...] I could breastfeed on the other side, and when he came along, I was like, oh my God, I can do it, I can do it, I can do it and I was so proud of myself, that I was still this woman that could do this stuff. It was the one thing that I could do for him that nobody else could do and I wasn’t allowed to do it and I hated that. Nadine}

Whilst Daisy’s baby is in the neo-natal unit she feels as if she must practically fight to be able to breastfeed her son during what seems an unhelpful and unkind response from hospital staff. Her physical and emotional need to be with her baby is expressed through her drive to breastfeed him in unsympathetic and unsupportive circumstances.

\textit{I said, “Could I borrow a breast pump while I’m here?” “Yes, you can, the breast pump room’s just down the corridor.” “Well, if it’s all right with you, I’m going to go and get it, because I need to be... I’m trying to establish my milk supply and it’s not going very well, so I need to be near him, skin to skin, you know, and try and get my supply going.” Daisy}

Daisy expresses her anger towards the HCPs for what feels like preventing natural mother-infant interaction and for causing what she considers hurt to her baby, towards whom there is a feeling of guilt.

**Loss of conceptions of parenthood**

Participants experience that they are physically prevented from following their maternal drive and instinct in relation to their newborn, and therefore prevented from carrying out behaviour that

\textsuperscript{13}Feelings of guilt apply across different themes, and are discussed in relation to attachment in Sub-theme 3c.
they feel is normal, and which they may have been able to carry out with their older children. As a result, there is a sense that the development of their role and identity as a mother to the PABC child is compromised. They feel they are prevented from being the mothers they wanted (and had imagined) to be.

Corinne articulates this poignantly, as she describes how her suppressed emotions of fear, frustration and anger come to be expressed and, in that process, taken out on her older child. She seems aware that her difficult emotions are interfering with her ability to parent the way she wants to, and this evokes strong and current feelings of shame and guilt that she acknowledges.

There was a lot of suppressed emotion going on and [husband] and I we said, you know, with disciplining, no smacking, you know, and then when I was pushed to the limit… with having the baby and looking after [older child], being just a normal toddler, when I got angry, I used to lose my temper and I’d whack him over the top of the head because that was the height he was [sobs]… and then when I really lost it, I’d pick him up and then I’d shove him on his bed, you know, like manual handling him to stop him, and I felt so awful inside after I’d done it, because it was me losing it and I was taking it out on him… there wasn’t anything worse than that, that I did, but for me that was really bad and I felt so awful. Corinne

For most participants, there is a sense that the opportunity of being an ideal or ‘good’ mother is taken from them, and they have to give up their conceptions of family and motherhood. This results in experiencing a loss of identity and opportunity as a parent.

 [...] it made all that a bit worse because I’d just had a baby and I thought, this isn’t what I should be going through right now [...] to have to start treatment again so soon after he was born and actually all I wanted to do was just be a mum. I don’t remember the first year of his life, hardly at all. Nadine

I feel devastated because, you know, this isn’t how it was meant to be and everyone’s had such a normal experience, all my friends, thank goodness… Lorna

Chrissy experiences it as unnatural and wrong that she herself is unable to look after her baby and therefore has to leave him with family members.

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14 Feelings of guilt apply across different themes, and are discussed in relation to attachment in Sub-theme 3c.
15 Theme: Expression of emotions: see Appendix 9 for a table of themes identified in the data but not included in the main thesis.
16 Re. the participants saying they do not remember the first year after giving birth, see also Sub-theme 3b.
Yes, that was the worst part for me, relying on others to look after your newborn. Everybody has an image in their head, the pregnant mummy, the daddy, the family and it's all cosy at home... Chrissy

For Nadine, it is a struggle to establish her identity as a mother even further on, including figuring out what the baby might need from her, and also how to feel about it at the same time as being a seriously ill cancer patient. This is causing her to feel inadequate as a mother, and to feel that her husband’s caring for their son is inadvertently exacerbating her helplessness.

[...] when I was at home, I just didn’t feel like it was up to me to do stuff, so I'd think, well, oh, he's crying, well, I won't go to him, 'cause I don’t know how to do it and [husband] knows best because he's been there, and he struggled as well, because sometimes when I'd be like holding him, trying to stop him from crying, [husband] would take him off me, ‘Oh, don’t worry, I'll do it, he likes it like this’ and then eventually I had to say to him 'Can you not do this, 'cause it’s really making me feel bad’, and the baby would always cry whenever he went out. Nadine

Linda seems to feel defiant in her acknowledgement of how cancer has changed the way she wanted to be as a mother and what she has lost in that process.

I felt like what had happened had taken enough away from me and I wasn’t going to give it any more. So from this point onwards it’s not going to interfere with the way I am as a mother, yeah. Linda

The early period after giving birth where identity as a mother and a family is forming, is experienced as sensitive, and there is a vulnerability in the participants’ accounts of their loss which is poignant. For Chrissy, what is happening feels disruptive to the establishment of her core family, and for her as a new mother, and leaving her child (even with family) feels instinctively wrong.

As I say I was reluctant to leave him, I didn’t want to leave him and I felt as if it was invading our privacy as a new family, but I am thankful on the same hand as well, that I did have family close, I could leave him with. Chrissy

Throughout participants’ accounts of their experience of loss of ‘new mother identity and behaviour’ there is a sense of sadness and an expression of grief for what they felt was taken from them and their children. Most participants also indicate that they have feelings of guilt about what they, by becoming ill, somehow caused their children in terms of having to be born preterm, missing out on mother-infant interaction and attachment, being denied breast milk and
being brought into the world in less than ideal circumstances (according to how it was envisaged by their mothers).

\[ \text{I'm always going to feel a bit guilty that she couldn't come out when she wanted to. Anna} \]

And I suppose a bad time was when she was in special care and you know they used to do the handover between the shifts, and they used to go round each baby and they always used to say, and that one is [baby], she is in here because her mum had an elective caesarean because she’s got cancer. I used to feel really guilty that I’d put my child in special care. Katie

**Losing out on having more children**

For a few participants, the ‘loss of being a mother’ includes a loss of being able to have more children after their illness. This has wide emotional and practical repercussions, and Chrissy speaks of the cancer experience as having changed her life plan.

\[ \text{[...] they’ve told me I can’t get pregnant and you know, you can’t have any more children, I find that quite hard to deal with as well... Yes, it’s changed my life plan, because I know I wanted to have four babies, that was the plan with my husband... Chrissy} \]

For Rebecca, not being able to have more children is a painful issue, and a significant symbol of what she feels cancer has taken from her, as she describes it as ‘having eaten her up’.

\[ \text{Yeah, I wanted three, because of my age at one time I would have wanted four, but knowing my age I thought I could fit three in. Sometimes people make plans, and I do feel sometimes envious of those people that their plans are completed or they are able to carry on with those plans. Rebecca} \]

**Interviewer:** What would you say was the worst thing about this, the fact that this has happened?

\[ \text{Not having [more] kids. Yeah, because even at the first few weeks that is what would be on our minds, not the illness. I felt confident that I would beat the illness. I felt that I would be able to handle most things, but that was out of my control not having babies, and that is what has eaten me up. Rebecca} \]

Similarly, for Linda, the vision of a family with more children seems at least temporarily disrupted.

\[ \text{[...] if this hadn’t happened... we would have had more, and probably more than one more because I mean [husband] would love a} \]
houseful, he really would. But I mean because of everything that happened, you think well, there's a million reasons not to now...  

17 Linda

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17 Eight months following participation in this study, Linda gave birth to a second healthy baby.
Sub-theme 3b. ‘That year should have been all lovely’: Bonding and attachment – disrupted by circumstances

For the participants, the natural bonding process with their newborn feels complicated by the practical and emotional circumstances around treatment, in particular being physically separated from their baby. The participants convey how being diagnosed and starting treatment takes over their daily lives, and in a metaphorical (and actual) way takes away from them their pregnancy, the experience of becoming a mother and even part of their relationship with their baby. At a very crucial and vulnerable time for parent and baby bonding and attachment, the cancer experience physically and emotionally interferes with, and sometimes overrules, the mother-infant experience, resulting in what the mother comes to feel are devastating consequences for herself and her child.

Daisy describes this experience as a loss of her entire pregnancy, and a loss of opportunity to engage with her new baby, which any amount of practical and emotional support she receives from other people cannot relieve.

I feel like I kind of lost my pregnancy, and I kind of lost those early days of bonding and being together, and that little bubble you go into when you have a newborn and you’ve got the skin to skin, you’ve had your, hopefully, lovely birth experience, and while we had a lot of support from a lot of people, it was different support. Daisy

[...] obviously, I’d had a prem baby and had a really tough time with that, and we didn’t bond, and I had loads and loads of issues with that. Daisy

The physical separation from the baby whilst having treatment at hospital is difficult and painful for Linda, and brings with it resentment and frustration that was hard for her to express at the time.

I was just really angry that things had to change so much. [baby] was two weeks old and I found it incredibly frustrating because I had to leave him at home and go to the hospital. And everything seemed to be taking so long. It took forever for the chemo to come up to the day unit and it took forever for them to get a line in, and it took forever to get things set up. And it was more and more time that I’m losing with my baby because things just aren’t prepared. And that was frustrating, it really was. Linda

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18 See Sub-theme 2c. regarding participants’ description of family life as a protective ‘bubble’.
19 Support: see Appendix 9 for a table of themes identified in the data but not included in the main thesis.
I had to go for another scan, which meant that I was radioactive. So I couldn’t be within six feet of him for 24 hours. [husband] had him, yes. But it was sort of the additional time that was taken away. Linda

I ended up in the [hospital] for five days. Again, really difficult because [baby] wasn’t allowed on the ward, so I was only allowed to see him in the family day room, if no one else was using it. You had to book it. So I was only seeing him a maximum of two hours a day over that time. I think he was about 12 weeks old at that point... It was horrific, it was really bad. Thankfully, I was sleeping for a lot of it, was really unwell. But it was hard, it was really hard being away from him. Linda

Because you don’t want to be [separated from baby] and you shouldn’t be, and it’s the frustration that if this wasn’t happening, I would be with my child. Linda

Nadine feels similarly that being away from her newborn is painful and frustrating, and that the daily separation from her son after he has visited is particularly heart breaking for her.

I was in hospital with MRSA that was driving me potty, ’cause I had to spend two weeks in hospital away from my baby, [husband] was bringing him in every day but he wasn’t allowed to stay with me, it broke my heart... Nadine

For Nadine and others, treatment and illness dominate their lives in the early days after giving birth and being with and trying to bond with the baby. Further on, there are both physical and emotional problems with managing to look after the baby that overwhelms, and this happens whilst Nadine is still going through treatment with all the effects this has on her. It seems that, in addition to any physical separation from baby due to treatment, there is an emotional separation occurring and that the mother is unwillingly emotionally engaged elsewhere, namely in cancer coping and survival. Nadine is painfully aware of this.

I can remember one day going, just pop to the post office, which was just, literally just up the road, baby started crying and I could not cope. I put the baby in his cot, ’cause I knew he’d be safe and I closed the door on him and I walked away and I just sobbed, ’cause I just couldn’t stop him crying, I couldn’t deal with it right that second, yeah and I don’t know why I couldn’t, you know, I desperately wanted to be involved with his life and do everything for him. Nadine

Several participants feel guilty for not living up to felt expectations about being a mother, and like Nadine, they blame themselves for what seems like missed opportunities to engage, bond and care for their baby with long-term consequences.
I literally wasn’t doing anything with [baby], I think I was struggling, big time… and it hit me like a ton of bricks that, oh my God, I’ve got a baby and I’m bloody lucky to have that baby and I need to start pulling my finger out, so when [husband] arrived with him I was like, right, I’m doing it now. I did really feel like a spare part, I certainly wasn’t really a mum and actually I think it’s had quite a knock-on effect even now…. yeah, I feel like I’m not really the greatest mum, to be honest, because of that. Nadine

For Chrissy and others, it is difficult to let others help with the baby and thereby partly perform what she sees as her role, but she feels this is necessary as she cannot physically be with him as much as she feels she needs to. Something important is taken from her and from her child, both literally and metaphorically, as she passes her child over to other people.

[Baby] was tooty, to me [...] and just getting other people to have mummy time with the baby, that absolutely annoyed me, but I had to do it, because I had to go and get treatment and such like. Chrissy

That was definitely the worst, yes, I couldn’t... having to rely on other people and you know, when you get a new baby, you want to keep it all to yourself, it’s your new baby, you like visitors coming, but they have a wee hold and they give you him back, type thing. I didn’t like having to pack a bag up for him, hand him over and not seeing him till later on that day and stuff. That for me was the worst thing, having cancer and having a new baby. Chrissy

...but to me a wee baby that size needs his mum, and I think the mum needs the wee baby as well, that’s what I didn’t like about it. That’s what I would say cancer really bloody annoyed me, making me having to leave my wee new, tiny baby. Chrissy

The problems are extensive, with some participants feeling that these are mortally impacting the early sensitive mother-infant relationship. This brings about a sense of ‘Yes, I survived, but look at what I lost’, as articulated by Nadine and Daisy.

I think the difference is the effect that it has on your, personally, for me, I’m sure for everybody it’s very different, but for me, it was the relationship that I had with my son that I’ll never get back, never, and it does upset me. Nadine

Interviewer: Do you feel like... is there a sense of sort of missed opportunity with [baby]?

Daisy: Yes, very much, very, very much. I still look back at that time and I still... mine and [baby]’s bond, although it’s there and it’s massive now, it’s much, much better than it was, at one time there was nothing. No, not nothing, that’s not fair to say really, I’ve always loved him and I
would always walk through fire for him but there was something just missing, just...just some connection there that just wasn’t, you know, that should have been. And although it’s better it’s different. Does that make sense?

The sense of loss extends into the past, the present and the future, as there is loss of family life memories, as well as the vision of a life that should or could have been, but seemed pointlessly and permanently taken away from mother and child. Several participants express how they cannot remember much during the first year of baby’s life. There are questions about what may cause this. Are participants’ memories blurred by the physical effects of treatment and the turmoil of daily life as a cancer patient and parent at the time? Or could it be that not remembering is an unacknowledged way of coping with the overall memory of a time filled with fear and worries and thoughts of death and separation from loved ones? These questions are discussed further in Chapter 6.

I just feel sad that we didn’t have that year that should have been all lovely... I mean, I’ve watched videos that we’ve taken, ’cause we did film a lot and I just can’t remember him babbling away like he did or anything and I wish I could have that back, even if it was just a day and I do feel a bit cheated of that, I suppose. Nadine

I mean, it’s sad to say now, but the first, kind of, six months of [baby]’s life, just, kind of...that’s what upsets me now that, it’s hard to remember when he was a baby. Chrissy

We had friends here yesterday with little babies and just holding them and I just thought, I can’t remember my little boy being like that because I was in hospital, I was drugged up on God knows what and a lot of the time was spent in bed, being really, really ill... Nadine
Sub-theme 3c. ‘I think I kind of withdrew from him’: Protective distancing myself from baby (and from others)

Withdrawal

Some participants express how they intentionally distanced themselves psychologically from the pregnancy and from their baby out of fear that they or their child might not survive the illness. This active disengaging from the pregnancy and/or the baby is experienced as being for the emotional protection from the loss which would have occurred had one of them not survived.

[...] it was almost as if with the pregnancy, it wasn’t a pregnancy at all because I was definitely protecting myself in case the baby, you know, wasn’t going to survive. I can remember sort of with [older child], [my husband] and I used to look in the book and say “Oh after so many weeks, you know, that’s been developed and what have you”... we didn’t do that with [PABC baby] at all... Yeah, I was sort of, yeah... distant, and as well with telling people, it wasn’t sort of like with [older child], “Oh I’m pregnant” and all really great news, because I didn’t know how to feel about this one. I was really pleased because we obviously wanted the pregnancy but because I was so concerned about whether or not the baby would be alright, let alone me, I didn’t go round telling people, I just kept it quiet. Corinne

Corinnee seems to be holding off engaging with her pregnancy until she can be more certain that the baby (and she) is going to be alright. She avoids investing her emotions in her baby by denying or ignoring that she is pregnant. Even considerably further along in her pregnancy, when Corinne and her husband have told people about her pregnancy, she feels uncertain about her baby surviving, to the extent that she does not prepare in practical terms for the baby’s arrival in the way she might otherwise have.

Yeah, with the pregnancy, my sister’s friend had a double buggy and... she said “Oh you’re going to need this, you know, you’re going to need a double buggy”, but... I didn’t want it in the house just in case [baby did not survive], you know... I thought ‘Na, just in case’ and I didn’t get the baby clothes out that [older child] had... Corinne

For Daisy, whose baby was very preterm, there is a clear sense of her loss of time and opportunity to engage with her newborn which is driven by her fear of death. This fear seems unwarranted to her as she thinks back on it in the present.

I think part of the reason... I’ve always said this... part of the reason why we didn’t bond was like self-preservation, not just for me but for [baby]. I think it was kind of I withdrew from him because I didn’t know if he was going to be okay, but I also withdrew because I didn’t know if I was going
to be okay, and it was almost as if I wanted to protect him, which is silly, really silly. Daisy

Daisy describes the fear of dying as a physical hindrance to bonding with her baby, and how it feels practically impossible for her to do what she feels naturally compelled to do, which is invest her feelings unreservedly in her child.

[...] you do have those thoughts, ‘Am I going to be here in five years? Am I going to be here in a year?’ You just don’t know, do you? And I think that was part of it, it was like self-preservation because I didn’t know whether he was going to make it and I also didn’t know if I was going to make it, so, again, it’s like a barrier, isn’t it... Daisy

For Katie, the prospect of dying evokes a maternal protective instinct towards her older child, and this is whom she distances herself from.

I suppose the other feeling I had was my elder daughter, she will have been four at the time... I think I pushed her away a bit because I didn’t want her to be too close to me in case anything happened to me. I pushed her towards her dad. Katie

I protect them both but I protect [older child] I suppose by pushing her away so she could get used to things without me. Katie

In Rita’s case, it is her husband who seems to initiate an emotional and practical disengagement from the pregnancy, out of fear and worry for the survival of the baby. By disengaging emotionally from the pregnancy until they are sure that the baby will be fine, the parents seem to distance themselves psychologically from any potential negative outcome, the worry in the moment is lessened, and they are better able to cope with the situation.

My husband said the other day [...] something about he didn’t even let himself think what [PABC baby] might be because he was so worried about whether or not [baby] would be okay, he didn’t want to even focus on whether [it]’d be a boy or a girl because he didn’t want to let himself think far ahead enough. Rita

Feelings of guilt
In relation to their fears and worries about the survival and well-being of the baby, the participants’ behaviours of emotional and practical distancing themselves from the pregnancy and the baby invoke feelings of guilt in the mother that seem to linger into the present.
I think just a massive sense of guilt. I think, you know, as a mum it’s one of the strongest emotions I think... [...] just a massive sense of guilt, and a loss, I think, I feel like I kind of lost my pregnancy, and I kind of lost those early days of bonding [...]. Daisy

Daisy feels she has difficulty bonding with her infant, and as a very preterm baby with the early period spent in the neo-natal unit, she also feels her baby took time to learn to engage with her as his mother. This is painful to her, and leaves her with guilt.

It was awful, it was absolutely awful, and I think because we’d already had problems with bonding I think that made me feel even more guilty, and it made me feel rejected, and, again, even more like I’d done something wrong. Daisy

Four years after giving birth to her son, Nadine continues to have guilt feelings about not being the kind of mother she feels she ought to be, including being attentive and connected to her son, which means hearing him call out during the night.

I can't hear him, you know [...] randomly in the night, I can't get up and it's crazy, you know, how can you not wake up to that, but it’s true, I can't hear a thing. Nadine

For her, breast cancer has disrupted her maternal instincts and confused her role as a mother, and in that process she feels she has lost some of the relationship she might otherwise have had with her son. This is the actual effect of the event.

[...] cancer wise, I don’t feel that there is [a difference between PABC and being diagnosed when not pregnant]... but the effect that it has on the baby, on your relationship with the baby, I think that’s where it comes into it. Nadine

There is a sense amongst the participants that the PABC child lost out because of the mother’s illness and treatment, that the mothers put the children through the trauma of being born preterm, being deprived of breast milk and experiencing a lack of maternal attention and attachment opportunity. The mothers put a large amount of blame on themselves for these occurrences.
The women participating in this study are all ‘survivors’ of PABC\textsuperscript{20}. Some of the guilt feelings that participants feel towards their children may be linked to a realization that, because death ultimately did not occur, distancing themselves emotionally from their baby for emotional protection was effectively unwarranted. It may unnecessarily have caused damage or loss to their relationship and/or to the well-being and attachment health of their child. Subsequently, there is a feeling of wanting, or needing, to compensate the PABC child for the damage/loss, and this is done through the continuous construction of the relationship with the child as ‘special’.

**The Special Relationship**

The participants who have other children seem to perceive their relationship with their PABC child as ‘special’ in comparison. The notion exists that, even though the PABC child would not have known or been aware of the mother’s illness due to being a fetus/newborn, the two of them have been through the emotional and physical trauma of the illness together. They ‘fought’ cancer together, and therefore have a special connection to each other (this links in with Super-ordinate theme 2: My baby saved me). In spite of it being the older children in the family who would have consciously experienced the mother’s illness and treatment, it is the PABC child who is perceived by the mother as having been present with her in the experience, by being physically located inside her body at diagnosis.

 […] but I’ve always felt really close to [PABC child] because we had gone through this trauma together, I felt closer to her. And still now, if something happens I always go for [PABC child] first, because I know that [older child] will be alright with her dad. Katie

It seems it is the ‘sharing’ of the illness, the timing and combination of mother, baby and illness, that stands out for the participants as being significant, and the baby is implicated both physically and emotionally in the experience more so than the rest of the family. Even if there was never any actual threat to the baby’s well-being or life, being a PABC baby is construed as being his/her mother’s special child. Corinne describes her son as ‘the baby that’s lived through’.

I’ve got a really close bond with [PABC child] […]. But then part of it is he’s gone through that experience with me so in a way that’s given me perhaps also another closer bond because he’s the baby that’s lived through […] Corinne

\textsuperscript{20} Lorna and Chrissy were diagnosed with secondary breast cancer following their initial PABC diagnosis, and were stable at the time of participating. Nadine was diagnosed with secondary breast cancer whilst pregnant (see Chapter 2, Table 1).
This perception of the special relationship and special bond affects the mother’s relationship with her other children as again, in the case of Corinne.

*I’m finding it difficult to juggle the two relationships to show [older child] that I love him very much. On the other side it’s an easier relationship with [PABC child] than it is with [older child]. [...] Don’t get me wrong, [PABC child] has a lot of difficult traits in his personality as well, but I’m just saying in terms of like the bond, you know.* Corinne

Corinne is aware that her special bond with her PABC child has affected the relationship with her older other child who was present and at the receiving end when she expressed her fear through anger and frustration (see Sub-theme 3a).

*There’s going to be other women like that that are going to feel really guilty and out of control and then I think it has affected my relationship with [older child], I really do. And then I do worry about him so you know I hope he’s okay [sobs].* Corinne

Linda describes herself as a ‘clingy’ and ‘overprotective’ mother, and explains in vivid terms how her relationship with her son is emotionally close, and how she maintains and nurtures this closeness. It could even appear that she has developed a degree of separation anxiety around being away from her young child.

*[I am] very clingy, didn’t want him to sleep out until he was two. I [wouldn’t] even allow him to stay at my mum’s... [...] if he stays out on a Saturday, I get up on a Sunday morning I’m like, I have to go and get my baby. I think I am a lot more clingy. I think I didn’t hand him to other people as much as I probably would have if I hadn’t been going through that.* Linda

*Then when I was having to be away from him, I found that really difficult. Anyway, like the second I got back I was... yeah. So yeah, anyone else getting a look in, sort of other than my mum if I wasn’t feeling too good or whatever, I mean she’d hold him all day. But she’d sit next to me so I could look at him. Yeah, now I think I am incredibly overprotective, I know I’m overprotective.* Linda

The notion of the special relationship is discussed further in Chapter 6.
Chapter 6 Discussion

Overview

The aim of this study was to uncover the phenomenological experience of having breast cancer diagnosed during pregnancy or within the first year of giving birth. The emphasis was on identifying and understanding the aspects of the experience unique to the condition, which is under-researched in the field of counselling psychology. As such, it was important that this was carried out mainly from an ‘insider’ position in order to achieve enhanced access to participants, their experiences and particularly, to their meaning-making (Woolfe et al, 2010).

The study provides direct evidence from PABC-affected women that the experience of cancer during pregnancy causes significant psychological turmoil and distress, which in its quality is unique to this particular condition. It details participants’ concerns and demonstrates how these are underpinned by experiences of anguish, loss and grief, and how this is countered by the generating of coping mechanisms and adjustment.

This discussion presents the superordinate themes identified within the context of the existing literature and theoretical background, and reflects upon their practical implications. The study’s limitations will then be considered and suggestions for future research offered.
6.1 Main findings conclusions based on the data analysis

“Parenting is a mirror in which we get to see the best of ourselves, and the worst; the richest moments of living, and the most frightening” Kabat-Zinn (2009).

Super-ordinate theme 1: Whose life comes first?

The experience of ‘whose life comes first’ concerns an internal struggle (the mother’s experience of her life positioned against the baby’s) juxtaposed with an external struggle (obstetrics versus oncology). See also Chapter 3.

Sub-theme 1a. ‘I’m not putting [my baby] in danger’

Good mother ideology

The experience of ‘whose life comes first’ may be explored through contributions to the ‘good parenting debate’ (Campbell, 2013) and specifically, to shared notions of motherhood. In Western society, our dominant social norms around parenthood involve the conception that an essential part of being a morally ‘good’ mother means putting your child’s needs first and above your own (May, 2008; October et al, 2014). Research shows that most Western women recognise this standardisation of ‘good’ mothering (Hays, 1998; cited in Sevón, 2009). This is not ‘natural’ or evolutionary, but a socially constructed guide for behaviour and action (Smart, 1996). It is therefore pertinent to ask the question of what kind of parents we are judged to be, if we do not put the needs of our children before our own? There is a felt obligation as parents (and perhaps particularly as mothers) to self-sacrifice for our children, and this is a principle, which is used to certify the ‘good’ parent (Ribbens McCarthy et al, 2003). In the participants’ case, we might add the question of what mother would risk harming her baby by prioritizing herself (thereby displaying her ambivalence about motherhood for all to see), and society’s answer is likely to be only the most incapable kind (Hollway and Featherstone, 1997). We all strive to be good parents because that is one way of earning our place in society. If we neglect to be good parents, society places social sanctions on us, in the form of withheld understanding and empathy, social exclusion and stigmatization. Presenting with two very ‘public’ conditions that are pregnancy (Taylor and Langer, 1977) and cancer (Gibson et al, 2016), there really is no choice for the mother other than to choose from a position of self-abnegation and put her baby first. The question of ‘whose life

21 We even nurture the culturally dominant fantasy of ‘the perfect mother’, an idealized and unattainable ‘omnicOMPETENT angel’ (Davis, 1996, p.366; Chodorow and Contratto, 1982).
comes first’ becomes more complex as the women who have older children\textsuperscript{22} feel an additional impulse to prioritise their own survival and health in order to be there for them.

**Denial as method of coping**

Most people associate cancer with death, and even if it is somewhat expected, most cancer patients experience shock at being diagnosed\textsuperscript{23} (Brennan, 2004). An early and common response, before any ‘adjustment’ to the situation can begin (Brennan, 2001), is to distance oneself psychologically by (subconsciously) denying the reality of the situation. As a coping strategy, this helps to reduce the patient’s short-term distress and is an adaptive response (Vos and De Haes, 2007). Focusing on and prioritizing your baby at diagnosis seems to enable participants in this study to suspend the shock, the immediate thoughts and worries about themselves, and temporarily deny (and avoid) the impact of having just been diagnosed with a potentially fatal disease. By putting baby first, baby, with all the positive associations that the concept of a new baby typically holds for its parents (Delmore-Ko et al, 2000), becomes what matters in the here and now, and participants can push off the many psychological complexities of the diagnosis, or adopt the stance that they may deal with these later or let others (such as HCPs) deal with them. Denial of the (felt) severity of the situation may also contribute to the reason why some participants seem outraged at HCPs indication that they terminate the pregnancy in order to simplify and advance treatment. Being ill from treatment and dying from the disease may be a somewhat abstract and inconceivable prospect, and can therefore not ‘compete’ with the stronger and more (socially) acceptable maternal drive to protect the baby at a point where it is perceived that a choice is required.

**Control, psychological defence and hope**

As described in the findings chapters of this study, participants typically perceive their situation as very threatening and uncontrollable at diagnosis and in the early days after. Some participants contemplate resisting a termination of the pregnancy even before having discussed it with any HCPs, and without knowing if termination is a relevant issue at all. It could therefore seem that the question of terminating the pregnancy represents an important element of control in the situation. It is known that a sense of control plays a role in the cognitive adaptation of threatening events such as a cancer diagnosis, and that a sense of control helps subsequent adjustment to the experience (Taylor, 1983; Taylor et al, 1984)\textsuperscript{24}. Is putting baby first and above themselves immediately upon diagnosis, participants’ way of seizing any such control that they

\textsuperscript{22} Eight of the eleven participants. See also Table 1.

\textsuperscript{23} Emotions (shock): see Appendix 9 for a table of themes identified in the data but not included in the main thesis.

\textsuperscript{24} Control: see Appendix 9 for a table of themes identified in the data but not included in the main thesis.
feel can be had? As such, it may also function as an emotional ‘grounding’ mechanism for participants, including a way to establish some damage limitation (my child shall not be affected by this) or control the ‘worst case’ scenario, as a type of ‘terror management’ (Buss, 1997; Solomon et al, 1991). Rushing into considering the non-question of termination could also be understood as a form of ‘catastrophising’ about the perceived uncertain situation, as the participant imagines she will be forced to abort her baby. Norem and Cantor (1986) discuss ‘defensive pessimism’ as a method of unwarranted pessimistic response in preparation for failure. Seeking control and catastrophising are then considered here to be adaptive psychological defences against the problematic thoughts and emotions occurring around diagnosis, and are designed to minimize the manifestation of these in the participant’s conscious awareness (Blackman, 2004; Brennan, 2001).

In line with the above, notions of hope and continuity of life may also play an important role. Studies have found that factors such as attitude (e.g. hope and optimism, or a lack of it) (Applebaum et al, 2014; Carver et al, 2005) and style of coping (e.g. avoidance, emotion-focused coping, problem-focused coping) (Lazarus and Folkman, 1984) will significantly affect a patient’s psychological adjustment to having breast cancer (Epping-Jordan et al, 1999; Rustøen, 1995; Watson et al, 1991). Hope is defined as an ‘intuitively positive future-oriented influence’ (Sanatani et al, 2008, p.494). Is the priority of the baby (in contrast to the question of termination explained above) a representation of hope, and an expression of optimism about survival and the future? Park et al (1997 and 2010) describe how constructive thinking during pregnancy, and finding positive meaning in cancer survivorship, can function as a significant and adaptive coping capability. In addition to psychological adjustment, emotional and attitudinal factors are in some studies believed to influence the physical survival of cancer (Creagan, 1999). As such, the mother may ‘need’ her baby for the purpose of surviving herself (see this chapter for Discussion of Superordinate theme 2). The baby thus becomes the mother’s hope (Little and Sayers, 2004) and her future.

The human survival instinct is strong, and the desperation to avoid death, and not be separated from the people we love, when it is stripped bare, may be too difficult to confront and manage. It could therefore be that patients feel a need defend themselves by wrapping this in a milder, more acceptable and positive narrative whenever they have to face or ‘handle’ it (such as in interview for this study). McAdams et al (2001) consider how people make sense of negative experience in a ‘redemption sequence’, where ‘the storyteller depicts a transformation from a bad, affectively negative life scene to a subsequent good, affectively positive life scene. The bad is redeemed,
salvaged, mitigated, or made better in light of the ensuing good’ (p.474). That narrative here is
clearly focused on the unborn child, and entails creating meaning and purpose and redemption
around a situation of existential fear, as an important part of psychological adjustment.

Guilt and shame
Guilt is defined as ‘self-conscious negative feelings about one’s behaviour or behavioural self-
blame’ (LoConte et al, 2008, p.172). Maternal guilt is well-documented and a pervasive part of
our culture’s ‘good mother’ ideology (Sutherland, 2010). Could feelings of guilt about having
contracted cancer whilst being pregnant contribute to making participants choose to immediately
put their baby above themselves? If so, guilt feelings could exist around the mother being
interrupted by cancer in the fostering of and relating to her unborn child (Vallido et al, 2010) and
perceiving to fail in the protective maternal role, including the notion of cancer ‘competing’ with
the child (and winning) for the mother/patient’s focus and concerns (Elmberger et al, 2005;
Elmberger et al, 2008). Self-blame is a well-documented way of finding cause and meaning in a
cancer diagnosis (Abrams and Finesinger, 1953). Some participants express feeling specific guilt
around having to give birth preterm due to starting treatment. Putting the baby first could be
helping to balance the guilt at both being diagnosed, and at allowing the baby to be born
preterm. Participants also seem to be feeling guilt about the idea of their cancer illness affecting
the baby negatively, e.g. harming the baby’s life in terms of its development and natural life
trajectory at its most early and vulnerable stage. In addition, guilt may seep in with the mother’s
fear that cancer could eventually kill her, and that the baby will then be motherless.

‘My first thought’
In discussion, it is necessary to acknowledge that participants may ‘simply’ prioritise their baby
and, when faced with their dilemma, feel that the baby’s well-being and safety is more important
than they are themselves. In studies of parenting and motherhood during cancer, a common
finding is the magnitude of parental concerns about the impact of the illness on their children
(Baltisberger, 2015; Moore et al, 2015; Rauch and Muriel, 2004). A recent study of how mothers
with breast cancer manage the balance of work and family (Mackenzie, 2014) is titled ‘It is hard
for mums to put themselves first’ (p.96). The diagnosed mothers may have felt the baby move,
and already be experiencing a strong prenatal/maternal-fetal attachment (Doan and Zimerman,
2003; Brandon et al, 2009) which, from an evolutionary perspective, develops for the baby’s

25 Emotion: Guilt - see Appendix 9 for a table of themes identified in the data but not included separately in
the main thesis.
26 Impact on baby: see Appendix 9 for a table of themes identified in the data but not included separately in
the main thesis.
survival and protection (Cortina and Liotti, 2010). Pregnant women typically start developing a maternal protective instinct around the time of feeling the fetus move (Reron, 1995). In most participants’ cases, theirs is a planned, wanted and longed-for baby, and the successful conception and pregnancy may be so elating for the mother, that the expected maternal gratification eclipses or even drowns the fears and worries about her own mortality. As she feels compelled to choose, the choice to prioritise herself above her unborn child would clearly bring on thoughts about the reality of having a termination of the pregnancy. A termination is actively choosing death for her (alive, kicking and healthy) baby in order to focus on her own provisional survival. What is the possibility for a woman who wants (and is set to have) a child to make that choice, even if (or, just because) her own life is perceived to be threatened? Carlsson et al (2016) claim that, in women carrying a wanted child, having a termination (due to fetal anomaly) ‘deeply challenged [their] maternal instincts’, as instead of nurturing the child, they are ‘part of ending its life’ (p. 57).

Sub-theme 1b. ‘I let them fight it out’

Instincts colliding
At diagnosis and until after giving birth, participants experience the development of a medical discord between their obstetric HCPs and their oncology HCPs concerning the prioritisation of healthcare. Although most participants accept giving their HCPs full control in their birth and cancer treatment planning, the conflict enacted within the healthcare setting feels pervading, and validates giving attention to the notion of a real dilemma between mother and baby. In the dilemma, the participants’ maternal protective instincts relating to their unborn children is pitched against the other strong human instinct that is their own physical survival. Evolutionary forces are played out against each other in the space of time from receiving the diagnosis to giving birth. This struggle between mortal instincts is mirrored and reinforced by HCPs explicitly discussing and arguing their different agendas. Should the baby be left in the womb for longer time to safeguard its health, or should the baby be born preterm to give the mother the best chances of effective treatment, or should we treat the mother now whilst still pregnant and manage the risk of harm to the baby?

The women may instinctively question whether their primary identity in this situation is that of ‘a person’ or ‘a mother’ or a ‘new mother’. Research shows that HCPs do not acknowledge women’s dual identities as mother and patient, and that ill women tend to view themselves as

See Chapter 2, Table 1. Participants’ Demographical Information, for how long this was for each participant.
mothers first and patients second (Vallido et al, 2010). In addition to any feelings of wanting to survive for one’s own sake, for entirely egoistical reasons, and the fear that the concept of death evokes, your own survival represents the ‘survival’ of your other children, and in the prevailing situation it is up against the perceived survival of your unborn baby.

In addition to and in accordance with the approach of oncology HCPs, the pregnant woman’s relatives and friends are likely to want to prioritise the woman over her unborn child, as this is the person with whom they already have an established relationship, and as they do not typically experience attachment to the fetus. The pressure felt by some participants from their oncology HCPs, and expressions of family and friends’ preferences and prioritisation may cause anxiety and confusion for the woman as it clashes with her own instincts.

It must also be asked, however, if the possibility exists that participants experience the dilemma and make the rapid choice in their minds of putting baby first, precisely because they feel a need and drive to put themselves first? Because they desperately (and naturally) want to survive as an individual, and not simply as mother to this baby, and at the moment of diagnosis there is ample feeling of chaos and threat (Brennan, 2004) stripping away anything but the most raw desire to survive. Participants then feel compelled to do the opposite of what they want for themselves, in a kind of automatic and conflicting behaviour – the ‘paradox of altruism’ (Churchill and Street, 2002, p.87), which is demonstrating of the complexity that goes on within participants’ internal state. However, this choice, which may be feel ambivalent to the mothers or it may not, is as previously discussed, intolerable by society’s mothering standards (Sevón, 2009). This behaviour may relate to the family systems concepts of self-differentiation and fusion (Jankowski and Hooper, 2012). Which anxieties are the mother’s own, and which are the mother’s on behalf of her fetus? As discussed below, participants feel in alliance with their baby, but to what extent are the boundaries between mother and fetus blurred? When it comes to life and death, does the pregnant woman feel that she is one person carrying a child, or two persons combined in one?

‘Maternal-fetal conflict’

There is no medical protocol for PABC that prescribes that a choice must be made of whether to terminate the pregnancy or not (Eedarapalli et al, 2006) and ‘termination of pregnancy and postpartum delayed treatment are not routinely recommended because they do not improve survival’ (Rovera et al, 2013, p.65). However, participants still describe experiencing a dilemma concerning the balancing of their own life and health against that of their baby, and most immediately rank their unborn baby as more important than themselves. It becomes clear that in
spite of the immediate experience of being in a dilemma, the mothers also feel themselves to be in a form of alliance with their baby, that they are in the difficult situation together, ‘fighting’ on the same side, rather than being opposed to their baby. Where HCPs may have decided that a medical maternal-fetal conflict exists, the mothers clearly experience the opposite, a maternal-fetal alliance, which is of psychological benefit to them, as it offers a sense of reciprocal closeness and protection which seems to provide some psychological strength.

The term ‘maternal-fetal conflict’ is both useful and problematic in this study. Flagler et al (1997) discuss the wrongfulness of the indication of a conflict between the interests of mother and the fetus, when in fact it exists between the woman and the HCPs. This study represents the mother’s perspective, and examines the experience of being implicitly informed that you are in virtual competition with your unborn and wanted child for survival. The mothers feel distraught, but they are experiencing a dilemma which may not be entirely theirs, but may belong in healthcare practices and norms. Oberman (1999) describes the maternal-fetal conflict from the traditional perspective of when the pregnant woman makes choices which could compromise the well-being of her fetus, and points out that the doctor is not a neutral party here: ‘Doctors project their own estimations of the optimal course of action onto their pregnant patients and invest the fetus with interests that directly coincide with his own personal treatment preferences. The pregnant woman’s interests are rendered in direct opposition to those attributed by the doctor to her fetus’ (Oberman, 1999, p.454). Oncology HCPs working with PABC patients, whose focus is to cure the woman from cancer, also work with a conflict–based model of the situation (Harris, 2000; Pinkerton and Finnerty, 1996), and automatically cast the mother and infant as adversaries, affecting the participants’ experience of the mother-fetus relationship negatively. ‘Pregnant women must confront the diametrically opposed facts of a life-giving and a life-threatening process’ (Oduncu et al, 2003, p.134). The perception of the dilemma could therefore be understood to having originated in external influences, namely healthcare models and services, and HCPs’ interpretation of cancer and cancer treatment. The mothers in this study are never in an ‘impossible’ dilemma, because most of them immediately and without hesitation prioritise the health and well-being of the baby. It could therefore be due to a perception of a conflict between mother and baby, which is communicated to the mothers through their healthcare, that a dilemma is created.
Doctors’ inexperience, a lack of training and preterm delivery

PABC is still a rare occurrence, but estimated incidence figures vary greatly\textsuperscript{28}, and no UK national register exists. Official ‘Green-top’\textsuperscript{29} guidelines for medical management are issued only by the Royal College of Obstetricians and Gynaecologists (RCOG, 2011), and research into treatment options is increasing, continuous, and international (Amant et al, 2010). In 2016, a comprehensive book was published on oncological and obstetric care of women with pregnancy-associated cancer of several types, and including psychosocial management (Azim, 2016). Most participants reported that theirs was the first and only case of cancer in pregnancy in the history of the healthcare team that treated them. One doctor openly expressed that he was entirely unsure what approach to take with the participant in terms of birth and treatment planning and implementation. No participants experienced that their HCPs consulted with other HCPs about optimum treatment, or at least, let them know about any such consultation. For participants, this felt worrying at the same time as offering them a special and favourable status with their HCPs, which lead to some gratification\textsuperscript{30}. Only a few participants experienced a multidisciplinary management of their condition or saw a mental health practitioner in the first year after diagnosis. There seemed to be little consideration from HCPs of patients’ parental responsibilities and urges.

The lack of general awareness and information extended to the participants, most of whom were unsure that their unborn baby would be safe in the womb whilst they were having chemotherapy. Pregnant women are generally told not to smoke or drink alcohol (NHS, 2016a, 2016b), and so would seem reasonable to be worried about exposure to chemotherapy. However, chemotherapy has now been established as safe for both mother and fetus during pregnancy after the first trimester (Amant et al, 2012; Becker, 2016), and in some places in the UK, it has been administered for several years\textsuperscript{31}, although this information does not seem to be widely shared in maternal-fetal medicine or oncology (Ring et al, 2005). Likewise and depending on individual presentation, research has now established that there is no medical need to deliver the baby early to start treatment (Azim, 2016). Preterm delivery is shown to be a major cause of worry for pregnant women (Yali and Lobel, 1999). However, the majority of participants in this

\textsuperscript{28}See e.g. Azim (2016) compared to CRUK (2016b).
\textsuperscript{29}A Green-top guideline is a concise document providing specific practice recommendations on focused areas of clinical practice, not intended to dictate specific treatment but to be adapted for individual cases. (See also: https://www.rcog.org.uk/en/guidelines-research-services/guidelines/about-rcog-guidelines/#gtg)
\textsuperscript{30}Theme: Doctor takes personal interest: see Appendix 9 for a table of themes identified in the data but not included separately in the main thesis.
\textsuperscript{31}Participant Corinne was treated in the UK with chemotherapy whilst pregnant in 2001, and gave birth at full term to a healthy child.
study had elected preterm deliveries, with the earliest baby delivered at 32 weeks gestation. Although necessary in some cases, this practice conflicts with patients’ wishes, and there is evidence that HCPs are aware of the mother’s moral dilemma as additional to their own medical one. Rovera et al (2013) describe this as HCPs showing ‘recognition of the patient’s desire to complete gestation’ (p. 66). The most recent treatment guidance for obstetricians says treatment should be carried out within oncology centres offering expertise in cancer during pregnancy (RCOG, 2011). In many cases, it is not yet, and women are treated by their nearest cancer service. This raises the question of whether a lack of medical expertise is the reason most of the participants’ babies are born by elected preterm delivery, in spite of evidence to say preterm delivery is not necessary. If that is the case, many women diagnosed with PABC may have been forced to give birth preterm, with unidentified consequences for their children, not due to treatment requirements as may be the patients’ general perception, but due to a lack of experience and training within healthcare teams. This inexperience therefore poses ‘a threat to pregnant breast cancer patients and their fetuses’ (Becker, 2016, p.83).

**Oncology rules**

Participants’ accounts demonstrate that they experience that it is the patient’s oncology team who sets the agenda and decides when and how the birth will take place. Determining the diagnosis, oncology assumes power, and the HCPs within this field control the overall birth and treatment plan. You could say that the pregnancy and birth are, alongside some consultation with obstetrics, adapted to fit in with and around the start of cancer treatment as the primary focus (NICE, 2004). Although hesitant and worried, participants seem accepting of this, or at least to feel that they have little choice. van Kleffens et al (2004) state that the amount of pressure oncologists will put on their patients to follow recommended treatment is linked to the question of whether the treatment is curative or not (with more pressure applied for curative treatments). At the same time, the responsibility of being an ‘empowered’ patient who makes treatment decisions herself, can be too overwhelming for the patient at this initial stage (Salmon and Hall, 2004).

Patients’ perceptions of cancer are historically those of a disease which is frightening, involves high levels of pain and suffering, is often non-curable and leaves the patient with little control (Bell, 2009; Kaptein and Lyons, 2010). As such, it is interesting to speculate whether oncology is perceived as a higher order of medicine because it is about ‘curing cancer’ and saving lives from a serious external threat, and because oncology intervenes at a crucial point when disaster has already struck (in contrast to obstetrics where a typical and normal pregnancy and birth is

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32 See Chapter 2, Table 1 for participants’ demographic information.
relatively ‘unchallenging’ from a medicinal viewpoint). It could be argued that oncology seizes upon this power with guidance statements such as: ‘The fetus may be allowed to mature until 24 weeks of gestation’ (Oduncu et al, 2003, p.134). And it may help explain oncologists’ documented low ability to identify patients’ emotional distress, as patients suppress this for fear of disturbing the oncologist in their imperative work (Söllner et al, 2001).

For participants in this study, their passive disposition may be diminishing their autonomy in the obstetrics versus oncology disparity. In addition, perhaps a sense of urgency and fear (a deer in the headlights response) overwhelms participants’ faith in their own decision-making and information-gathering abilities, and oncology unintentionally exploits this opportunity to take control and ensure optimum success rate for their particular treatment course. However, as the highly vulnerable party (including participants’ felt vulnerability), it is understandable that the participants would need their HCPs to be the authority, to take charge and manage the birth and treatment and enable a recovery. Between obstetrics and oncology, it could be difficult for participants to know what is the right or best or safest way to proceed. This may be why many fall back unto their basic maternal protective instinct to prioritise and protect their baby. This fits in with sub-theme 1a.
Super-ordinate theme 2: My baby saved me

Super-ordinate theme 2 is concerned with the participants’ experience of being saved from cancer by their pregnancy and baby (see also Chapter 4). The theme examines participants’ efforts to make sense of (and find meaning in) the collision of the two life events, pregnancy and cancer. Meaning-making is here defined as ‘meaning-based coping strategies through which individuals cognitively change their interpretations of events or standards for comparison’ (Danhauser et al, 2005, cited in Park, 2010, p.263) and ‘the restoration of meaning in the context of highly stressful situations’ (Park, 2010, p. 257). Finding (or constructing) meaning as both an automatic/subconscious process and a conscious effort, is known to be important for longer-term psychological adjustment to distressing experiences and traumatic events (Park, 2010). The conceptualization of the pregnancy and baby as an essential physical and psychological rescue device for the mother-with-cancer conveys important meaning to the unfortunate and rare timing of the two events.

The participants’ experience contained in the theme ‘My baby saved me’ are complex and open to multiple interpretations. It is posited here that the participants experience that their pregnancy and baby save them by helping their coping and adjustment, including providing motivation and distraction, and getting to a level of acceptance by finding meaning in the event that is cancer and in post-illness life. Reflecting on this mechanism, it can seem logical that participants should feel lucky to be pregnant at diagnosis, as despite the initial shock and devastation, the baby is the ultimate incentive and an effective instrument in their survival and adjustment.

The interpretation of each sub-theme 2a and 2b is highly relevant for the other and overlap. However, discussion of these two sub-themes is presented separately to reflect the difference in the conceptualization of the pregnancy/baby as a physical rescue (2a), and as a psychological, emotional and motivational rescue (2b) for the mother.

Sub-theme 2a. ‘I could have been dead a long time ago’

Extra power

The participants describe how they felt that being pregnant (and having the baby) physically rescued them from their cancer illness. Many of them believed that it was their pregnancy which initially alerted them to their disease, as despite existing indications, physical cancer symptoms were only investigated after early pregnancy consultations with their GP, or in connection
with giving birth. As such, participants felt they owed the detection of the illness and the introduction of treatment to their baby. Some felt that their bodies became stronger because of the pregnancy, that the pregnancy gave them ‘extra power’ (Corinne) physically, and that they therefore were able to withstand or ‘fight’ the cancer and cope better with treatment. Semple and McCance (2010) describe how being a ‘good parent’ (i.e. having both physical and emotional strength, and focus on the children) seems to become more important for parents with cancer, as the fragility of illness seems effectively transferred from ill parent to their child in a balance between needs. In an investigation of mothering experiences during cancer, Elmberger et al (2000) relay how women find ‘meaning and strength to fight’ (p.491) through their young children and through attending to their needs in spite of being ill. Vallido et al (2010) describe how women with cancer feel that their children make them obligated to recover but also give them ‘the will to live’ (p.1443). Billhult and Segesten (2003) suggest that when interviewing mothers with breast cancer (and dependent children), thoughts about looking after the physical (and other) needs of the children dominate, and taking care of these needs keeps the mothers ‘out of bed’ which is construed as positive for their coping and recovery (p.125). Similarly, in the present study, participants feel that caring for their babies forces them to keep physically active throughout treatment, and that this contributes positively to their coping and survival.

Some participants recount how their earlier misdiagnosis is seen as a positive occurrence, as they believe this has protected the pregnancy from termination, and the baby from extreme preterm delivery and being exposed to chemotherapy in utero. The sense from participants’ accounts is that, in a roundabout way, the misdiagnosis helps the baby help the mother survive (and be a mother to the baby). This ties in with the notion of a mother-baby alliance as discussed in Superordinate theme 1. As already mentioned, some participants even express feeling lucky that they had been pregnant when cancer ‘happened’ to them.

Finding meaning and cause
Participants seem to find significant meaning in the clash of pregnancy and cancer by conceptualizing the pregnancy/baby as the physical reason they were able to cope and survive. In producing these (valid) theories that cast the baby as the saviour of the mother, participants seem to be seeking and developing an understanding of their physical survival, as well as of the underlying cause of the timing of their cancer illness. This experience can perhaps be understood in terms of what we know about the human strive to find meaning in life and particularly in distressing events that occur to us. Meaning in life may be defined as ‘the belief that life is worth

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33 See Chapter 2, Table 1. for participants’ demographical information.
living, that suffering can be valuable, and that an individual plays an integral part in the web of connections to others’ (Jim et al, 2006, p.759). Most people will actively seek to understand and find meaning in events that affect them, especially objectively negative events such as a cancer experience, which may threaten perceptions of personal control, and beliefs of the world as a benevolent place (Jim et al, 2006; O’Connor et al, 1990). For women with breast cancer, the search for meaning (when successful, i.e. meanings are established) is said to lead to better adjustment (Kernan and Lepore, 2009).

Meaning-making may include the motivation to find a cause for (and a purpose of) a negative event such as serious illness, known as causal attribution (Clark and Folkman, 1997; O’Connor et al, 1990). Lavery and Clarke (1996) describe how causal attribution has important long-term implications for breast cancer patients because it enables a sense of ‘mastery and control’ (p. 20) as well as influences the types of coping strategies used in the continuous adjustment to a changing life. In particular, causal attribution is known to strengthen cognitively based (emotion-focused) coping strategies which, in turn, positively influence psychological adjustment (Roesch and Weiner, 2001) and quality of life (Ferrucci et al, 2011).

Cancer is considered the most feared illness in Western society (Donovan et al, 2006) and is still viewed by many as a death sentence (Brennan, 2004). In Western media, we are inundated with messages about cancer and its human cost (Mazor et al, 2010). For some cancer patients it may therefore feel imperative that, following successful recovery, they are able to establish some form of reason for their long-term physical survival, in addition to the reason as to why they developed cancer initially. Whilst causal attribution for cancer has been investigated to some extent, little research exists on cancer patients’ perception of the cause of their survival, as well as the timing of their cancer (why me, why did it happen at that particular time, and why did I survive when others perish?). Williams (2000, cited in Wilson, 2007) calls for further inquiry into the ‘timing, context and circumstances within which illnesses are ‘normalised’ or ‘problematised’ (p. 610). Perhaps causal attributions for the survival of cancer can be hypothesized to help patients in similar ways that causal attributions for cancer itself might help them. Believing there is a tangible cause for the timing of the cancer and their survival would then be aiding cancer patients integrate the overall experience into a new ‘life narrative’, to move forward, and ‘re-engage productively with the rest of their lives’ (Brennan, 2004, p. 21).
Finding benefit

In spite of the initial shock\textsuperscript{34} and devastation, the participants express that the pregnancy element of PABC had been beneficial in helping them survive. In the literature on both short-term and long-term adjustment to the cancer experience, the concept of ‘benefit finding’ is mostly investigated as part of patients’ post-traumatic growth capabilities (Dunn et al, 2011; Helgeson et al, 2006; Lechner et al, 2003; Luszczynska et al, 2007; Schulz and Mohamed, 2004). Park et al (2010) claim that, as part of post-traumatic growth, younger cancer patients assign positive meaning to aspects of their cancer experience in an attempt to manage intrusive thoughts and protect themselves from negative affect. Helgeson et al (2006) define benefit finding as the perception of ‘positive effects that result from a traumatic event’ (p.797), and as with the concept of ‘uncertainty in illness’ (Mishel, 1988 and 1990), benefit finding relates to the relief of emotional distress and emotion-focused coping strategies. The concept of finding benefit in the cancer experience has been considered as a delayed coping strategy of ‘positive reframing and religious activity’ linked to a breast cancer experience (Urcuyo et al, 2005, p.175). As such, benefit finding is a cognitive mechanism in line with cognitive adaptation theory (Taylor, 1983) where construing benefits from adverse life events functions a way to relieve distress (rather than the actual obtaining of any benefits or growth) (Frazier et al, 2009). Manuel et al (2007) describe positive cognitive restructuring as the most frequently used coping strategy, and as associated with better quality of life after breast cancer. Correspondingly, Yali and Lobel (1999) emphasize positive appraisal as a frequent coping strategy used by women experiencing a high risk pregnancy. Thus, the perception of benefit and growth is a positive reinterpretation coping process, often containing a spiritual dimension (Öhlén and Holm, 2006; Shaw et al, 2005; Tanyi, 2002), rather than a particular outcome.

In the participants’ perception, the pregnancy masked the cancer symptoms for long enough for the fetus to have developed well, then alerted them to the symptoms, and ensured that their body gained extra physical strength for ‘fighting’. After birth, the baby then kept its mother active during treatment and made sure her life felt constructive and had purpose. The participants had to survive for their baby, in order to take care of it and fulfill the role of a ‘good mother’, and this is why and how they were saved by the baby. As the conceptualizing of motherhood and cancer illness in this manner acquires a spiritual dimension (my baby saved me so I could live and be a mother to him) (Acklin et al, 1983; Holness, 2004; Öhlén and Holm, 2006; Shaw et al, 2005; Tanyi, 2002), it seems valid that the participants consider themselves lucky to have been pregnant when

\textsuperscript{34} Theme: Emotions (shock) – see Appendix 9 for a table of themes identified in the data but not included separately in the main thesis.
they got cancer, because in the strive to find answers, the important relationship between mother and fetus/baby and the uniqueness of their condition is what stands out. The benefit in the experience they relay is the physical survival via the pregnancy and baby, and the timing of cancer and pregnancy as advantageous for the mother. The experience of benefit for the participants may also involve long-term acceptance of the trauma of cancer, and a conceptualisation of the baby as saviour, as a way of expressing resignation that what happened to them was ultimately endurable, as both mother and child came through it in the end.

Sub-theme 2b. ‘You have to keep going for this baby’

**Motivation to survive**

Whilst participants relate how their pregnancy and baby saved them in a physical sense, they also seem to feel that their psychological coping and survival is strongly linked to the baby’s presence. In one important way, the baby brings its mother motivation to cope and survive, as he/she helps fulfil the participant’s post-natal need to embody a desired maternal role and actively be a mother. This function involves an ongoing construction of a maternal identity, and pursuing maternal drive and behaviour, and is twofold, as motivation to cope and survive includes being needed by the baby (and by other children) in addition to needing to be a mother oneself.

Maternal identity is defined as ‘the incorporation of motherhood into a woman’s concept of herself’ (Rossman et al, 2015, p. 3), and is established by a ‘commitment to and involvement in defining herself as a mother’ (Mercer, 2004, p.226). The balancing between the different needs (one’s own as a mother and cancer patient, and those of children) is a shared theme in the literature on experiences of cancer illness and motherhood (Billhult and Segesten, 2003; Dannstedt, 2016; Fitch et al, 1999; Helseth and Ulsæt, 2005). The participants in this study talk of ‘wanting’ and ‘needing’ their baby, and describe how the baby keeps them ‘going’, keeps their mood stable, and compels their recovery through increased motivation to ‘fight’. For the mother, the baby comes to represent the motivation as well as the tool to cope and survive. Billhult and Segesten (2003) discuss how the meaning of being a mother with breast cancer is to use the ‘strength of motherhood’ (p.122) to balance a situation of suffering and pain with the alleviating pull of being needed by one’s children, in order to continue everyday life. Öhlén and Holm (2006) describe this dynamic as ‘tensions between alienating desolation and connectedness-creating consolation’ (p.38), i.e. transforming desolation into consolation and finding harmony between both ‘bright and dark sides’ through reciprocal relations with one’s children (p. 39).
Survivor guilt

The participants’ accounts of this particular aspect of their experience (‘my baby saved me’) could also be interpreted as explanation and/or justification for the outcome of their cancer illness (i.e. their survival and the bequest of motherhood and their baby). Survivor guilt is recently defined as a ‘highly individualized interpersonal process involving the status of being spared from harm that others incurred, which is adversely experienced as distressing’ (Hutson et al, 2015, p.30), and is a well-known phenomenon in cancer experiences (Ferrell et al, 1996). Friedman (1985, cited in Hutson et al, 2015) describes this particular form of guilt as ‘depletion guilt’, which is based on the belief that the total quantity of success is limited amongst people – i.e. ‘if I survive, someone else will perish’. By using the pregnancy and baby to explain survival, it removes personal accountability for survival from the participant herself and justifies it, and this may thereby bring alleviation of guilt feelings over an otherwise inexplicable ‘privilege’ of survival. This way of defending the self against (death) anxiety by rationalizing (Gershuny and Burrows, 1990) would fit into an interview situation, where the woman is questioned about her near-death experience, and may feel pressure to justify or explain her very positive individual outcome. It also seems to fit with findings from the pilot study (Rodsten and Jenkinson, 2013) where PABC patients differentiated themselves from other breast cancer patients as ‘special’ in a ‘them and us’ juxtaposition of mothers with and without cancer. In that study, the PABC patients felt that, due to the tragic circumstances, timing and complexity of their condition, they were granted a special status as breast cancer patients. Outwardly, this led to an apologetic expression of greater entitlement to survive (I had to survive because I had to be a mother to my newborn), but was partly arisen as a result of the burden of survivor guilt.

Distraction and Focus

As part of the experience of being saved from cancer through pregnancy and motherhood, the participants in this study relay how their baby functioned as both an efficient distraction and a focal point to help them cope throughout treatment and afterwards. The effects of intentional distraction and distraction exercises as a psychological coping aid in cancer have been investigated in the medical treatment of children and adolescents (Broome et al, 1994; Gershon et al, 2004; Windich-Biermeier et al, 2007), and in the reduction of anxiety in adults undergoing chemotherapy (Vasterling et al, 1993). Whilst distraction techniques have been found to successfully reduce distress during treatment, less is known about the effects of inadvertent and longer-term sustained distraction sources or measures used by breast cancer patients, such as e.g. the presence and needs of the mother-patient’s newborn baby.

35 Pilot study: see Appendix 12 for poster presentation. A copy of the study is available from the researcher.
Particularly during the earlier stages of their cancer experience, the participants seem to have a strong need for distraction in order to cope, and it seems helpful for them to be able to delve into mothering practices. There is literally no time for them to ‘dwell’ on their suffering or their mortality, but a drive to focus on the practicalities of taking care of and trying to bond with a newborn. Even later, when treatment has finished, the participants recount how having the baby feels like the route into long-term adjustment, as it helps fill the ‘void’ that is commonly felt by cancer patients at this stage (Harvey, 2016). It seems that employing the baby as a distraction may therefore be an adaptive response to the participants’ stressful situation and that this helps their short-term coping and adjustment. At the same time, this coping strategy might be understood as a form of avoidance. Billhult and Segesten (2003) describe as a strategy used by mothers with cancer to handle daily living, the non-engaging with negative thoughts, and an attempt to focus solely on the positive, including optimistic reflecting on their diagnosis and lives. Part of this strategy may be understood as distancing or denial, and cognitive avoidance (Dunkel-Schetter, et al, 1992; Lazarus and Folkman, 1984). Avoidance coping has frequently been found to be associated with higher distress in both short-term (McCaul et al, 1999; Stanton et al, 2002) and long-term (Hack and Degner, 2003) adjustment to breast cancer. However, these investigations do not consider the added element of an essential and generally considered life-affirming focal point, such as a new baby, alongside the avoidance behaviour. This may be making a difference for these participants’ experience of coping during the first year after giving birth, even if levels of emotional distress may be similar.

The meaning of becoming a parent is broad and complex, and situated within cultural and social contexts (Simon, 2008). Multiple factors affect a woman’s adjustment to motherhood (McCourt, 2006). Whilst generally likely to be a stressful life transition (Belsky and Pensky, 1988), becoming a parent to a wanted child is known to provide greater global life quality (Abbey et al, 1994) and higher life satisfaction (Pollmann-Schultz, 2014). Fear and uncertainty about the future is found to be a main concern in cancer patients’ experiences (Dunkel-Schetter et al, 1992). However, as they bring new dimensions of meaning to their parents’ lives, babies can come to symbolize their parents’ future and represent the continuity of life itself (Dubinsky, 2012). For the participants, their babies seem to help balance the distress of the situation with something inherently positive, and this may help them in coping.

The practicalities and the emotional appeal of mothering, including the multitude of ways in which a mother is needed, provides a firm motivation for the mothers to ‘keep going’, i.e. gather their physical and emotional strength, and fulfil the maternal role as best they can. The baby is
unaware that the mother is ill, there is little choice but to provide some level of care for him/her, and this functions as a positive motivational circumstance. There is a strong emotional pull to perform the mothering tasks in spite of suffering, and this pull recompenses the mother by keeping her active and keeping her difficult intrusive thoughts and negative emotions regarding being seriously ill at bay. One participant (Linda) describes her baby as ‘incredibly beautiful’, in stark opposition to the ‘ugliness’ of her cancer illness and treatment.

Sub-theme 2c. ‘As much normality as I could squeeze in’

The participants express how, during the early period after giving birth, coming home and going through treatment, they yearn for ‘normality’. The family bubble (Chapter 4, Fig. 1) illustrates the restorative functions of normality in the family. See also Chapter 4.

Younger women’s experience of yearning for family normality throughout a breast cancer illness is well-known and described in the literature on motherhood and cancer (Arès, 2013; Baltisberger, 2015; Elmberger et al, 2000; Fisher and O’Connor, 2012; Helseth and Ulfsæt, 2004; Semple and McCance, 2010). Versions of the theme ‘seeking family normality’ are found in several studies of the cancer experiences of people with minor children. Although not unique to PABC, the theme is included in this thesis due to the direct connection that the strife for normal family life has to the PABC baby. Here, there seems to be an extra dimension to the quest for normality amidst the perceived chaos, and following treatment, the perceived sense of abandonment. The baby forces, helps and enables the family to install an amount of normality through the establishing and maintaining of a routine, continually needing care and eliciting caretaking behaviour from its mother. In contrast to families where the children are older, the PABC baby is unrelenting in its demands for care and completely unaware of its mother’s condition. This seems to be an advantage to the mothers’ coping and adjustment. Through the establishing of family normality, the mother is able to find some time and opportunity to bond with the baby and further develop her maternal identity and take on the role as mother. This part of motherhood and family intimacy therefore seems to work in a remedial way for her. Vallido et al, 2010 posit that women who are ‘disrupted in their mothering by illness view themselves as a mother first and a patient second’ (p.1435). In the restoration of family normality, the maternal

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36 See Appendix 9 for a table of well-known themes in cancer experience identified in the data but not included separately in the main thesis.

37 Theme: After treatment: see Appendix 9 for a table of themes identified in the data but not included separately in the main thesis.

38 See the next section for discussion of Super-ordinate theme 3: The loss of being a mother, which includes the struggle to fulfill the maternal role and bond with baby.
identity is reinforced, and is allowed to overshadow the identity of cancer patient. This feels motivating and protective for the mother, as there is a clear aim for her to survive (I cannot die, I am needed too much). It is because it facilitates the much-needed levels of normality in this way, that the baby is perceived by the participants as a saving influence.

Strickland et al (2015) emphasise the protective function of family normality and reducing disruption to family life as a child-safeguarding strategy employed by young mothers. Maintaining routines was one of four parts of the authors’ strategy model, which also included ‘customizing exposure’ (shielding the children from cancer and treatment-related effects), ‘finding new ways to be close’ (for mother and children, due to reduced physical strength) and ‘increasing vigilance’ (close watching and being mindful of children’s well-being) (p.537). This and other studies on seeking normality do not situate the children as the main enablers of family normality, but rather discusses the behaviour as a coping strategy used by the parents, and in particular the mother with cancer, proactively implementing steps to achieve protection for their children.

Most participants in the present study were already mothers when they were diagnosed with PABC and had therefore already established a maternal identity39. In a study of motherhood during cancer, Fisher and O’Connor (2012) add another function of maintaining routines and mothering practices, namely the opportunity to maintain a link between the present and the mothers’ life and (maternal) identity before diagnosis. Drawing on past experiences including conceptions of self and one’s life course may feel reassuring, especially for the recently diagnosed (Baker et al, 2014). However, due to the circumstance of the illness, this function clearly does not enable a complete reinstatement of past family life. Family (or individual) normality cannot be the same as before diagnosis, but rather only be a re-formulated normality (Baker et al, 2014) with added dimensions and an evolved maternal identity for the new mother. Wilson (2007) discusses the idea of ‘biographical reinforcement’ (as related to Bury’s (1982) concept of ‘biographical disruption’40, and originally formulated by Carricaburu and Pierret (1995)) in which aspects of an existing maternal identity are reinforced rather than undermined in the mother’s life, post-diagnosis41.

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39 See Chapter 2, Section 2.5, Table 1 for participants’ demographical information.
40 The concept of biographical disruption in mothering during illness is discussed further in the next section under Super-ordinate theme 3.
41 See also discussion of sub-theme 3a re. biographical disruption and continuity.
Super-ordinate theme 3: The loss of being a mother

The super-ordinate theme concerning ‘the loss of being a mother’ is considered to be the main finding of this investigation, because it is central to the overall experience of PABC. The findings here are comparable to findings from the sizable literature on experiences of mothering during illness, however most studies start their investigation at a later point in participants’ lives, typically more than a year post-partum (with participants described as having ‘minor’ or ‘dependent’ children), and therefore do not cover the period of the transition from pregnancy to mother-infant, and the mothering of the newborn during the early months (Arès et al, 2014; Baltisberger, 2015; Billhult and Segesten, 2003; Campbell-Enns and Woodgate, 2013; Elmberger et al, 2008; Elmberger et al, 2005; Elmberger et al, 2000; Fitch et al, 1999; Helseth and Ulfset, 2004; Hymovich, 1993; Mackenzie, 2014; Moore et al, 2015). Mothering is defined as the physical and psychological tasks that provide for the sustenance and protection of children, including the facilitation of growth and social acceptability (Baltisberger, 2015). Most of this literature focuses on the mothering or ‘biographical’ (Williams, 2000), disruption, whilst very little focus on the experience of illness as a painful loss of being a mother. Arès (2013) discusses illness intrusiveness ‘as interference of disease and treatment with various life domains’ (p. 653). Williams (2000) suggests that the maternal identity is ‘threatened’ (p.62), with mothers having to surrender part of this identity to their illness (Wilson, 2007).

Sub-theme 3a. ‘We didn’t go to any baby groups’

This theme is concerned with participants’ experience of losing the opportunity to physically engage with their baby and family, and to carry out the desired mothering behaviour (see Chapter 5).

Mother-infant interaction

Psychotherapist Sue Gerhardt describes babyhood as something that is ‘lived out through a relationship between a woman and a baby’ and takes place within ‘a woman’s realm’, as she is hormonally primed, not just for baby caregiving, but also for touching, looking at, responding to and engaging with her newborn (Gerhardt, 2015, p.31). Physiologically, the baby is still connected to the mother’s body (through touch and feeding) and depends on her for a period of many months. A baby’s demands are relentless during this time, but most mothers respond readily, as the baby’s needs become her needs. Mother-infant attachment research states that a mother’s brain is wired to react uniquely to her infant’s different expressions (Strathearn et al, 2008), and that the (maternal) physical and emotional
attachment relationship is considered a ‘major organiser’ of the baby’s brain development (Fonagy and Target, 2005). Bowlby (1969, cited in Hock et al, 1989, p.794) posits that the maintenance of physical closeness and affectionate interchanges between mother and infant is a mutual endeavor that is pleasurable to both. The baby elicits the mother’s emotional and behavioural responses through its voice, by seeking to breastfeed and instigating eye-to-eye contact, and the mother’s attunement and physical proximity helps calm the baby (Klaus and Kennell, 1976). The mother’s ‘primary maternal preoccupations’ (Winnicott, 1956, cited in Feldman et al, 1999, p.930), sustain an ‘obsessive-like’ psychological and behavioural involvement with her child which is critical for mutual attachment (Klaus and Kennell, 1976). Although most sensitive during the first year after birth (Moehler et al, 2006), this bonding process extends throughout the early years into a continuously evolving attachment outcome between mother and child (Ainsworth, 1989).

**Cancer treatment and child-rearing**

Western mothering practices are often viewed as intensively child-centred and emotionally engaging, and the reserve of only the mother’s instinctive skills and behaviours (Hays, 1998). Wilson (2007) describes the substantial investment that a mother may hold in her mothering role, and how illness may threaten a mother’s maternal identity by interfering with her ability to nurture and care for her children. Vallido et al (2010) define ‘disrupted mothering’ as ‘a woman perceiving that her maternal life has become disordered’ (p.1436) in a literature review on mothering during illness. The participants in the present study experience that their mothering becomes disrupted by the copious cancer treatment obligations, which distance them physically from their children, by the incapacitating physical treatment effects, and by the accompanying distressing emotions which come to dominate their emotional lives (Elmberger et al, 2000, 2005, 2008; Fitch et al, 1999). The illness prevents the mothers from caring for their children, by literal and virtual separation from their infant (Vallido et al, 2010; Walsh et al, 2005). This results in lower levels of ‘maternal preoccupations’, and decreased frequency of bonding behaviours and signs of attachment. As the mother has diminished opportunity to develop and express her maternal identity, and less stimulation for maternal behaviour (Strathearn et al, 2009), she becomes less ‘maternally sensitive and attuned’ (Tester-Jones et al, 2015) and is forced to disengage from her baby (Lovejoy et al, 2000).

**Loss of being a mother**

Personality and cultural background influence how mothers feel about being separated from their infant. However, as separation may cause a break down in the ‘synchronized interaction’
between mother and baby, it is the maternal-infant dyad that is affected, and must readjust\footnote{Re. readjustment to this loss, see also the discussion section for Sub-theme 3c.} (Hock et al, 1989, p.793). The participants’ accounts evidence high levels of maternal separation anxiety, i.e. complex multidimensional maternal concerns about separation (Hock et al, 1989, p.794; Hock and Schirtzinger, 1992), during the early weeks and months following diagnosis. In particular, it is the loss of their baby’s mother (as felt on behalf of the baby), and correspondingly, the loss of being a mother themselves, which feels deeply painful and saddening to participants, more so than the actual disruption to the provision of baby’s care. Although care for the baby delivered by husbands and relatives is generally deemed proficient, the loss of the maternal role is felt severely by most participants (Arès, 2013) who perceive themselves as negligent to their children, resulting in feelings of self-blame and guilt about the baby’s loss. Elmberger et al (2005, 2008) suggest that women with cancer feel guilt towards their children about numerous aspects of being ill and being unable to fulfill the ‘good mother’ role, ranging from being too tired to mother, to merely looking different than normal. Vallido et al (2010) posit that the loss of the mothering role, including its developing meaningful identity and its associated feelings of safety and belonging tendered to mothers, creates a sense of lacking purpose and a perceived state of being a childless mother.

The attraction of a baby to its mother is hormonally stimulated (by oxytocin and prolactin), but it is not an easily definable phenomenon (Klaus and Kennell, 1976). Similarly, the pro-breastfeeding message that ‘breast is best’ is about more than merely nutrition, and involves socio-cultural ideologies that impact on the development of the maternal identity, including a mother’s sense of self (Faircloth, 2010; Lee, 2008). Breastfeeding in Western society has thus become a cultural standard of ‘exclusive mothering’ and a ‘measure of the mother’ and good motherhood (Wall, 2001, p.594). For the participants, breastfeeding seems to become a symbol of the maternal-infant interaction and reciprocity, as well as the least of maternal tasks to require fulfilled. As they are disallowed breastfeeding their babies, (not) breastfeeding also comes to symbolize the disconnect between mother and infant, and the lack of mother’s control, the lost maternal behaviours, and even the loss of maternal status. Being prevented from breastfeeding therefore elicits feelings of pain and shame in the participant mothers towards themselves, and failure and guilt towards the infant.

This experience becomes increasingly problematic as participants feel that HCPs lack understanding, and show little support of mothers’ early breastfeeding compulsions. Vallido et al (2010) discuss how HCPs consistently fail to acknowledge patients’ identities and their felt
obligations as mothers, and that this is a long-standing but ongoing phenomenon. Equally, Power et al (2015) state that mothers trying to simultaneously mother their children and receive hospital treatment perceive nurses and midwives as judgmental and unhelpful, resulting in the mothers feeling invalidated and not facilitated, and adding to the distress of being ill.

The participants describe as a loss the changes caused by cancer to their ‘life plan’, including not being able to be the kind of mother they envisage. Some participants also experience the loss of not having more children, which is deemed physically too ‘risky’, as well as improbable after chemotherapy. When trying to understand the meaning this holds, it is perhaps helpful to apply the sociological concepts of biographical disruption and continuity (Bury, 1982; Williams, 2000) as explanatory frameworks. Hubbard and Forbat (2012) report that patients construct cancer as a chronic disease bringing long-term and persistent disruption to their everyday lives, even years after diagnosis and treatment. Previously taken-for-granted visions of life course or trajectory are lost, and this is attributed to the diagnosis and treatment as an ongoing biographical disruption, as the illness disrupts the ‘anticipated life course’ and ‘leaves no opportunity to plan’ (p.2036).

Sub-theme 3b. ‘That year should have been all lovely’

This theme concerns the participants’ experience of losing the ability to engage and bond emotionally with their infants (see Chapter 5).

Loss of mother-infant bonding

In a psychotherapy case study, Wendland (2009) describe how a mother’s physical and psychological availability towards her infant is reduced due to her cancer treatment obligations, resulting in a disrupted bonding process and an inability to establish a stable emotional connection with the infant. The impact is likened to the mother’s abandonment of her child. As discussed above, the participants in the present study experience the physical separation from their baby as complex, frustrating and painful. The psychological disconnect elicits comparable emotions, and it is pertinent to ask what longer-term consequences for the mother and her child and their attachment relationship this holds. The participants’ sense of loss includes the impeded ability and opportunity to physically express attachment behaviour towards their newborn, leading to anxiety, frustration and sadness, and consequently further decreased bonding behaviours and mental representations of attachment (Feldman et al, 1999). There may

43 Some participants did have children following the PABC pregnancy. See Chapter 2, Table 1 for participant demographical information.
44 See also Section 6.4 Further research.
be psychological barriers to bonding with the infant also. According to Romano (cited in Lof, 2012), the diagnosis of cancer for a pregnant woman can cause a form of narcissistic injury, which overwhelms her and compels her to withdraw from others close to her, in the inability to contain or process the distress. In addition, levels of depressive symptoms are found to be associated with lower quality of maternal bonding in early mother-infant dyads, leading to bonding ‘impairment’ or ‘disturbance’ within the first year after birth (Moehler et al, 2006, p.277).

In a recent case study, Ferrere and Wendland (2013) present a hypothesis that the two processes of psychological adjustment to the disease and the maternal development process are mutually susceptible and ‘antagonistic’ (p.163), because mothers cannot (without difficulty) go through a maternal development/the motherhood process at the same time as adjusting to the disease. Both cancer and childbirth are events that generate major life changes (physical and psychological) and these require psychological adaptation over an extended period of time. Both events profoundly question the identity foundations of the mother-patient. In participants’ cases, much to their despair, the cancer experience comes to dominate this standoff, and the ‘new baby experience takes a real back seat’ (participant Nadine). Wendland (2009) posits that the psychological maternal development process is necessarily ‘suspended’ (p.88) during this time, resulting in high levels of separation anxiety, feelings of worthlessness in the role of mother, guilt and loss of control, and disposing the woman to depression.

**Loss of support as a mother-patient**

The bonding process between mother and infant is experienced as being further hindered by what some participants report is an unsupportive healthcare system. HCPs are perceived to not recognize or acknowledge the patient’s invested mothering role and identity, felt to be unhelpful and, at times, obstructive in facilitating mothering behaviour for the patients during their treatment (Vallido et al, 2010). This is a well-documented phenomenon for mothers across several types of illness (Fisher and O’Connor, 2012; Vallido et al, 2010; Wilson, 2007). Power et al (2015) describe how mothers and HCPs seem to ‘read from different scripts’ (p.374) and misunderstand each other when it comes to playing their respective roles of mother, patient and HCP, with the latter felt by mothers to be policing the prioritization of medical treatment and the resulting separation of mother-infant. Similar experiences are described in studies into the hospital care of neo-natal infants, in one of which mothers report cases of ‘enforced separation’ of mother and child, where nurses ‘exert control by withholding access to infants’ (Johnson, 2008,

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45 Emotional withdrawal is discussed further in the discussion section of Sub-theme 3c.
This leaves mothers feeling disempowered, inadequate and unacknowledged, and negatively affects their adjustment to both illness and motherhood (Elmberger et al, 2005).

Some participants in the present study express how they also felt a different loss of support. This was fraught with ambivalence. It seemed reassuring and alleviating to the women that their husband became an efficient main carer for the newborn during the early months whilst the mother was incapacitated (Walsh et al, 2005). However, there was a sense of loss and pain connected to not being more supported (by the husband) in attempting to fulfill the early mothering role as much as was desired, and this appeared to lead to a complex feeling of resentment mixed with gratitude, directed at both husband and illness itself. Similarly, the fact that family members and other relatives took over and cared more for the baby than they might otherwise have done, was also felt as a lack of understanding and a loss of support for the mother-infant bonding process, and how this process, in the mother’s perception, ought to have been protected and prioritized more. There is a sense in some participants’ accounts that if she as a mother had been supported more in her endeavor to bond with her child, she would not have needed, and would rather have been without, the wider family’s more frequent interventions. Similar to the experience with HCPs, it seems the family was perceived by the mothers as not understanding the real importance of the mother-infant bonding process and were not respectful of the priority this had in the mother’s estimation. In a study reviewed by Vallido et al (2010) it is described how mother-patients display a ‘submissive demeanour and stance’ in their communication with HCPs and other people, and how this may contribute to feeling unable to express, or broach, problems such as the above dilemma.

**Loss of mother-infant memories**

Several participants relayed how they felt they had little memory of time spent with their infant in the first year together as a new family, whilst they were having treatment. At the point of interview, these participants seemed to feel the lack of mother-infant memories as a tragic and irreparable loss, which caused a grief-like reaction of anguish, sadness and anger. The loss nevertheless seemed to be somewhat accepted, or acceptable, as a byproduct of what had been a chaotic and frightening experience, that ultimately ended well for them. To understand this experience it is useful to explore different explanations.

Cancer treatments, such as chemotherapy, are known to cause a range of physical and cognitive problems, and memory may become affected in both the short and the long term (NHS, 2016). Equally, cancer fatigue (the impairment of physical functioning) has been found to produce a loss
of memory (mental fatigue) (Dimeo, 2001). It is therefore plausible that participants’ long-term memories have been affected by (temporary) cognitive impairments triggered by the cancer treatments at the time. Besides cancer treatment itself, it is known that psychosocial factors, such as stress from adverse life events, have an impact on working memory (Klein and Boals, 2001). This means processing of events can have been muddled by the physical effects of treatment and by felt stress, in addition to the turmoil and strain of daily life as a concurrent cancer patient and new mother.

It is worth considering other perspectives for what seems a very significant part of participants’ long-term experience and adjustment. Is the blocking of memories a coping and/or defence mechanism against difficult thoughts and emotions relating to a time which was filled with fear and worries, death anxiety and pain of separation from loved ones? According to Sigmund Freud's psychoanalytic theory (Madison, 1956), repression of memories is the involuntary, unconscious concealment of uncomfortable thoughts and desires in the unconscious. People tend to repress memories when these are too painful or difficult to deal with in the moment.

Slightly contrary to the above, participants may also have ‘lost’ their memories of the early period as a characteristic of their personality. Seidlitz and Diener (1993) suggest that people who are overall ‘happy’ (defined as having a high long-term subjective well-being score) find it more difficult to remember circumstances and details of negative life events. Perhaps it could be hypothesized that cancer ‘survivors’ who had newborn babies whilst going through treatment feel ‘happy’ (and appreciative in particular) that they and their children came through the illness and treatment, that it all ended well, and that this long-term ‘happiness’ is part of the reason why (negative) aspects of the experience come to be difficult to recall some years later.

Sub-theme 3c. ‘I think I kind of withdrew from him’

“Only babies know the secret of how mothers love.” Stadlen (2011)

The final theme included in this thesis is concerned with participants’ experience of needing to withdraw themselves emotionally from the pregnancy, the baby and from others in the family, and the implications this may have (see Chapter 5).

Withdrawal

How do people manage close personal relationships as they experience death anxiety? Throughout this thesis, it has become clear that aspects of the PABC experience interfere with the
mother-patient’s relationship with her pregnancy, her infant and other children, her partner and herself. Fisher and O’Connor (2012) describe withdrawing as the result of the mother feeling objectified as a cancer patient, with her maternal identity ignored and undermined by HCPs and friends and family. This causes confusion and isolates the mothers. Withdrawing psychologically and emotionally from the pregnancy or child(ren) could be interpreted as a complex but unintentional measure taken to cope with anxiety and protect the self. In a study of mothers with dependent children, Mazzotti et al (2012) describe how mothers detach from their children in the attempt to protect them, by claiming the illness as theirs alone (i.e. not communicating with the children about it), and thereby avoiding the ‘contamination’ of fear of death through ‘damage limitation’. Similarly, Elmberger et al (2000) report how mothers will try to avoid involving older children in their illness, and hide difficult emotions at all cost, but at times out of fear that their children themselves will withdraw for self-protection. In their early study on mother-infant separation, Barnett et al (1970) report how mothers withdraw intentionally from their neo-natal infants when there is a risk the infant may not survive. The mothers ‘recognised implicitly that increased contact with the infant would produce attachment’ (p.202) which would then worsen the psychological impact of the potential loss.

Ferrere and Wendland (2013) relay how PABC mothers’ emotional experience of anguish and fear of death and separation, loss of control, guilt and worthlessness as a mother, leads to difficulty in establishing an ‘appropriate’ closeness with their infant, and that this causes the mother to withdraw emotionally and physically from the infant and from others. A struggle arises for the mother to invest emotionally in the child in a typical maternal manner, and in creating and maintaining a positive level of quality early interaction between her and the infant. At first, this seems inconsistent with Bowlby’s classic theory (1973) of proximity and togetherness, (cited in Mikulincer et al, 2002) as an individual’s psycho-evolutionary search for protection from the fear of death. Through activating inner resources, strong interpersonal bonds are usually deemed to help people cope with the awareness of death, as a psychological defence and a ‘terror-management’ function (Mikulincer et al, 2002, p.296; Vance, 2014). However, as they withdraw from their children, the participants do not seem to utilize these close relationships to buffer or mitigate their felt death anxiety. Rather, they talk about withdrawing as a quest for self-preservation, and protection of their children against the emotional impact of impending death. Vance (2014) posits that because death is a threat to the close personal bonds between people,

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46 Relationships: See Appendix 9 for a table of themes identified in the data but not included separately in the main thesis.
47 Positive changes and growth in participants’ spousal relationships were identified in the data. See Appendix 9 for a table of themes which were not included separately in the main thesis.
attempts to avoid death anxiety through this bond can have a paradoxical effect, and ‘actually strengthen death anxiety’s accessibility to the conscious mind’ (p.425). The emotional investment that is placed in close relationships is a stark reminder of what people will lose if and when they pass away. For the participants, this means they feel compelled to reject the personal relationships perceived as the most painful to lose, i.e. that which involves their children.

Guilt and the special relationship
As evident, feelings of guilt permeate the participants’ accounts of their PABC experience. Generally, cancer patients’ guilt narratives revolve around the belief that patients are personally responsible for their illness (Willig, 2008), and for parents with cancer around the abandonment of their children (Arès et al, 2014). This thesis has discussed commonly-found guilt in connection with being unable to fulfil the practical mothering role as desired, and guilt is often deemed a ‘natural’ part of mothering, promoted in the previously discussed ‘good mother’ ideology (Bekteshi and Kayser, 2013; Sutherland, 2010; Vallido et al 2010). However, the guilt explored in this section relates to the above psychological withdrawal and disengagement from the participant’s pregnancy and children. The behaviour of withdrawing is accompanied by guilt and a sense of loss (felt in the present) of the relationship. The participants seem to feel they have (inadvertently) done something wrong, that they have violated the good mother ideology, that their relationship with their baby (or other child) is damaged or lost, and that their children have lost out. This leaves a pervading sense of guilt. Guilt feelings may also link to the fact that, because death ultimately did not occur, distancing themselves from their children is an unnecessary measure that may have caused much hurt. The child becomes an emblem of the woman’s perceived failure as a mother, accentuating her negative self-evaluations and in particular her maternal guilt.

Because of these highly painful negative connotations, the mother could perhaps intuitively have rejected her PABC child, and focused on her other children with whom she bonded as infants and for whom she feels it is confirmed that she has been a ‘good’ mother. But in the participants’ case, the extreme opposite seems to happen. Her performance as a mother is compared between children, and the mothering of the other children perceived to have been ‘good’, i.e. uninterrupted. In order to compensate her PABC child and alleviate her own maternal guilt feelings, the mother creates ‘the special relationship’ which allows her to return to a status of ‘good’ mother, by putting this child first. In ‘the special relationship’, the mother feels she has a special connection with the child because they share a special life/death history, having ‘shared’ the illness and ‘fought’ together. This may be the mother’s best way of negotiating and reducing
her maternal guilt towards her PABC child. Sutherland (2010) describes how mothers ‘use different measures to deflect the bad mother image and thus reduce mama-guilt’ (p.317). These involve ‘neutralizing techniques’ such as constructing narratives that allow the mother to ‘remain attached to ‘good mothering”’. Similarly, Vallido et al (2010, p.1440) cite studies that found mothers were able to ‘reframe the mother role’ to convey to researchers how they were ‘good’ mothers in spite of feelings of guilt and failure. In the construction of ‘the special relationship’, mothering the PABC child then becomes the mother’s new representation of her ability to mother, confirming to her that she is competent after all, and re-establishing her identity as a mother.

Guilt feelings may then arise towards other children who are felt to be less ‘special’ than the PABC child, as in the case of Corinnee and Katie. In Katie’s case, these are managed by confirming to herself that the other child has an enhanced attachment to the father, that the child does not need her as much, and thereby dismissing any child-felt and child-centred disparity. For the family as whole, the relational consequences are long-term. For example, Wendland’s (2009) study illustrates one aspect of these consequences when the author posits that mothers find it continuously difficult to regulate their growing PABC children’s behaviour, because upholding boundaries or reprimanding their children will activate feelings of guilt linked to the perception and memory of failure as mother.
6.2 Implications for psychology practitioners

Psycho-oncology services play an important role in meeting psychological needs of people affected by cancer, however service provision throughout the UK is inconsistent (MacMillan, 2011). Similarly, service provision in perinatal mental health care and support for families is currently ‘patchy and fragmented’ (BPS, 2016, p.5; NICE, 2004). Specialist training of psychology practitioners is imperative as patients’ demography is changing, and survival is now higher than ever (NHS, 2016). Treatment for cancer is increasingly delivered by multidisciplinary teams (MDTs) and their use can help to make cooperation between different specialities of healthcare a more natural, more consistent and smoother process (Fleissig et al, 2006). Current medical management recommendations for PABC all support a multidisciplinary approach (see e.g. Czaplicki, 2012; Amant et al, 2010 and 2015; Albright and Wenstrom, 2016). As part of MDTs, counselling psychologists can function efficiently as important mediators in the tension between patients (and families) and HCPs, at the decision-making stages of treatment planning and implementation, giving birth and throughout aftercare. Armed with knowledge and understanding of the psychological issues, counselling psychologists will help to ensure that appropriate levels of patient involvement at all stages, and in any and all decision-making, are effectuated, as prescribed in NICE recommendations (NICE, 2004).

Emotional distress in breast cancer patients is said to be under-recognised by HCPs (Clark et al, 2009). This study ascertains that there is scope for counselling psychology to support HCPs, including surgeons, midwives and nurses, with knowledge of the psychological implications of PABC that they may not have reflected on, and thereby help enable better ‘attuned’ communication with patients and families (Mendick et al, 2011; Salmon and Young, 2013). The more HCPs understand about the psychological effects of cancer treatments, as well as mothering during illness, the better positioned they are to minimize damage to patients’ quality of life (Brennan, 2004). For example, HCP-patient relations will benefit from HCPs knowing about the role of the PABC child in the mother’s coping with illness and her recovery, the mother’s felt alliance between herself and baby, as well as how feelings towards the baby might bring shame and guilt as well as relief. As discussed, maternal identity is a central issue to patients as the patient feels the need to justify her own drive to survive. In most cases, not least when very preterm babies are born, patients would benefit if HCPs were mindful of the importance of being allowed to carry out as much typical maternal behaviour as desired. It would be beneficial for patients to receive validation of this behaviour, which at times is felt to be judged by HCPs to be abnormal or unconstructive. HCPs’ insight into these internal dynamics during treatment may bring relief and less self-blame for patients, and
better cooperation and communication for HCPs, as well as improvement of attachment in the relationships between mother, children, partner and others. Counselling psychologists with knowledge of the issues can provide training, consultation and supervision for these front line HCPs who are in an optimal position to identify and recognise psychological distress as a direct result of the condition.

Cancer and childbirth generate distinct experiences, but both events are likely to tap into highly personal questions of an existential nature (Baker et al, 2014; Prinds et al, 2014). Given the complexities of the qualitative experience of PABC demonstrated in this study, it is critical that counselling psychologists working in either psycho-oncology or perinatal mental health services use their core competencies to work with PABC patients’ unique psychological issues, as well as receive additional training to form a specialised and advanced skill set designed for this work. Appropriate psychological assessment should be offered to patients by designated HCPs at key stages in the illness pathway (NICE, 2004; Baker et al, 2013) and, if required, co-ordinated support (including referral to specialist support) provided, to elicit basic concerns, address individual adjustment and coping needs, emotional well-being, parent-infant relationship (including bonding and attachment process and outcome) and systemic concerns.

It is evident from this study that the PABC population has psychological care and support needs which are over and above the care which is routinely offered by psycho-oncology and perinatal mental health services. Understanding the experience is the first step in helping psychology practitioners identify the women and families susceptible to long-term and severe distress, and consequently intervene to treat these patients proficiently and with tailored approaches. Based on performance indicators previously developed by the British Psychological Society, Table 3 presents a list of suggested main target outcomes for PABC patients and families, along with the appropriate mechanism of change supplied by counselling psychologists working in psycho-oncology and/or perinatal mental health.

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48 These are defined by NICE as a) around the time of diagnosis, b) during treatment episodes, c) as treatment ends and c) at the time of recurrence (NICE, 2004, p. 79).
49 Based on and developed from section 4.4 of the briefing paper “Perinatal Service Provision: The role of Perinatal Clinical Psychology” (BPS, 2016, page 15-17).
Table 3. Suggested target outcomes and mechanisms of change in PABC mental healthcare services

<table>
<thead>
<tr>
<th>Target outcome for PABC patients and families</th>
<th>Mechanism of change by Counselling Psychology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improved mental health and emotional well-being.</td>
<td>High quality psychological interventions provided by counselling psychologists for women in the moderate to severe range. Includes support with: Antenatal issues: consideration of new onset or pre-existing (mental) health conditions, adjustment to pregnancy, maternal-fetal attachment. Intrapartum care: support during birth planning, labour and birth incl. patient’s expectations, vulnerability and agency. Postnatal care: adjustment to parenthood, trauma, mood. Emotions, such as stress, guilt and anger, across the PABC experience.</td>
</tr>
<tr>
<td>Improved psychological adjustment to motherhood and enhanced maternal-infant relationship.</td>
<td>Supporting and fostering maternal-infant attachment and bonding through the provision of effective mental health interventions. See also Table 4.</td>
</tr>
<tr>
<td>Improved parenting quality and satisfaction.</td>
<td>Parenting interventions to support patients’ capacity and opportunity to parent optimally in the circumstances (requires multidisciplinary team involvement and contribution).</td>
</tr>
<tr>
<td>Improved psychological adjustment to circumstances around breastfeeding.</td>
<td>Supporting women to adjust to the emotional aspects of exclusion or discontinuation of breastfeeding.</td>
</tr>
<tr>
<td>Improved psychological adjustment to breast cancer and treatment.</td>
<td>Targeted psychological interventions which improve daily functioning due to improvements in mood and coping.</td>
</tr>
<tr>
<td>Enhanced informed consent procedures and protected autonomy.</td>
<td>Healthcare staff trained by counselling psychologists can better support women during the consent process and protect their autonomy and sense of control.</td>
</tr>
<tr>
<td>Improved treatment adherence.</td>
<td>With psychological support during adjustment, individuals are more able and motivated to maintain adherence to treatment.</td>
</tr>
<tr>
<td>Improved coping with physical symptoms.</td>
<td>Provision of evidence-based psychological interventions relating to adjustment to physical symptoms, to increase coping.</td>
</tr>
<tr>
<td>Improved inclusion and quality of life for individuals and families.</td>
<td>Support with feelings of being different and isolated (Ives et al, 2016, p.82). Systemic interventions to explore and ease the impact on family relationships. Involvement with practical arrangements to support the family.</td>
</tr>
<tr>
<td>‘Joined up’ care experience.</td>
<td>Ensuring that women experience smoother transitions between maternity care to oncology, and can access appropriate levels of care as necessary.</td>
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</table>


Counselling psychology is aptly suited to help PABC patients and their families, and psychologists can build on existing knowledge of effective ways of helping and supporting both breast cancer
patients, as well as expecting (and new) mothers and their families. This will enable faster and better adapted psychological assessment and treatment for patients and their families, including fewer and better targeted therapy sessions.

Based on the findings from this study, and the targeted outcomes presented above, some suggested models and interventions for managing the psychosocial side of PABC are outlined in Table 4.

Table 4. Suggested therapeutic approaches and their rationale for use with PABC patients and families.

<table>
<thead>
<tr>
<th>Therapeutic approach or model</th>
<th>Interventions and rationale for use with PABC patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion-Focused Therapy (EFT) (Greenberg, 2002)</td>
<td>Emotion-focused therapy can give patients opportunity and permission to safely feel, explore and express difficult (e.g. shameful) emotions where they may have no other viable opportunity or outlet. This aims to enable greater acceptance of problematic emotional states, and subsequent better management and coping.</td>
</tr>
<tr>
<td>Person-Centred Therapy (PCT) (Mearns &amp; Thorne, 2000)</td>
<td>With an unstructured approach, PCT is helpful for exploring issues that are present-in-the-moment. Patients will benefit from having their views acknowledged and being heard. Existential elements of person-centred therapy provide an opportunity to acquire a stronger sense of self, and can provide support and empowerment relating to the experience of the mother-infant alliance. PCT can also provide support in personal decision-making.</td>
</tr>
<tr>
<td>Cognitive Behavioural Therapy (CBT) (Moorey &amp; Greer, 2011)</td>
<td>CBT can help patients identify metacognitive beliefs, negative thoughts and their impact on mental health (Cook et al, 2015). Psychologists can help establish positive changes where needed and possible. Developing and implementing a weekly routine may help produce a sense of control and protection. Relaxation training, visual imagery skills and symptom management are other helpful supportive interventions.</td>
</tr>
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</table>
Family Systemic Therapy (FST) (Dallos and Draper, 2010)

Family therapy and systemic practice is based on the idea that family relationships form a key part of the emotional health of each member within that family. Family Systemic Therapy can help the family explore and understand thoughts around the interpersonal dynamics generated by the experience of PABC, in particular the impact on close relationships within the family and the changes experienced. This is relevant in helping families to manage and protect the ‘Family Bubble’ described in this thesis.

FST can address the implications of the woman’s withdrawal from the maternal role, and the emotions connected with this. FST can provide support with management and protection of ‘memories’ generated during the first year by including all family members.

FST provides a shared space for enhanced family communication.

Couple counselling (Hooper & Dryden, 1991)

Couple counselling seeks to improve communication and resolve issues within an intimate relationship. Couple counselling will provide support for both patient and partner. Issues that may be particularly relevant for treatment include:

- Loss of fertility and the impact on both adults and the family.
- The loss of envisaged parenthood.
- Termination of the pregnancy.
- Treatment information and decision-making.
- Mediation and communication with HCPs.
- Palliative care for the patient and support for partner.

Group Therapy and/or Support Groups (Weis, 2003)

Psychosocial group interventions have been developed to help cancer patients cope better with the psychosocial effects of cancer. Groups can include a variety of different approaches (e.g. focus on behavioral aspects and symptoms or the expression of emotions). Groups will give patients access to other younger cancer patients, and thus create a confidential space for sharing experiences to relieve distress. Groups will also create a sense of inclusion for the individual patient.

Ives et al (2016) recommend that support groups are set up specifically for younger women to include PABC patients.

Integrative Therapy (Gilbert & Orlans, 2011)

This is a combined approach that brings together different elements of specific therapies. Integrative therapists take the view that there is no single approach that can treat each client in all situations. Like other humanistic approaches, Integrative Therapy will enable the patient to address psychological issues, according to immediate needs.

The patient will benefit from the therapists’ ‘meta-perspective’ in exploring ambiguities and philosophical and existential issues.

Cancer can be understood as a family crisis partly because it causes disorganisation of family life and thereby affects all family members (Asen et al, 2004). The family’s usual coping mechanisms and ‘overall belief system’ (Rolland, 1987, p.486) may become inadequate, and involvement of the whole family in psychological treatment is encouraged. The creation of The Family Bubble (Chapter 3, Figure 2) exemplifies how mothers are trying to reinforce the family’s coping by taking control. Similarly and within The Bubble, a degree of denial can be upheld by the family in...
proactively maintaining family normality. ‘Just getting on with it’ as some participants do, can also be regarded as a resilient coping strategy. These are short-term adaptive responses with which psychology practitioners can work in an empowering way in family systemic therapy, and thereby enable vulnerabilities to develop into strengths. For example, the perception of loss is known to be a cause of mood disorders (e.g. depression) (Bowlby, 1980). Exploring this in therapy early on with the family can allow preventative measures to be put in place.

Finally, it is suggested that the implementation of further ‘key stages’ in addition to NICE recommendations, at which formal psychological assessment is carried out by a counselling psychologist, are necessary to identify and assess psychological issues in PABC patients and their families. Depending on the take-up of psychological support and treatment already offered, these assessments could take place a) immediately upon diagnosis: to assess pre-existing problems and immediate impact (mental health first aid), and inform of available support and ways to access this, b) immediately before and after giving birth: to elicit and ease concerns and help transition and adjustment to motherhood, c) at regular intervals during treatment, in line with the framework for health visiting and health and development reviews (NHS, 2016c), e.g. two weeks after birth, six to eight weeks after birth, every three months, until a year following the end of treatment (with no recurrence). Patients should be offered home visits for assessment during the early period in order to minimize disruption to family life, and at least some should include the patient’s partner for assessment of couple and overall family well-being.
6.3 Limitations

The present study has generated an extensive amount of rich and compelling information about the phenomenological experience of being diagnosed with breast cancer in pregnancy. There are limitations, however, which need to be acknowledged.

Homogeneity in the sample
Homogeneity in the sample is an important criterion of IPA research, and this thesis is necessarily limited by the lack of consideration for all PABC patients’ diverse social and cultural contexts. I have argued that the participants are demographically homogenous (gender, age, ethnic origin, marital status and social class), however there are important differences between them, which relate to their experience of PABC and have undoubtedly influenced the data. In particular, the time that had passed since cancer diagnosis until the point of interview varies considerably across the participants, with the longest being 12.5 years (Corinne) and the shortest 7 months (Rebecca). The length in time may have affected the accuracy of participants’ memory and shaped their perception including aspects of their experience which were prioritised at interview (Boot et al, 2010) (Table 1).

Similarly, the participants showed substantial variation in the length of time each of them spent being pregnant with the diagnosis, i.e. the time from being given diagnosis to giving birth to their child. This time varies from 4 weeks (Lorna) to 35 weeks (Corinne). Two participants (Nadine and Rebecca) were diagnosed a few days after having given birth. The length of this time may have influenced stress levels in the participant, in particular the quality and quantity of worry about the well-being of their unborn infant (Table 1).

Whilst most participants had never spoken at length and to a stranger about their experience, a few participants had previously been interviewed by journalists and researchers. One participant had even published a book about her experience. Having already been ‘questioned’ in depth and thus developed some reflexivity may have influenced participants’ perceptions and given them a practiced approach to expressing themselves during interviews for this study.

Finally, it is worth considering that participants’ individual cancer diagnoses differed in terms of type and grade, and subsequent treatment type and length provided to participants was not the same across the group. Cancer treatment (including its efficiency, effect and impact) is person-specific. Three participants had been diagnosed with secondary breast cancer at the time of
interview. See also Table 1.

Size of the sample
The current sample was very large. Smith et al (2009) recommend four to ten interviews for professional doctorate projects (with a smaller number of participants). There is therefore the possibility that the overall analysis has not received the optimal amount of time, reflection and dialogue. The analysis of each case was less detailed than anticipated. However, the application of a group level analysis has emphasised key emergent themes across the group illustrated with examples from individual participants. See Chapter 2.

Disposition of participants
The participants volunteered to meet with the researcher and talk openly about their experiences. It is important to acknowledge that the method of semi-structured interviews attracts certain types of participants. For this study, the method generated rich and engaging data. However, the disposition of participants always influence the data, and at any given time only certain discussions can be had. In addition, women who experienced PABC and were aware of this study but chose not to participate, may have found it too difficult to talk about their experience (to a stranger), even when knowing that the researcher had been through a similar experience herself. Therefore, there will undoubtedly be other experiences of PABC that contain valuable additional input in the future creation of a knowledge base of the psychological impact of the condition.

Dominant constructions of breast cancer
Willig (2012, p. 53) describes how Western society employs ‘legitimate’ and ‘socially accepted’ constructions of what it means to have cancer. Some of these are a) the imperative on the patient to think ‘positively’, b) the construction of cancer as a ‘war’ or ‘battle’ that must be fought and c) the construction of cancer as a moral concern and an individual responsibility. As described in the discussion section of this chapter, most participants in this study seem to adopt these culturally preferred and prescribed narratives. They construct their experience according to the accepted and dominant narrative at the exclusion of a less acceptable and less socially supported narrative. This means that significant and valuable information about the individual experience of PABC, which could prove helpful to patients and HCPs, can be very difficult to access.
6.4 Further research

The current research project has attempted to generate a broad understanding of the experience of pregnancy-associated breast cancer from the mother-patient’s perspective, and as such was designed to guide future research into PABC. The limited amount of existing research in this area seems to suggest that cancer diagnosed during pregnancy can cause important psychological and relational issues to be considered by counselling psychology practitioners, as is the case with non-pregnant cancer patients. In particular, the current research points to complexities that are unique to PABC. However, further research is needed to understand these issues in more depth.

While significant aspects regarding the mother’s coping strategies and her thoughts, emotions and behaviours were articulated by participants in this study, there remains a need to investigate these aspects more fully. Regardless of the ‘time since diagnosis’ (see Table 1) most of the recounted experiences discussed here take place in the first year after diagnosis. Therefore, a more detailed exploration of the longer-term experience of the mother, her partner and her children is relevant to knowledge about longer-term adjustment and its promotion, as well as carers’ experiences. Additionally, it would be appropriate to look into older children’s (both the PABC child and others) experiences and perceptions of the impact of PABC on their relationship with their parents and their position in the family. There was not enough evidence of long-term relational consequences in this study, including consequences of long-standing withdrawal from close family members and systemic issues. It may be fruitful to investigate any experienced ‘attachment disturbances’ (Stiefel, 1997) or ‘bonding disorders’ (Brockington et al., 2001), in addition to the impact on systemic dynamics and organisation. Can the disruption to mothering, which is directly and indirectly induced by the experience of PABC, lead to an attachment impairment or disturbance, or at worst, trigger an attachment ‘disorder’?

Children’s adjustment to PABC might successfully be researched through standardized interviews, observational and questionnaire measures of maternal wellbeing, mother–child relationships and child adjustment, administered to mothers, fathers, children and teachers. It would be relevant to know if there is any experienced deprivation (of parental attention and support) in family relationships.

A pregnant woman’s own attachment style is known to impact on her attachment to her fetus (Mikulincer and Florian, 1999). Attachment style also impacts on affect regulation (Mikulincer et al., 1990). Prenatal (maternal-fetal) attachment of women recently diagnosed with PABC could be
measured using the Prenatal Attachment Inventory (Müller and Ferketich, 1993). Aspects of both children’s and mothers’ attachment styles could be explored to generate valuable information about the impact of attachment style on adjustment to PABC (Main and Hesse, 1990; Mikulincer and Florian, 1999). In children, a Strange Situation Classification (Ainsworth and Bell, 1970) would reveal information about what the baby has learnt during its first year of life about getting his/her needs met. For mothers, the Adult Attachment Interview (Hesse, 2008) (used as a research tool, not clinical) may reveal her internal model of attachment, and the influence on her experience. More detailed explorations into how these aspects are played out would be productive.

Furthermore, the comparative qualitative experience of other types of cancer occurring during pregnancy (including different types of treatment delivered, their effect and patients’ response) warrants investigation.

Last but not least, there is a need to ascertain which therapeutic approaches, psychological interventions and types of support will work for whom and in what context, with regards to method and timing, as well as effect (Baker et al, 2013). It will be necessary to thoroughly test the acceptability, feasibility, efficacy and effectiveness of the psychological approaches and interventions suggested in Table 4, as interventions are unlikely to be commissioned and rolled out without accompanying evidence (BPS, 2015; JCPMH, 2015). These decisions are likely to depend on ‘type’ of patient, i.e. background, preferences and specific problems, the location and timing of the treatment and the resources available, further to the practitioner’s training, style and personality (Margolies, 2016), and existing practice and research findings on therapy for cancer patients. Any approach must always be firmly based on theoretical knowledge, understanding and psychological formulation for individual patients and families, in accordance with the philosophy and consistency of counselling psychology (James, 2011; Woolfe et al, 2010).
6.3 Conclusion

The main motivation for carrying out this project was the contribution of knowledge about the experience of PABC to the field of counselling psychology, as well as personal achievement and development. This thesis has argued that the phenomenology of PABC is complex and challenging, has substantial relational and psychological implications, and primarily involves an experience of coping and loss during the first year following diagnosis. The experience can severely impact on a mother’s attachment to her infant, as well as on her other close relationships. Women who took part in this project felt that they lost a significant amount of mothering ability and opportunity, and that there was a lack of understanding and support from others, including some family members and HCPs. Although these findings may not be generalizable to the whole PABC population, this knowledge will assist counselling psychologists in carrying out an all-important role in the mediation between patients and HCPs, and the efficient psychological support and treatment for patients and families who struggle to cope.

In summary, Table 5 lists a range of applications according to either counselling psychology, healthcare professionals or patients and families, that are deemed necessary in order that the overall experience of PABC can be made easier and the negative impact on psychological well-being and relationships is minimized.
Table 5. Necessary applications in the good psychological management of PABC.

| Counselling Psychologists | In depth knowledge of psychological issues and how to address these with patients who are referred from HCPs. Awareness and understanding of important role as mediator between HCPs and patients. A proactive approach to provision of support that includes tailored psychological interventions and practical help. Provision of training and support for all types of HCPs in direct and frequent contact with patients and families. |
| Healthcare Professionals (HCPs) | Awareness and understanding of typical psychological issues of PABC. Identification and onward referral of moderate to severe psychological difficulties. Flexibility in approach to, and implementation of, physiological healthcare provision during cancer treatment. Acceptance of training and support from Counselling Psychologists and of the role these can play in the mediation with patients and families. Recognition of (and respect for) patients’ maternal role and identity, and its significance for patients’ and infants’ well-being, their relationship, and patients’ recovery. Expression of empathy and support for patients’ dilemmas as patient-mothers. Expression of normalisation/validation, and de-pathologising, of patients’ typical and ‘appropriate’ affective responses, e.g. fears and worries. |
| Patients and families need | Access to information and support, including permission and opportunity to ask questions and express concerns. Support to increased awareness of typical psychological issues: what is normal and ‘appropriate’ affective responses, what calls for further intervention? Extra flexibility (time, space and support) to parent their infant and other children. Support to actuate agency and autonomy in treatment planning and implementation. |


Baker, P., Beesley, H., Dinwoodie, R., Fletcher, I., Ablett, J., Holcombe, C. and Salmon, P. (2013) "You're putting thoughts into my head": a qualitative study of the readiness of patients with breast, lung or prostate cancer to address emotional needs through the first 18 months after


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Appendices

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Appendix 1   Ethical approval letter

UWE REC REF No:  HAS/14/03/53
Date:  2nd April 2014
Janne Rodsten
Woodbine Cottage
Church Hill
Olveson
BS35 4BZ

Dear Janne

Application title: Double Distress? Understanding the experience of pregnancy-associated breast cancer and the counselling needs of survivors – An interpretative phenomenological analysis

Your ethics application was considered by the Faculty Research Ethics Committee and, based on the information provided, has been given ethical approval to proceed with the following conditions:

You have addressed potentially difficult issues (given the sensitive and emotive topic it covers) well.

The application does offer to provide info sheets in other languages and an interpreter if necessary. This is good practice, but is it really practical or feasible? Do you mean any language at all? I think it would be preferable to keep this to those who are able to conduct an interview in English and flag up the need for research into the experiences and needs of women who would need an interpreter as being a topic for future research. In which case, the information sheet needs to state interviews are in English.

The interviews are being conducted at UWE or a public place and only in participants’ homes in exceptional circumstances. Will they be reimbursed for travel costs for getting to UWE, their time and any child care costs? If not, I’d suggest the interviews should usually be in their own home (following lone working health and safety protocols) and only elsewhere in exceptional circumstances so that the cost of travel is borne by the researcher not the participant. This may also make participation easier if they have child care commitments.
Are the supervisors Naomi and Liz, or Tony and Liz? The application form states Tony, but the information sheet has Naomi.

If these conditions include providing further information please do not proceed with your research until you have full approval from the committee. You must notify the committee in advance if you wish to make any significant amendments to the original application using the amendment form at http://www1.uwe.ac.uk/hls/research/researchethicsandgovernance.aspx.

Please note that any information sheets and consent forms should have the UWE logo.

Further guidance is available on the web: http://www1.uwe.ac.uk/aboutus/departmentsandservices/professionalservices/marketingandcommunications/resources.aspx

The following standards conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application. These include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.

You must notify the University Research Ethics Committee if you terminate your research before completion.

You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

We wish you well with your research.

Yours sincerely

Dr Julie Woodley
Chair
Faculty Research Ethics Committee
c.c Liz Jenkinson
Appendix 2  Participant recruitment letter 1

Dear [Name],

You may remember that early last year you took part in an online survey about your experience of having breast cancer diagnosed whilst you were pregnant.

Your participation was most appreciated, and you contributed to important knowledge of this rare and worrying phenomenon.

As mentioned in the survey briefing, I am now progressing into my doctoral thesis on the same subject.

The title of my thesis will be: Understanding the experience of pregnancy-associated breast cancer.

This is a qualitative study, meaning that it delves deeply into the experience of the individual woman, and acknowledges that this person is the ‘expert’ on their own experience.

I am looking for people like you who had first-hand experience of pregnancy-associated breast cancer to take part in a face-to-face interview (1 hour approx.) at some point during the summer 2014. Would you be willing to participate in this?

I can come to your home, or you could choose any other setting for our interview, like an office or the local library. I will audio-record the interview, but all details will be kept confidential.

If you would like to participate, please let me know as soon as you can. I can be reached at this email janne3.rodsten@live.uwe.ac.uk or by phone 07866 571778 or 01454 612 650 (evenings best).

You may also like to look me up on my social media pages:

Facebook: https://www.facebook.com/pages/Pregnant-With-Cancer-UK/187593184655775

Blog: http://jmrodsten.wordpress.com

Twitter: https://twitter.com/JMRodsten

Thank you for your time, and I hope to hear from you again soon!

Regards,

Janne Rodsten
Appendix 3  Participant recruitment letter 2

Bristol, 21st May 2014.

Dear Ms [Surname],

I read about you in an article published in [publication] on [date], concerning women who are diagnosed with breast cancer whilst being pregnant or soon after giving birth.

I am a 43 year-old female trainee psychologist and researcher at the University of the West of England in Bristol, and I am in the process of writing a doctoral thesis on the subject of pregnancy-associated breast cancer.

The title of my thesis will be: Understanding the experience of pregnancy-associated breast cancer.

This is a qualitative study, which means that it will investigate the experience of the individual woman, and acknowledge that this person is the ‘expert’ on their own life and the experience they had. The aim of the study is to develop an understanding of the psychological impact of being pregnant with breast cancer, which may help shape support services that are being designed to make women (and their families) feel and cope better during and after their illness. I am also hoping that the findings will help families directly - I was myself pregnant when I was diagnosed with breast cancer 8 years ago.

I am looking for people like you who have first-hand experience of pregnancy-associated breast cancer to take part in a face-to-face interview (approx. 1 hour) at some time during August-September 2014 (or later if preferred). I would be very interested to hear about your experience, and I wonder if you would be willing to participate.

I can come to your home for the interview, or you can choose any other location, such as an office or the local library. I will audio-record the interview, but all details will be kept confidential, and destroyed after submission of my findings.

If you are interested, please let me know as soon as you can. I can be reached on email janne3.rodsten@live.uwe.ac.uk or by phone 01454 612 650 (evenings best).

My supervisors are also available for you to contact, should you have any questions for them:
Liz Jenkinson: Elizabeth2.Jenkinson@uwe.ac.uk
Tony Ward: Tony.Ward@uwe.ac.uk

I hope to hear from you!

Kind regards,

Janne Rodsten
PTO
p.s. I attach a participant information sheet with this letter.

p.p.s. You may like to look me up on my social media pages:

Facebook:
https://www.facebook.com/pages/Pregnant-With-Cancer-UK/1875931846555775

Blog:
http://jmrodsten.wordpress.com

Twitter:
https://twitter.com/JM Rodsten
EXPLORING WOMEN’S EXPERIENCES OF HAVING BREAST CANCER WHILST BEING PREGNANT

You are being invited to take part in a research study. Before you decide whether or not to take part, please read the following information. If there is anything that is not clear or that you would like more information about, then please do ask the researcher.

What is the purpose of the investigation?
This study collects information about the experience of having breast cancer whilst being pregnant. The aim of the study is to explore the experiences of women who have had this condition. The information gathered may inform psychologists and other health professionals in order to shape services designed to provide help and support.

Why have I been invited to participate?
You have been invited to take part because you have experience of having breast cancer during pregnancy. In order to be eligible to take part, you must have completed all active treatment for the disease.

Do I have to take part?
Participation in this research study is completely voluntary, and you have the right to withdraw your answers at any point until such time that the data will be analysed (withdrawal agreement period is anytime from participation until 1 December 2015). Upon request of withdrawal, data will be deleted by the researcher within the withdrawal agreement period.

What will the investigation involve?
The investigation will involve meeting for an interview with the researcher at an agreed location and answering questions and talking about your experiences of having breast cancer during pregnancy. The interview will take between 1-2 hours. It may be that the researcher would like to follow up on an interview to clarify and expand on issues raised, and this could happen either in person in follow-up interview, or by telephone/email.

Will what I say be kept confidential?
All data obtained from you will be kept confidential and will only be reported in anonymous format (participant codes will be assigned). The data collected will be stored in a private secure database at the researcher’s home, until deleted by the researcher. Deletion of data will take place at the latest by the end of December 2017. Withdrawn data will be deleted upon request of withdrawal within the withdrawal agreement period.

What should I do if I want to take part?
Once you have read through this information sheet, please contact the researcher by message, email or telephone to say that you would like to take part. We will then agree on a mutually convenient time and location for the interview to take place.
What will happen to the results of this study?
The information gathered may inform psychologists and other health professionals in order to shape services designed to make people better. It is hoped that the study might also help patients and their families in trying to make sense of their experiences. Therefore, the results will be analysed and written up for a doctoral study and published in an academic paper, so professionals can read the findings.

About the researcher
I was diagnosed with breast cancer 8 years ago when I was 35 weeks pregnant. I had a c-section immediately to start treatment, including chemotherapy, surgery, radiotherapy and eventually also counselling. As I am now training to become a counselling psychologist, I aim to help both patients and health professionals by exploring patients’ experiences of this condition.

Contact for support and further information
We understand that talking about your experiences may evoke strong feelings for you. If you feel that you would like support, please contact your GP in the first instance, or contact the following support organisations:

Breast Cancer Care - www.breastcancercare.org.uk
MacMillan Cancer Support - www.macmillan.org.uk
Cancer Research UK - www.cancerresearchuk.org
Marie Curie Cancer Care - www.mariecurie.org.uk
Mummy’s Star - http://www.mummysstar.org

Please also contact the researcher, Janne Rodsten (janne3.rodsten@uwe.ac.uk), if you have any concerns about taking part and wish to discuss the study - or if you wish to withdraw from the study later on.

If you have questions about this research which you do not feel comfortable asking the researcher, you may contact the supervisor Dr Elizabeth Jenkinson, Elizabeth2.Jenkinson@uwe.ac.uk or the Director of Studies Tony Ward, tony.ward@uwe.ac.uk.

I am happy to send you a summary of the results once the study has been completed. Thank you for taking the time to read this information.

Janne Rodsten
April 2014
Appendix 5  Participation Consent Form

Participant Consent Form

Title of research project: *Understanding the experiences of pregnancy-associated breast cancer and the counselling needs of survivors – An interpretative phenomenological analysis.*

I have read the Participant Information Sheet and agree to take part in this study. I consent that:

- The purpose and details of this study have been explained to me
- I understand that my participation in the study is entirely voluntary
- I understand that I have the right to withdraw from the study within the limits specified on the Participant information sheet without the need to give a reason
- The use of information that I provide has been explained to me
- I am aware that my anonymity will be maintained and no personal details will be included in any write-up of the study
- I understand that information I provide will be treated confidentially
- I agree to the study procedures
- I understand that I can contact the researcher at any time if I have any queries about the study
- I have had an opportunity to ask questions about my participation

Name of participant (Please print) ________________________________

Signature of participant __________________________________________

Date __________________________________________________________
Appendix 6  Interview Schedule and Topic Guide

Topic Guide

- How do people experience having breast cancer diagnosed whilst they are pregnant?
- What were their main concerns and stresses at diagnosis, when giving birth and throughout treatment?
- How did the participants see themselves during and after treatment? As a mother, partner, woman, patient, survivor, etc.?
- What does the relationship with health professionals mean to the experience?
- Where might there have been a need for psychological support, and what does this need look like?

Q. What is it like to be concerned for your unborn child at the same time as being concerned for your own survival?

Q. Does ‘survival’ from breast cancer hold a unique meaning for pregnant women, e.g. is there a sense of purpose, a sense of empowerment and growth, and/or a sense of fate or meaning accompanying the experience?

Interview Schedule

- Anonymity protected – names and places synonymised or blanked out
- Right to withdraw at any time during the process of the research (with limitations)
- Research is about the experience of illness and pregnancy, and the time that followed after giving birth

Q. Tell me the story of when you first learned that you had breast cancer while being pregnant
Prompts: diagnosis, pregnancy news, treatment plan, coming home

Q. What was it like to experience having cancer and being pregnant at the same time?
Prompts: how did you feel/thoughts/coping?

Q. What was it like when you came home from hospital with the baby?

Q. I wonder if we could talk about the most difficult times for you.

Q. How did you and your family cope with what happened?

Q. Tell me about a time when that happened?

Q. Who and what was the most helpful to you during this time?

Q. Do you feel your experience has affected you and your family’s life, and if so, how?

Q. In your opinion, how does being pregnant influence the experience of having breast cancer?

Q. Is there anything about the experience that you value now, looking back?

Q. Is there anything else you would like to tell me about your experience of breast cancer during pregnancy?
Appendix 7  
Examples of the NVivo software analysis

Themes: COPING and EMOTIONS with sub-themes
Themes: HEALTHCARE experience, IMPACT, RELATIONSHIPS, SENSE OF LOSS, SUPPORT
Appendix 8 Yardley’s guidelines for assessing qualitative research

The quality and validity of the analysis in this study was established by applying the guidelines of assessing qualitative research as described by Lucy Yardley (2015). Yardley sets out four broad criteria, and Smith et al (2009) describe how these are met through an IPA study. The principles are a) sensitivity to context, b) commitment and rigour, c) transparency and coherence and d) impact and importance. Their application to this study is discussed here.

a) Sensitivity to Context
The researcher must demonstrate sensitivity to context in all areas of the project. Smith et al (2009) suggest that choosing IPA as a method in itself demonstrates sensitivity to the idiographical human experience. As an ‘insider’, I was familiar with many aspects of the experience itself, and took great care to collect data with heightened awareness and empathy for participants’ private and sometimes anxious reactions. Sensitivity was also demonstrated throughout the analysis and write up, where care was taken to make claims and interpretations appropriate to the sample, and to ensure that these were grounded in the data by using verbatim extracts as periodical illustrations. I wrote an extensive reflexive account of my own PABC experience and the experience of conducting this research, to ensure that I would be sensitive to the participants’ different experiences and perspectives. In addition, I conducted an in-depth literature review in order to orient the study and place it in the relevant context.

b) Commitment and Rigour
As an ‘insider’, I had considerable personal investment in the study, and was committed to delivering a high quality. The commitment was demonstrated in the passion for investigating the topic, and acquiring and disseminating the new knowledge. Rigour is about the thoroughness of the study (Smith et al, 2009). I was thorough in the selection of the homogenous sample, in being attentive to participants’ discourse and their needs during interview, using my skills in active listening, and balancing the closeness and separateness in the conversation, reading cues and probing as appropriate. IPA addresses the requirement for rigour with a systematic and idiographic approach to analysis, including a good level of interpretation, with claims illustrated by a proportionate amount of verbatim extracts from participants’ accounts.

c) Transparency and Coherence
The research process, including steps taken throughout design, data collection and analysis, must be clearly described at all stages to enhance the transparency of the study. This was attempted in Chapter 2 of this thesis. Because of my personal experience of PABC, I found it essential to overall
transparency of the study to include a section on my positionality (section 2.9), and further reflexive sections in Appendix 11. Qualitative research must also be coherent throughout, from representing a good fit between the nature of the research and the theory and principles of the approach, to a coherent argument and logical arrangement of themes. This requirement was met through extended drafting and re-drafting as well as through dissemination and triangulation methods. As a methodology, IPA corresponded to my personal ontological and epistemological assumptions.

d) Impact and Importance
Yardley states that the validity of qualitative research can in fact be measured by the impact and importance it may have, whether it is truly justified and has a strong purpose in telling us something that is useful and interesting. I hope this is the case with this thesis. The emphasis is on the general purpose of giving a voice to individuals who have experienced PABC and thus create a presence in the literature specifically addressed to psychology service providers, practitioners and other HCPs.
Appendix

Themes and patterns identified in the data but not included or discussed separately in this thesis.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme 1</th>
<th>Sub-theme 2</th>
<th>Illustrative verbatim transcript extracts</th>
</tr>
</thead>
</table>
| Coping                    | Different       | Determination                   | Chrissy: I was just really, ‘I’m going to fight this, I’m going to get rid of this, I’m going to do this’
Daisy: I was determined there was no way in the world I was going to die.

Positive mind set          | Rebecca: I think it is better to be a ‘this will be okay and I can do this’, rather than a ‘oh no I’m not going to be able to,’ I think emotionally and mentally you cope better if you feel strong in your mind.
Daisy: it seems to me that those people who have a more positive outlook and a more positive attitude seem to do better with a cancer diagnosis.

Appreciation              | Katie: I think I’ve come out the other end. I’ve got a lovely daughter, and it has changed me into a more relaxed person.
Lorna: I do know how lucky I am, in many, many ways.

Acceptance and resignation | Katie: I just took it in my stride.
Jane: Sometimes I don’t think it was that big a deal. But I know it was.
Anna: Well you’ve got no choice but to get on with it. I mean people keep saying ‘oh you’re so strong, you’re so this’, and I was like ‘no I’m not’. You just have to do it.

A sense of control        | Jane: I remember the surgeon being there and I was coming around and she was like, ‘I assume baby’s staying?’ I was like, ‘Yes, baby is staying.’
Corinne: I said ‘For the first month I want to breastfeed and then I’ll take the Tamoxifen’.
Corinne: I self-medicated on those because the amount they told me to take was a lot more than I actually took.

I put myself in their hands | Linda: I mean I never asked what grade it was, I never asked how far along it was, I didn’t want to know. I didn’t need to know. It wasn’t going to change the outcome, so they were going to do what they were going to do. They were going to do their thing. I was going to let them and I was going to do as I was told.
Katie: I just put myself in their hands.

The important role of knowledge/information | Anna: That’s the whole thing, it’s just so grey. There’s no black and white. All they can go on is statistics. There’s no definitive answers. So it is a really hard thing because I like knowing the information. I want to know things, but no one can tell you...‘this worked for so many people so we’ll do that for you’.
Corinne: I was desperate to find more information because I felt so bad having chemo...and I needed answers for me to come to terms with it psychologically, to be able to do it.

Detaching then, reconnecting now | Jane: About a year after, because I was...I was actually off work for about six weeks, I kind of hit a wall mentally and I couldn’t stop crying. I’d kind of forgotten about that actually.
Linda: I think I handled it a lot better at the time than I appear to be now. I mean I wasn’t like this at the time, which is really strange.

Disbelief & denial         | Katie: ...It was just like oh there’s nothing wrong with me...it’s because I’m pregnant that they are treating me very well.
Chrissy: It’s weird when you look back and talk about it now, because if you had sat and told me your story, I would think, ‘Oh my god, poor woman, how did she deal with that?’

Distancing/avoidance       | Daisy: You know, even like... yes, yes, yes, I’ve got breast cancer, yes, yes, I’m pregnant, yes, yes, it’s fine. Anyway, did you have a good holiday?...
Rita: like I say, I suppose to cope I’d just then switch on to ‘I don’t know until I know, I’m not going to let myself think about it’.
<table>
<thead>
<tr>
<th>Rationalising</th>
<th>Rebecca: Again I am trying to rationalise things like that. I think it is really important, you can let your mind run wild, it is so important to rationalise it. Otherwise being a nervous wreck every day would be miserable. Katie: I’ve had other cysts and your heart goes into full scale panic mode, and you have got to try and rationalise that.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffering and struggling</td>
<td>Physical / Emotional Jane: I felt as if I was just, kind of, letting everyone down... Nadine: ...just seeing him with the baby in his arms, trying to help me, baby screaming, it was awful. He was crying, I was crying, baby was crying, it was just, you know... Daisy: I had flu, [older child] had flu. I was having chemo. [Baby] spent a lot of time at my in-laws because I was just too poorly to look after him, I just couldn’t... [Husband] was working nights, he was doing as much as he could. We were living with my mum, but my mum worked, my dad worked, he worked away. So it was just so hard, it was absolutely exhausting.</td>
</tr>
<tr>
<td>Emotions</td>
<td>Being younger, alone and isolated Rebecca: I think it has been difficult. I remember the first time I went into have my scan and seeing everybody older. That is nobody’s fault, but that upset me. I burst out crying in a corner in the hospital. I think when you are on the ward having your operation you just feel like the young person, you feel odd, you feel on your own.</td>
</tr>
<tr>
<td>Anger</td>
<td>It’s unfair Lorna: I’m just getting on with what I’ve got, you know burdened with, lumbered with, I wish I hadn’t been, wish it had all gone like it should have gone and maybe I would be in a great place right now and working hard and you know [baby] would be going to the nursery and [husband] would still be in the same job. Jane: ...just thinking, ‘do you know what, I don’t drink, I don’t smoke, I’m not overweight,’ do you know, I don’t do any of the things that... but why me?</td>
</tr>
<tr>
<td>Expression of my emotions</td>
<td>Katie: But I used to do all the crying when... I think she would have been at school, so I was back to normal by 3 o’clock. If I was going to get upset it was between 9 and 3 and I would then go up to school as normal and just get on with it. Chrissy: Even just her saying, ‘Are you sure you’re okay? In her nice, kind of, reassuring voice, that made me, kind of, burst into tears. The tears didn’t stop for about a week, I think I was just letting it all out. Jane: ...you have to, kind of, not let anyone know how you’re feeling... for instance, ‘Oh, you’re so brave’... but it’s sometimes the face you just put on during the day. Corinne: I would in the night feel a heaviness on my chest and then think Oh there’s something wrong inside. There was a lot of suppressed emotion going on...</td>
</tr>
<tr>
<td>Fear</td>
<td>Fear of dying / existential angst Nadine: ...thinking that actually, I may not be seeing his third, fourth, fifth birthday, maybe not even his first, who knows... Corinne: ‘Oh the baby’s healthy, everything’s going to be fine’. Yes, that’s fantastic, but for me, yes, I’d lived a year but then in the back of my mind there was still this discussion about the likelihood of living five years and that doesn’t go away and of course other people aren’t aware of that and so far other people everything was almost back to normal, happy families, “it’s worked out fine, [she] is going to be okay”, but for me the reality... [becomes upset].</td>
</tr>
<tr>
<td>Fear of recurrence</td>
<td>Jane: It’s just that feeling will never go away... I’ll never be 100% relaxed again in my life, no matter how unconcerned about it you are, there won’t be a minute of a day at some point, where it doesn’t cross your mind and it’s almost like still there, kind of, part of you. Corinne: ...my chest felt heavy and I thought ‘Oh maybe there’s something wrong with my heart’, thinking ‘Can you get cancer in the heart?’ Because I’m thinking it’s come back and it’s causing constriction inside somewhere, is it my lungs?</td>
</tr>
</tbody>
</table>
## Mixed emotions

*Dawn*: I think a whirlwind of emotions... it’s literally the only way you can describe it is it is like being on a rollercoaster. It’s up, it’s down, it’s round and round. In a way the only other way I described it is it’s a bit like white noise, you’ve kind of got all these feelings and all these words and all these questions... it’s mind-blowing.

### Shock

*Anna*: So yeah, of course initially you just feel like you’ve been smacked in the face with a sledgehammer, so obviously we were both upset.

*Rita*: I remember it was like somebody had thrown something at you. Total shock, completely... the surgeon said ‘Shall I keep talking?’ and she did keep talking, but after she’d said it kind of nothing else went in.

### Worry

*Corinne*: I’m thinking about [child] who is only one year old and I’m so sort of worried that I’m going to die and he’s not going to remember me, that was my, I think one of my main concerns that how long will I live for?

*Rita*: With [baby], I don’t know, I suppose there’s a part of me that worries... you can’t help at the back of your mind think ‘is he going to be different because of it?’

## Health-care experience

### Relationships with HCPs

*Corinne*: I knew my case was very rare, and I’m not even seeing the top man, I was so distraught I just burst into tears, when I had this other person, you know, I was just sort of a mixture of disappointment, anger, scared, thinking, you know, because this person was asking this other person... I was asking and they couldn’t answer any of my questions.

*Nadine*: I don’t think they were really going to tell me if I didn’t ask what it meant and I was really shocked at that.

### Communication

*Corinne*: I’m thinking about [child] who is only one year old and I’m so sort of worried that I’m going to die and he’s not going to remember me, that was my, I think one of my main concerns that how long will I live for?

*Rita*: With [baby], I don’t know, I suppose there’s a part of me that worries... you can’t help at the back of your mind think ‘is he going to be different because of it?’

*Corinne*: I did look a bit daft really because it was all fluffy and chunks had gone out but I didn’t want to wear a wig so I just had it cut really short.

## Treatment

### Effects

*Katie*: I had six lots every three weeks. But by the end of it as soon as I used to turn into the hospital drive I used to start feeling sick. It is all just psychological.

*Nadine*: Literally, any bug that was going around, I’d have my chemo and within two days, my temperature went through the roof and I’d be in hospital, so literally every three weeks I was having a two, three, four, five night stay in hospital because I was so ill.

*Corinne*: I did get very tired, I was very achy and very tired.
<table>
<thead>
<tr>
<th>After treatment adjustment</th>
<th>Daisy: ...they were also talking about discharging me... it really panicked me. I felt really scared. I felt quite frightened, really, of, well, what next? And then quite relieved that they decided to keep me on. Rita: I didn’t understand before, the hurdle was it, and it’s not. It’s a bit like the pregnancy, when you have a child, the pregnancy isn’t all that, almost nothing, it’s looking after the child that’s the big thing, and the cancer, the chemotherapy, you had to get through it, but the actual living with it afterwards is much harder. Katie: I felt abandoned. Absolutely abandoned. I felt on my own, I did feel totally lost. It was like somebody had taken away the support net, it had gone, and it did take quite a while to get used to it.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact of cancer</td>
<td>Personal development / growth</td>
</tr>
<tr>
<td>Impact on baby</td>
<td>Rebecca: ...he didn’t get the same as my daughter did. Rita: ...there was the extra stress of what might happen to him, to the baby... Anna: I’m always going to feel a bit guilty that she couldn’t come out when she wanted to.</td>
</tr>
<tr>
<td>Relationships</td>
<td>Community</td>
</tr>
<tr>
<td>Core family</td>
<td>Mother - other children</td>
</tr>
<tr>
<td>Wife and husband</td>
<td>Lorna: It’s so unfair, I think he just saw me as a very stable person and that was, kind of, what was going to carry on, you know, as far as he was concerned and then look what happens, I get breast cancer. Chrissy: It was just us bouncing our feelings off each other. Jane: [Husband] was just lying in bed beside me, like stroking my head and he was just sobbing and for me that was just the worst. Jane: ...when they were doing my bone scan and he didn’t quite understand that, he thought, ‘Well, if it’s back in her bones, they will just treat it,’ but he didn’t understand that it’s not like that, if it’s in my bones, it’s going to get me. Corinne: And then I had my husband saying to me “Oh, yeah, you cried so that you could get to see that doctor”. So, you know, that was the emotional support that I got at that moment in time which was zilch!</td>
</tr>
<tr>
<td>Siblings</td>
<td>Corinne: ...the last year, maybe couple of years, it’s become more difficult. So I’ve sort of been careful with how it’s been handled with [PABC child] going to [PABC research] for his tests and being given all this attention. When we’ve been interviewed with the newspaper I’ve involved [older child] because it’s, at the end of the day, it is a family thing.</td>
</tr>
<tr>
<td>Other people’s emotions</td>
<td>Other people bring it home</td>
</tr>
<tr>
<td>Causing distress to others</td>
<td></td>
</tr>
<tr>
<td>Own parents and in-laws</td>
<td>Lorna: I don’t want to die before my parents, I’m probably going to, you know, I want to be their good girl. Chrissy: I had to leave the kids with family. That was the bit that really affected me the most, but at the time, I still had to do it, I just got on with it. Jane: [My father-in-law] he didn’t want to be involved, he was the only person that never saw me without hair, so I had to quickly pull it up and get the scarf. He just couldn’t really deal with it… Nadine: I wasn’t getting on very well with my parents, my Mum had made the diagnosis all about her, obviously they didn’t cope very well with it. My Dad very much is just, closes down and ‘let’s us not talk about it’.</td>
</tr>
<tr>
<td>With self</td>
<td>Chrissy: I feel like I couldn’t give him my undivided attention, I had to rely, maybe on help. I don’t like asking other people for help, I’m very much, ‘I’m doing it,’ it’s my way, I like to do things my way and if someone tries to help me and don’t do it my way, I get pretty offended. Nadine: I really cannot stand is wasting my times on things that I shouldn’t have to. I think, why should I have to spend my time doing your job because you’ve not done it properly and that rubs me up the wrong way. Corinne: And then another part of it was a selfish thing that I’m not going to be there when he has certain milestones and I wanted to be remembered, you know, there was sort of a feeling, I can remember that was a strong feeling, that I didn’t want him to not remember me [cries]. Anna: I mean it doesn’t matter really how they’re fed, but I just felt like everyone’s looking at me and saying ‘oh, it’s such a tiny baby and you’re giving it formula’, so I felt like I needed a t-shirt saying ‘I can’t feed her’.</td>
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<tr>
<td>Support</td>
<td>Lack of acknowledgement and understanding from others</td>
</tr>
<tr>
<td>Meaning of therapy</td>
<td>Chrissy: [My therapist] said, ‘It’s alright, it’s okay to feel like this and you are allowed to feel guilt for still being here and people have passed away, you are allowed to feel, like screaming at people or saying you are brave, you know, and that.’ Just the three sessions with her made me feel…I now feel back to me, back to Chrissy, who I was before this all happened. Corinne: If I could have spoken to someone about it and that they could have said to me “Yes Corinne, you know, that’s why that’s happening” and that I could have worked through the emotions and found a reason for things, that would have helped me I suppose release… So for me that is a really, I think, important thing.</td>
</tr>
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Appendix 10  Brief overview of findings as presented to participants at write-up stage

Understanding the experience of Pregnancy-Associated Breast Cancer (PABC)
– An interpretative phenomenological analysis
by Janne Marie Rodsten

Abstract

Counselling Psychologists who work with breast cancer patients are expected to understand and be able to empathise with the experience of being diagnosed with breast cancer. But the experience of younger patients who are diagnosed with breast cancer whilst they are pregnant is both physically and psychologically diverse from that of non-pregnant cancer patients, and has challenged practitioners’ competence in this area. Because pregnancy-associated breast cancer (PABC) is rare and has been little researched, there is a significant dearth in the understanding and guidance for practitioners.

This study explores the qualitative experiences of women diagnosed with PABC, seeking to understand the features that make these experiences unique to the condition, and thereby facilitate comparisons with commonly known and well-documented breast cancer experiences.

Interpretative Phenomenological Analysis (IPA) was conducted on data from 11 semi-structured interviews. Participants were 32-44 years old and from the UK. Major themes arising were: (1) perceptions of a clash of priority between baby’s life and mother’s life versus mother feeling in alliance with baby, (2) perceptions of being physically and emotionally rescued by the pregnancy and baby, and (3) perceptions of a loss of being a mother.

Importantly, these findings support the idea that the experience of PABC involves distinct psychological challenges with potential long-term consequences for patients, and for close relationships within affected families. It is argued that practitioners need education about these emergent experiences to avoid their being misunderstood or misinterpreted as unusual or problematic. Psychologists working in cancer care will find it increasingly difficult to work proficiently without a good understanding of the experience of PABC, and continuing professional development around this phenomenon is strongly encouraged.

Main Findings

Analysis of the data set identified participants’ experience of PABC through three super-ordinate themes with a number of sub-themes emerging within each super-ordinate theme. These findings present extracted features of participants’ experiences, and draw attention to commonalities and divergences in narratives. Upon choosing features of experiences, prominence was given to experiences that were judged to be unique or particularly salient to Pregnancy-Associated Breast Cancer.
<table>
<thead>
<tr>
<th>Superordinate theme</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Whose life comes first?</strong></td>
<td>1a. <em>I’m not putting [my baby] in danger’</em>&lt;br&gt;Maternal protective instinct and drive</td>
</tr>
<tr>
<td></td>
<td>1b. <em>I let them fight it out’</em>&lt;br&gt;The experience of a conflict between obstetrics and oncology</td>
</tr>
<tr>
<td><strong>2. My baby rescued me</strong></td>
<td>2a. <em>I could have been dead a long time ago’</em>&lt;br&gt;Coping and surviving in a physical sense</td>
</tr>
<tr>
<td></td>
<td>2b. <em>You have to keep going for this baby’</em>&lt;br&gt;Coping psychologically by keeping a focus</td>
</tr>
<tr>
<td></td>
<td>2c. <em>As much normality as I could squeeze in’</em>&lt;br&gt;Seeking family normality</td>
</tr>
<tr>
<td><strong>3. The loss of being a mother</strong></td>
<td>3a. <em>We didn’t go to any baby groups’</em>&lt;br&gt;Loss of new mother behaviour and identity</td>
</tr>
<tr>
<td></td>
<td>3b. <em>That year should have been all lovely’</em>&lt;br&gt;Engagement and bonding: complicated by circumstances</td>
</tr>
<tr>
<td></td>
<td>3c. <em>I think I kind of withdrew from him’</em>&lt;br&gt;Protective distancing myself from baby (and from others)</td>
</tr>
</tbody>
</table>

**Super-ordinate theme 1.**

Upon diagnosis the participants describe how they find themselves projected into a sudden psychological and physical dilemma involving their own survival and the survival of their unborn child. This is experienced as an existential dilemma about whose life comes first and whose health and well-being warrants priority above the other: the mother-cancer patient needing urgent treatment, or the unborn baby needing more time to grow and develop naturally in the womb. Cancer treatment is here generally perceived as a threat to the health and well-being of the baby (having treatment whilst baby is still in the womb, or electing baby to be born preterm). Conversely, remaining pregnant and delaying treatment out of concern for the baby is perceived as a threat to the survival of the mother-cancer patient.

The majority of the participants do not hesitate to think of the survival and well-being of their baby before their own, and thus to put their baby first. There may be a variety of reasons for this, including participants’ felt maternal obligations, denial of the situation and risk to themselves, and strong feelings of guilt for having ‘disrupted’ life as it was (including baby’s natural development during what was a normal pregnancy) by falling ill and needing treatment. At the same time, it seems that participants regard themselves to be in an alliance with their baby against the adversity of the disease and treatment, a maternal-fetal alliance. The sense of being engaged in a maternal-fetal alliance contrasts sharply with how HCPs may consider PABC likely to give rise to a maternal-fetal conflict, where the well-being of the mother conflicts with the well-being of the fetus.

**Super-ordinate theme 2.**

Throughout most accounts there is a sense that participants feel that the pregnancy and the baby somehow helps the mother cope practically and emotionally with the cancer treatment, and contributes to her survival and recovery of the disease. That mother and baby are in a maternal-fetal alliance of sorts. In some accounts, this sense is stronger still, and participants relay how they feel that they coped and survived only because they were pregnant and had a baby to give birth to, and to be a mother to, throughout the difficult times and until recovery.
The notion of pregnancy and baby serving as rescue mechanism for the ill mother holds both physical and psychological functions for the participants, and both types of functions are active at the initial stages of receiving the diagnosis, as well as through giving birth and throughout having treatment during the baby’s first year of life. The physical functions concern the pregnancy initially alerting the participant to the cancer during regular pregnancy consultations with doctors, as well as drawing attention to cancer symptoms, which may otherwise have gone unnoticed for longer. After giving birth, the physical presence of a newborn functions as instigator for the mother to attempt to remain active in the daily care of the baby (this is also described in Sub-theme 3c) and the maintenance of a normal family life. The emotional functions are more complex, and concern the mother’s motivation to cope and survive, being given purpose and having positive distraction from overwhelming negative emotions, and a meaning-making function of life as a cancer patient where the ‘bad’ is balanced with some ‘good’. The perception of the baby as a rescue for the ill mother brings sense and meaning to the unfortunate timing of the two events, and the clash of pregnancy and cancer therefore happens for a (good) reason.

Super-ordinate theme 3.

The theme ‘The loss of being a mother’ is central and pervasive in all the participants’ accounts of their experience of PABC. The previously presented Super-ordinate themes 1 and 2 contain elements of the experience of loss across both the balance of mother’s versus child’s life, and the mother being rescued by the baby. This super-ordinate theme focuses on the experience of loss across three sub-themes.

All the women who took part in the study struggled to come to terms with a sense of an irreparable and permanent loss, although expression of this loss seemed at times to be restrained. For all participants, the sense of loss brings with it deep-rooted feelings of pain and guilt, and an urge to compensate their child who they feel has also experienced a loss. For the mother, the experience concerns the loss of time, ability and opportunity to engage with the pregnancy and the baby, to bond and be a mother-infant twosome in the way it was imagined by the mother, and the way it is typically perceived as being the norm and the definition of new motherhood in Western culture.

Yeah, you just feel like a lot’s been taken away from you, that this isn’t how it’s meant to be, this isn’t what you planned. Linda

The following three sub-themes present participants’ experience of loss over three areas of motherhood, however, there is considerable overlap between these, and they are presented separately mainly to explore a particular part of the experience in a more detailed way. Sub-theme 3a. concerns the perceived loss of new mother identity and behaviour, i.e. experiencing being prevented from doing and being what they believe they would normally have done and been, had they not been diagnosed with cancer. This includes activities (e.g. walking with baby, going to groups) and interaction (e.g. breast feeding), involving their new baby, and family life as it was supposed to be, including having more children. The mothers convey how having cancer treatment is physically preventing them from forming an identity as their new baby’s mother, or at least, the identity they had envisaged and desired, caused by the blocking of typical parenting activities and behaviour. Sub-theme 3b. overlaps the preceding sub-theme, but focuses on the experience that the typical and desired attachment process and outcome between mother and new baby is disrupted by the illness and treatment. The participants’ accounts describe the loss of being able to, and being allowed to, express themselves physically and emotionally towards their baby. Sub-theme 3c. presents participants’ experience of withdrawing from their baby and from others, caused by the fear of loss. This behaviour triggers feelings of guilt. Since recovering from their illness, the participants try continuously to make good and resolve the loss through an intense nurturing of their relationship with their PABC child, including constructing this as a ‘special’ relationship.
Appendix 11  Reflections on insider positionality

This section is reflexive, and its purpose is to examine the research process in the context of my positionality as researcher. Specifically, I wish to reflect on the effects which I perceive that my unique positionality had on the process and outcome of this study. References are listed at the end of the appendix.

I am a White, middleclass woman aged in my mid 40s, mother of two children, in a long-term heterosexual relationship, and I have lived in Western Europe all my life. Prior to carrying out this research project, I experienced being diagnosed with breast cancer whilst I was 35 weeks pregnant with my second child. I had a C-section immediately after diagnosis and went through a year of invasive cancer treatment. This experience ultimately led me to train to become a counselling psychologist, and to the decision to conduct my doctoral research on women’s experiences of Pregnancy-Associated Breast Cancer. I searched the media and found some information about families’ struggle to make sense of their experience and wanting to have their stories heard. For this project, I aimed to develop an understanding of the ways in which women experience being diagnosed with PABC and what consequences they perceive it has for them and their families in the longer term.

Insider researcher
There were assumptions I made as a researcher regarding establishing a rapport with participants, understanding of their data and the topic, and course of the research, that relate to the concept of insider/outsider researcher. Insider research can be defined as when the researcher has a direct personal involvement or connection with the research setting (Rooney, 2005), e.g. in contrast to positivist researching as an ‘objective scientist’. Insider researchers are considered to have multiple commonalities with their participants (Adam, 2012; Chavez, 2008). In order to be an advocate for my participants, my work needed to reflect their voices.

Access and data collection
Having a status as ‘insider’ is often assumed to allow quicker access to potential participants (Breen, 2007). I was unprepared for the ‘expediency of access’ (Chavez, 2008) to my population, and had not anticipated to recruit as many participants and as quickly as I did. This preconceived notion about the limits of access is perhaps best explained through my relative inexperience as a researcher. Conversely, I did expect that my position of being a White middleclass forty-something heterosexual woman with a history of PABC would aid me in connecting well with all the participants. There was an obvious ‘sameness’ factor between them and me, and it felt very easy to develop trust and rapport (O’Connor, 2004). I feel certain that the positive interaction between us and the perception of a shared experience helped the generating of in-depth data which was authentic and rich in content (Breen, 2007; Dwyer and Buckle, 2009). However, personally, and with nearly all participants I felt that their personal experience had somehow been ‘worse’ than my own, that their circumstances were more serious, severe or life-threatening, and this produced an amount of guilt during the interview process which I did not acknowledge in myself. I felt admiration for what the participants had been through and how they had coped but I did not feel the same for myself. There were two possible explanations for this. The first was (my own and my family’s) denial or downplay of my own traumatic experience, including the severity of my condition and its devastating timing. I was able to recognize this as a frequent coping method in most of my participants, and now also in myself. The second explanation was that I really did feel that I had been luckier than most, in that at nearly full-term I gave birth by C-section the day following my diagnosis. My baby had grown enough and was ready, and so at least some of the problem seemed to be under control almost immediately. In contrast, most participants in my research had cancer treatment (chemotherapy and/or surgery) whilst still being pregnant, and spent many weeks or months with their cancer diagnosis until
giving birth. Whilst scientific research now shows that it is safe to have treatments such as chemotherapy and surgery during pregnancy (Amant et al, 2012), the great clash that is cancer and pregnancy combined often produces an experience of not having control at a sensitive point in time, and is a major source of stress for the patient and her family. The guilt I felt was a driving factor in my ambition to produce a high standard of work in my research, as I felt I owed this to my participants.

Shared knowledge
One advantage of being an ‘insider’ researcher is having greater awareness and understanding of the research group’s culture. Although I am not British by birth, I have been in close contact with British culture for more than 20 years, first living in Britain as a student in the early 1990s. Britain is now my adopted country, and I feel very familiar with general beliefs, norms and traditions. Having said that, I will always be a foreigner here, and thus demonstrating how insider/outsider status is never simple or an either/or dichotomy, but is rather more helpfully viewed as a continuum with the researcher changing status throughout the different stages of the process (Ritchie et al, 2009).

The participants and I were all parents and PABC patients. Consequently, our individual and shared perceptions of illness and of parenthood were likely to influence the data. Before embarking on this research project, I did not have in-depth knowledge of other women’s experiences of PABC. The pilot project had generated brief data from six women, and I had been following several chat forum discussions in the US and via the British charity Breast Cancer Care. As I interacted with my participants, my understanding of their experiences expanded very rapidly, and I began to see how my role as interviewer was (and had to be) an ‘outsider’s’ role, which gradually would change into taking an ‘insider’s’ perspective. However, my prior personal understanding of the phenomenon of PABC worked in my favour in several interview situations in that I felt an emotional connection with the participants, and an ability to speak frankly and be ‘on level’ without much effort. Above all, I feel it enabled me to ask appropriate and relevant questions, and to gauge when particularly salient issues arose that may have required elaboration. At these times, I felt very much like an ‘insider’, and I became aware of the fragility of trying to be as objective as possible, and to not apply a copious number of assumptions, at least without awareness of doing so (Hewitt-Taylor, 2002). In terms of knowledge, there is no doubt for me that an ‘insider’ position worked both for and against the research objectives. I believe there were times when participants did not go into as much detail as would have been helpful, and that we both might have assumed that I already knew (Dwyer and Buckle, 2009). Furthermore, I wonder if some participants may have held back, and felt that I was ‘the expert’ on the subject of PABC because of my personal experience (which in nearly all interview situations had taken place long before theirs) now being the subject of my research. With an outsider researcher, participants may have felt more empowered in this respect (Tinker and Armstrong, 2008).

In an effort to keep an open mind as free of assumptions as possible, and to identify personal preconceptions and minimize their influence, I kept a research journal, field notes or general notes throughout most of the research period (Ahern, 1999). This helped me ‘bracket off’ interfering assumptions and presuppositions (Langdridge, 2007), to get to the first hand experience as far as possible.

In spite of the possible limitations, I felt that my ‘insider’ position played an important part in the data collection process in this research. Apart from having experienced PABC myself, this included the position of being a woman and a mother. It felt like my position meant that the participant could get ‘straight’ to the most pressing issues, which I believe was what they wanted to do in the situation, and what they did. During all of the interviews, the participants would become visibly emotionally affected by what they were talking about. I never felt that anything
that they told me was not of importance to the participant, even minor events that had taken place years in the past. Perhaps they shared their experiences so readily because they perceived that as an ‘insider’ I would straightaway understand the complexity of these.

Relationships with participants
During interviews, I wondered from time to time how not being British and having a slight foreign accent in my spoken language would impact on my relationships with participants. However, I did not feel much impact in the moment itself, other than a very characteristic politeness shown by the women I met and talked with. I suspect that this politeness could both be a ‘British-person-meeting-non-British-person’ type behaviour, but also that it could be down to other individual factors that were less definable. The sense of being in the same boat – or at least having a shared understanding of cancer during pregnancy and its importance as a research subject, a joint mission so to speak – was more dominant than any cultural differences I picked up on. In that respect, the feeling of ‘sameness’ mentioned earlier went across our cultures. At the end of interviews I offered to keep each participant up-to-date about the research progress via twitter and the research blog, and most acknowledged this offer positively.

Analyzing data
It is clear there are advantages and disadvantages for a researcher to have either an ‘insider’ or ‘outsider’ position. Many of the advantages are of a practical nature and also include being closer to the data with a heightened accuracy in understanding the complexities of a particular experience. The disadvantages are mostly centred on being predisposed, having vested interest and maintaining a degree of objectivity (Dwyer and Buckle, 2009). For an optimal balance, it is beneficial to research as a team involving a mix of ‘insiders’ and ‘outsiders’ (Ritchie et al, 2009). In this instance, the supervisory team fulfilled these criteria. The principal supervisor was a White British Health Psychologist, female and mother of young children, and the Director of Studies was a White British Counselling and Health Psychologist, male and father of teenage children.

In an effort to establish a balance, the supervisors checked the findings against the raw data, and we discussed overall themes as well as nuances and characteristics in detail. Initially, I felt very much that my positioning was that of an ‘insider’. As I reflected more, I realized that as a non-Brit, I was also an ‘outsider’, and that my personal experience of PABC was unique and did not ‘correspond to’ or match my participants’ experiences, and neither was it supposed to. As a reflexive exercise, I recorded my own story before data collection, and this preparatory work helped differentiate experiences later on, and avoid being tempted to purely fit the data to my own understanding (Etherington, 2004; Josselson, 2013). The extensive personal reflection was shared with my supervisors who commented on the quality from a methodological stance, encouraging me to go way beyond description and get to the core of the experience and its held meaning. This was extremely difficult, as the very personal aspects of my experience were hard to access consciously for me. These are still a work-in-progress. However, doing this reflexive preparatory work tied in with the recommendation to ‘bracket or at least acknowledge’ my own preconceptions and ‘stand alongside the participant’ as well as taking the ‘insider’s’ perspective (Smith et al, 2009, p. 36).

Emotional impact
For me, it was liberating to have experienced breast cancer during pregnancy personally before starting to research other people’s experience of it. It meant that I did not have to subscribe to any public or mainstream narrative about cancer as being a frightening, deadly or mysterious illness and a devastating experience in any way. I already had a relationship with cancer, I felt I knew what I was dealing with, and was not afraid to look at it as closely as would be required. I recognised the same attitude in some participants – a few years down the line, and cancer as a phenomenon had ‘lost its teeth’. My ‘insider’ position felt like a definite advantage here. I sensed I was better at gauging the participants’ emotional and psychological state throughout the
interviews, and it was as if we were walking together down the road that became their story as it was relayed to me. I always felt completely drained after an interview. Although I was sometimes surprised by details of their experiences, I never felt shocked or perplexed by what they told me. It was a challenge to hold back and not offer my own take on the topic, and I did not master this well enough until the later interviews. For example, during the first interviews I frequently, but not intentionally, offered my own contribution to the description of a sentiment started by the participant, or to finish the participant’s sentence. I gradually became more aware of this, and subsequently was able to control it more efficiently during the rest of the interviews.

Personal stake
I assumed from the outset that a great deal of my motivation for choosing to investigate this particular topic was connected to my personal experience of PABC, but I was much less aware of the specific reasons why, and indeed what I was expecting to be able to produce. However, it felt important to me that I carry out this work, and as if I was in a unique position to investigate the phenomenon from both a counselling psychology perspective and as an ‘insider’, provided it was possible to balance the personal element with the requirement and desire for quality and validity. I gather that this was of equal important to whatever findings I might present.

I was conscious that there was a risk in doing this work for me. By laying out my understanding of participants’ experiences and also of my own experience, my perspective and my perception of the entire phenomenon became transparent, and was then changed through the communication with others who ‘might extend, challenge or validate’ it with their own explicit views (Etherington, 2004, p.29). The outcome may therefore not have felt comfortable to me or fit in with how I made sense of my life since my personal experience. For a topic this personal, it seemed a considerable risk, but a risk worth taking on account of the intended functional and practical value of the project once completed. The objectives of this study were to explore and identify the unique challenges integral to the experiences of women who were diagnosed with PABC as a basis and guide for future more focused research. Ultimately, the aim was to generate knowledge and awareness of the condition to make the experience better for future patients and their families.

Throughout the research process, I continually considered the many different limitations of my study. In particular, I thought about the limitations in the context of my positionality as a virtual participant myself, and felt that not only my findings, but also the whole project, demanded a good amount of justification. Reflecting on the research process now, however, I suppose that my positionality need not be seen as a limitation, but can in fact be a valuable resource. The entire project is shaped by who I am, and I am shaped by it in turn.

References for Appendix 11


Appendix 12  Pilot study posters submitted for DCoP Annual Conference, Cardiff, July 2013.

Exploring Women’s Experiences of Breast Cancer During Pregnancy
A Grounded Theory Approach

Breast cancer is the most common cancer to occur in pregnancy and incidence rates are rising (Cancer Research, 2013). Ca. 400 pregnant women are diagnosed with breast cancer in the UK every year. No theory existed of how women and their families experience the impact of being diagnosed with breast cancer whilst being pregnant, and how they make sense of their experience at diagnosis and beyond.

Extensive research testifies to the experiences of non-pregnant women who are diagnosed with breast cancer. Relevant findings include:
- Being of younger age (<50) at diagnosis is an important factor for greater emotional distress.
- Depression and anxiety experienced during pregnancy can negatively affect birth and the well-being of the fetus (Alder et al., 2007).
- Pessimism, or a helpless attitude towards the disease, is related to a poorer prognosis (Watson et al., 1991, p.51).

This study:
- aimed to generate a substantive theory by exploring how female breast cancer survivors who were pregnant at diagnosis understand and talk about their experience of breast cancer.

Method: A grounded theory ‘lilith’ approach (Braun and Clarke, 2006) was used, with primary data generated through an online questionnaire, and secondary data obtained via observed discourse in cancer chat forums.

Findings: My theory was based upon the finding that the women constructed their experiences through a sequential process:

- Facing death, managing trauma and practicalities
  Shock and trauma in the early stages shatter participants’ assumptive worlds and present a practical problem of managing a young family concurrently with having treatment.

- Making distinctions between them and us (and then me)
  Normal and healthy vs. not normal and unhealthy
  The women distinguish themselves from other women (abnormal and unhealthy) as part of a particularly unlucky and vulnerable, but resourceful and resource group.

- Working with healthcare professionals
  Positive experiences: Life-savers and angels
  Negative experiences: inexperienced, cold and inadequate
  Perceptual discord: the woman – part of a ‘patientship’

- Forming constructive ways now and for the future
  A greater purpose
  The women move into the final stages of forming constructive ways of understanding their experience and finding purpose and creating a future through personal growth and empowerment.

Implications for counseling psychologists include:
- More dedicated and appropriate service and support.
- Better ability to maintain focus in treatment.
- Better ability to demonstrate sensitivity to the issues and facilitate growth for the client.
- Insight into issues is known to positively affect the service and care provided by support workers, and can save money through enhanced efficiency (MacMillan, 2013).

Study limitations: This study was small scale (n=6) and it was difficult to know when and if saturation of categories was fully reached as per Charmaz’ guidelines (2006).

Janne M. Rodstein
University of the West of England
Appendix 13 Poster presenting this study submitted for the UWE Psychological Postgrad Conference, Bristol, September 2015.

Understanding the Experience of Pregnancy-Associated Breast Cancer (PABC) and the supportive care needs of affected families

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BREAST CANCER is the most common cancer to occur in pregnancy. Over 300 pregnant women are diagnosed with breast cancer in the UK every year, and incidence rates are rising (Cancer Research UK, 2015). As yet, no formal qualitative research exists concerning how women experience the long-term impact of being diagnosed with breast cancer whilst expecting a child or soon after giving birth, and how these women make sense of their experience at diagnosis and beyond.

Extensive research testifies to the experiences of women who are diagnosed with breast cancer, or who are pregnant.

Relevant findings include:

- Being of younger age (<50) at cancer diagnosis is a significant factor for greater emotional distress. (Buckley et al., 2004; Allen et al., 2015)
- Perinatal mood disorders, early family life stress, and defects in parental attention, negatively affect the well-being of the infant and the parent-child attachment process and outcome (Silver, 1997).

This study
- aims to explore and understand the subjective experiences and self-reported supportive care needs of women diagnosed with breast cancer whilst pregnant, and in particular, factors that make these experiences unique to the condition.

The study identifies the challenges women with PABC face in the long-term management of the psychological impact of the condition.

Method
The study is qualitative and takes a phenomenological perspective – data from 10 interviews is analysed using Interpretative Phenomenological Analysis (IPA), an idiographic approach that focuses on the individual person’s lived experience.

Preliminary Themes

<table>
<thead>
<tr>
<th>Relationships</th>
<th>Mother - Child</th>
<th>Attachment Disturbances</th>
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<td></td>
<td>Mother and Father</td>
<td>Parental Alliance &amp; Support</td>
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<td>Family &amp; Friends</td>
<td>Denial &amp; Lack of Understanding</td>
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<tr>
<td>Emotions &amp; Coping</td>
<td>Fear &amp; Anger</td>
<td>Visions of Motherhood, Family Life</td>
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<td>Expression of Emotions</td>
<td>Making It Meaningful</td>
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<td>Reality vs. Imagined Life</td>
<td>Something to hold on to &amp; Some Control</td>
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Preliminary Discussion

PABC presents unique and severe psychological challenges, which appear to have long-term consequences for the families affected. Interpersonal relationships within the care family seem particularly vulnerable to the stresses of facing death and going through treatment, and adjusting to life in the years following. Assessment of psychological needs and specialist supportive care is currently not automatically offered to all patients and their families. This seems critical at point of diagnosis and as treatment ends.
Appendix 14  Description of journal targeted for article submission

The journal targeted for article submission is:


Psycho-Oncology is a monthly peer-reviewed medical journal published exclusively online by John Wiley & Sons Ltd (Wiley-Blackwell). The journal was established in 1992, and contains articles related to research in the field of psycho-oncology. The current editors are Jimmie C. Holland and Maggie Watson. Psycho-Oncology was the first comprehensive text and remains the leading journal in the field today. It is developed in collaboration with the American Psychosocial Society and the International Psycho-oncology Society. The journal reflects the interdisciplinary nature and global reach of psycho-oncology, and is a current and comprehensive reference for seeking to understand and manage the psychological issues involved in the care of persons with cancer and the psychological, social, and behavioral factors that contribute to cancer risk and survival (source: Wikipedia).

Reason for targeting this journal:

Psycho-oncology is a highly respected and prestigious journal with a wide audience of psychiatrists, psychologists, oncologists, hospice workers, and social workers. Although inexperienced as a researcher, I believe that my topic is rare and under-researched, and that my perspective as a an ‘insider’ counselling psychologist adds a unique understanding on the experience of cancer during pregnancy. I particularly wish to address oncology healthcare professionals at all levels with my study, as I believe they generally have much to learn about the experience of pregnancy-associated breast cancer. I hope my study can stimulate them to educate themselves further on the topic. Psycho-oncology has previously published articles on PABC (Henry et al, 2012; Ives et al, 2012), and acknowledge that this topic is of interest to their audience.

Journal publication guidelines overview
(source: http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1099-1611/homepage/ForAuthors.html)

Psycho-Oncology operates an online submission and peer review system that allows authors to submit articles online and track their progress via a web interface. The language of the journal is English. 12-point type in one of the standard fonts: Times, Helvetica, or Courier is preferred. It is not necessary to double-line space manuscript. There should be a separate title page with full information and another page for an abstract, prior to the Introduction. Tables must be on separate pages after the reference list, and not be incorporated into the main text. Include an abstract of up to 250 words for all articles. It should contain no citation to other published work. The abstract must be submitted according to these headings: objective; methods; results; conclusions. Also include up to ten keywords which must contain the words cancer and oncology that describe your paper for indexing purposes. All manuscripts must include within the Discussion section a paragraph explaining the study limitations and a paragraph explaining the clinical implications of the study. Research Articles should not exceed 4000 words (including no more than four figures and/or tables) plus up to 40 references. All papers should use the following headings: Background, Methods (including statistical methods), Results, Conclusions. Word counts should include the title page, abstract, main manuscript, tables and figures, but exclude the references. Qualitative manuscript submissions should usually be based on a minimum of 20 respondents. Authors may contact the Editors if they require further details.
Reference style. All references should be numbered consecutively in order of appearance and should be as complete as possible. In text citations should cite references in consecutive order using Arabic superscript numerals. Tables should be part of the main document and should be placed after the references. Ethics. Authors of research papers should provide information about funding, a Conflict of Interest statement, the name and reference number of the Research Ethical Committee, and (if the paper is a clinical trial) details of trial registration, including the registration number and name of the registry. All of these declarations should be in the main paper itself, not in a separate document.
“That year should have been all lovely”: Understanding the experience of Pregnancy-Associated Breast Cancer (PABC)

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December 2016
Abstract

Breast cancer is one of the most common cancers to occur during pregnancy or in the first year post-partum, a condition known as pregnancy-associated breast cancer (PABC). In the UK, estimates suggest that up to 300 women are diagnosed with PABC each year, with incidence rates rising as women delay child-bearing. Insufficient qualitative research exists into how women experience PABC, and consequently no management guidelines for psychology practitioners have been developed.

Objective:
To understand the experiences of women diagnosed with PABC, focusing on aspects that are unique to the condition. To serve as guide to future research into the psychological impact of PABC.

Method: Interpretative Phenomenological Analysis (IPA) was employed and data collected from 11 semi-structured interviews. Participants were UK nationals aged 32-44 years.

Findings:
Major themes: (1) experiencing a clash of priority between baby's life and mother's life, versus mother feeling in alliance with baby, (2) having perceptions of being physically and emotionally saved by the pregnancy and baby, and (3) experiencing a loss of being a mother.

Discussion:
The experience of PABC involves distinct psychological challenges concerning identity and behaviour as ‘new mother/patient’, maternal-infant attachment, coping, and impact on family life and relationships. Healthcare professionals working in cancer care or perinatal care services need specialised education about PABC to work proficiently with patients and families. Findings suggest that both physiological and psychological management necessitate a flexible structural format to accommodate illness and treatment effects, as well as parenting needs and responsibilities.

Key words: pregnancy-associated breast cancer, oncology, pregnancy-related cancer, gestational cancer, cancer phenomenology.
Introduction

Cancer occurs in up to 300 pregnancies in the UK every year [1], but incidence rates increase as women delay child-bearing [2-5], and as breast cancer rates rise in the reproductive age groups [6]. Breast cancer is one of the most common types of cancer to occur during pregnancy [2,3], and the condition is known as Pregnancy-Associated Breast Cancer (PABC). Breast cancer is a challenging experience, encompassing physical, psychological and social consequences [7,8], with one third of breast cancer patients reported to experience psychosocial difficulties following diagnosis and treatment [9]. However, the number of pregnant cancer patients who are identified as clinically distressed is nearly 20% higher than that of non-pregnant breast cancer patients, and pregnancy and early motherhood is itself a time of heightened psychological vulnerability [10,11]. Cancer during pregnancy presents unique and complex psychological and relational challenges with potential long-term consequences for patients and relationships within affected families [12,13]. Studies show that healthcare professionals’ and psychological practitioners’ knowledge about breast cancer experiences and knowledge-related psychological interventions can help patients’ coping and adjusting to life during cancer treatment and after [14], and patients’ overall survival [15].

Little qualitative research has been carried out into the subjective experiences of pregnancy-associated breast cancer in the UK. Quantitative data does not reveal the diversity of experiences, attitudes and coping mechanisms [16], which are valuable in order that appropriate and acceptable interventions may be developed. The knowledge generated from this study will expand psychology practitioners’ and healthcare professionals’ (HCPs) understanding of the complex emotional conditions and needs of patients and their families, and may function as a guide for future research.

Methodology

Ethical approval was granted by the University of the West of England Faculty Research Ethics Committee.

Design, participants and data collection
This project used a qualitative methodology to explore first-hand accounts of participants’ lived experiences of having breast cancer whilst being pregnant or within a year of giving birth. Qualitative methodology offers flexibility, and is sensitive to a high level of diversity in the data set [16]. Eleven women, resident in the UK and aged over 18 years, who self-identified as having experienced PABC, were recruited via letter or online methods, and invited to take part in individual semi-structured interviews with the primary researcher, in a mutually agreed upon location. Table 1 presents participants’ demographic information.

This project was an ‘insider’ study as the primary researcher had first-hand experience of PABC, and therefore a direct personal involvement or connection with the research setting [17]. To enhance validity of findings, personal assumptions about the psychological impact of PABC were explored and noted continuously from data collection onwards.

Data analysis
Audio-recorded data from semi-structured interviews was transcribed verbatim and analysed using Interpretative Phenomenological Analysis (IPA) to generate the emergence of themes [18]. This method is suitable for under-researched phenomena as it allows in-depth participant-centred exploration [19]. The large sample enabled a ‘group-level analysis’ to be applied, and the written-up narrative was a summarizing account of recurrent themes in participants’ shared experiences [18]. All themes were evidenced through extracts from the original interview transcripts.
The researchers reviewed the data to agree on accuracy of analysis. The quality and validity of this study was established by applying the guidelines of assessing qualitative research as described by Yardley [20].

Findings

The analysis identified the participants’ experience of PABC through three super-ordinate themes with sub-themes emerging within each (see Table 2).

Super-ordinate theme 1: Whose life comes first

‘I’m not putting [my baby] in danger’: A maternal protective drive

Upon diagnosis, participants recounted how they felt projected into a psychological dilemma involving their own survival and the survival of their unborn child. This was experienced as an existential struggle about whose life came first and whose health warranted priority above the other: the mother-cancer patient needing urgent treatment, or the unborn baby needing more time to grow and develop naturally in the womb. Cancer treatment was generally perceived as a threat to the health of the baby (having treatment with baby still in the womb, or electing a pre-term delivery). Conversely, remaining pregnant and delaying treatment out of concern for the baby was perceived as a threat to the survival of the mother-cancer patient.

I just right away said, ‘Well, I’m not having the baby before 35, 37 weeks, because I’m not putting it in danger.’ I would rather just carry on with my pregnancy and deal with it after. They said then, ‘Well, you’d be putting your life at risk to do that,’ so I said, ‘Okay.’ Chrissy

Most participants immediately thought of the survival and well-being of their baby before their own. The dilemma became more complex as participants with older children felt an additional impulse to prioritise their own survival in order to be there for them. The women instinctively questioned whether their primary identity in this situation was that of a ‘patient’, a ‘mother’ or a ‘new mother’. In addition to feelings of wanting to survive for one’s own sake, and the fear that the prospect of death evoked, their own survival represented the ‘survival’ of their other children, and in the prevailing situation it was up against the perceived survival of the PABC baby. At the same time, participants considered themselves to be in an alliance with their baby against the adversity of the disease and treatment, a maternal-fetal alliance.

‘I let them fight it out’: The experience of a conflict between obstetrics and oncology

Participants experienced the development of a medical discord between their obstetric HCPs and their oncology HCPs concerning the prioritisation of healthcare. They readily gave HCPs full control in birth and treatment planning, but the conflict within the healthcare setting felt pervading, and validated the notion of a real dilemma between mother and baby. As participants’ maternal protective instincts relating to their unborn children was pitched against the other strong human instinct that was their own physical survival, the struggle between mortal instincts was mirrored and reinforced by HCPs discussing and arguing their different agendas. Should the baby be left inside the womb for longer time to safeguard its health, or should the baby be born preterm to give the mother the best chances of effective treatment, or should we treat the mother now whilst still pregnant and manage the risk of harm to the baby?
[...] they wanted me to give birth early because they wanted to start chemo as soon as possible, but there was a lot of to and fro between the oncologist and the obstetrician because obviously the obstetrician wanted to keep the baby in as long as possible, and the oncologist wanted to start chemo straightway. Linda

Super-ordinate theme 2: My baby saved me

Most participants’ accounts contained a sense that the pregnancy and the baby somehow helped the mother cope practically and emotionally with the experience, and contributed to her survival and recovery of the disease. For some, this sense was stronger still, and participants relayed how they felt they coped and survived only because they were pregnant, had a baby to give birth to, and to be a mother to, throughout their illness. This notion of pregnancy and baby serving as rescue mechanism for the mother held physical and psychological functions.

‘I could have been dead a long time ago’: Coping and surviving in a physical sense

The physical functions concerned the pregnancy initially alerting the participant to the cancer during regular pregnancy consultations with doctors, as well as drawing attention to cancer symptoms, which would otherwise have gone unnoticed. After giving birth, the physical presence of a newborn functioned as instigator for the mother to remain active in the daily care of the baby and the maintenance of a normal family life.

I think in a way, and other people have said it that have had treatment when they were pregnant, [being pregnant]’s almost an advantage, it’s almost like your body puts in this extra, kicks into extra power to deal with it... Corinne

[...] even on a bad day I had to get out of bed. I was obviously more tired after having chemo [...]. Rebecca

‘You have to keep going for this baby’: Coping psychologically by keeping a focus

The emotional functions concerned the mother’s motivation to cope and survive, being given purpose and having positive distraction from overwhelming negative emotions, and a meaning-making function of life as a cancer patient where the ‘bad’ was balanced with some ‘good’.

I just think it does give you something to get better for. More focus definitely. I think a lot of your treatment is to do with your mind. If you’ve got a positive ‘We can do this...’ Yeah, you’ve got to survive. If you’re in your fifties, you’re single, you could just fade away. If you’ve got a young family you have to get better. Katie

The perception of the baby as a rescue brought sense and meaning to the unfortunate timing of the two events, and the clash of pregnancy and cancer therefore happened for a (good) reason.

Super-ordinate theme 3: The loss of being a mother

All the participants struggled with a sense of an irreparable loss. This brought feelings of pain and
guilt, and an urge to compensate their child whom they felt also experienced a loss. For the mother, the experience involved the loss of time, ability and opportunity to engage with the pregnancy and the baby, to bond and be a mother-infant twosome in the way it was envisaged, and how it is perceived as the norm in Western culture.

‘We didn’t go to any baby groups’: Loss of new mother-infant engagement and behaviour

This sub-theme concerns the experience of being prevented from doing and being what the participants believed they would normally have, had they not been diagnosed with cancer. This included activities (e.g. walking with baby, going to groups) and interaction involving their new baby (e.g. breast feeding) and family life as it was envisaged, including having more children. The mothers conveyed how having cancer treatment was preventing them from forming an identity as their new baby’s mother, through the blocking of parenting activities and behaviour.

I wanted to be the first person to give him his bath and to put him in his new clothes and do all that sort of stuff, but actually, we got so wrapped up in medical issues and being in and out of hospital and worrying about that… the new baby experience took a real back seat. Nadine

‘That year should have been all lovely’: Bonding and attachment - disrupted by circumstances

The second sub-theme focuses on the experience that the typical and desired attachment process and outcome between mother and new baby was disrupted by the illness and treatment. The participants’ accounts described the loss of being able and allowed to express themselves physically and emotionally towards their baby.

I feel like I kind of lost my pregnancy, and I kind of lost those early days of bonding and being together, and that little bubble you go into when you have a new born. Daisy

The natural bonding process with the newborn felt complicated by practical and emotional circumstances around treatment, in particular being physically separated from their baby. The participants conveyed how being diagnosed and starting treatment took over their daily lives, and in a metaphorical (and actual) way took away from them their pregnancy, the experience of becoming a mother and even their relationship with their baby. At a crucial and vulnerable time for parent and baby bonding and attachment, the cancer experience physically and emotionally interfered with and often overruled the mother-infant experience, resulting in what the mother felt were devastating consequences for herself and her child.

‘I think I kind of withdrew from him’: Protective distancing myself from baby (and from others)

The final sub-theme presents participants’ experience of withdrawing from their baby and from others, caused by the fear of loss. This behaviour triggered feelings of guilt. Since recovering from their illness, the participants tried continuously to resolve the loss through an intense nurturing of their relationship with their PABC child, including constructing this as a ‘special’ relationship.

[...] part of the reason why we didn’t bond was like self-preservation, not just for me but for [baby]. I withdrew from him because I didn’t know if
he was going to be okay, but I also withdrew because I didn’t know if I was going to be okay, and it was almost as if I wanted to protect him [...] Daisy

I’ve got a really close bond with [PABC child], but then...he’s gone through that experience with me so in a way that’s given me a closer bond because he’s the baby that’s lived through. Corinne

Discussion

This study provides new evidence that the experience of breast cancer during pregnancy presents significant psychological and relational challenges, unique to this condition.

Theme 1: The baby comes first

Mothers in Western society historically have a felt obligation to self-sacrifice for their children [21]. This principle is used to certify the ‘good’ parent, and may explain participants’ immediate prioritisation of the baby over themselves, even as they are the more physically threatened of the two. Guilt feelings exist around the unborn baby being ‘interrupted’ by cancer in the otherwise normal and safe fostering of and relating to the unborn child [24]. These may compel the mother to self-abnegate. Furthermore, most cancer patients experience shock at diagnosis [22]. An early common response, before any adjustment begins, is to distance oneself psychologically by denying the reality of the situation. As a coping strategy, this reduces the patient’s short-term distress and is an adaptive response [23]. Prioritizing your baby at diagnosis helps participants to suspend the immediate shock, and temporarily avoid the impact of having just been diagnosed with a potentially terminal disease.

In spite of the sense of being in a dilemma, the mothers also feel themselves to be in a form of alliance with their baby, that they are in the difficult situation together, ‘fighting’ on the same side, rather than being opposed to their baby. Where HCPs may have decided that a medical maternal-fetal conflict exists in terms of treatment dilemma, the mothers clearly experience the opposite, a maternal-fetal alliance, which offers a sense of reciprocal closeness and protection and thereby carries psychological benefit.

Theme 2: Making sense of the timing

The participants make efforts to find constructive meaning in the collision of pregnancy and cancer. Meaning-making is defined as ‘coping strategies through which individuals cognitively change their interpretations of events’ [25, p.263]. Finding (or constructing) meaning as both an automatic/subconscious process and a conscious effort is known to be important for longer-term psychological adjustment to distressing experiences [26]. The conceptualization of the pregnancy and baby as physical and psychological rescue device for the mother-with-cancer attaches important meaning to the unfortunate timing of the two events.

Participants feel that their bodies become physically stronger because of the pregnancy, giving them extra ‘power’, and consequently they are able to ‘fight’ the cancer and cope better with treatment. One study described how being a ‘good parent’ (i.e. having both physical and emotional strength, and focus on the children) seemed to become more important for parents with cancer, as the fragility of illness was effectively transferred from parent to child in a balance between needs [27]. In an investigation of mothering experiences during cancer, researchers relayed how women found ‘meaning and strength to fight’ through their young children and through attending to their needs in spite of being ill [28, p.491]. The participants in this study feel
they have to survive for their baby, in order to give care and fulfill the role of the ‘good mother’, and this was how and why they are ‘saved’ by the baby.

The baby furthermore brings focus, and provides distraction from difficult physical and emotional aspects of the cancer experience for the mother. The participants talk of ‘wanting’ and ‘needing’ their baby, and describe how the baby keeps them ‘going’, keeps their mood stable, and compel their recovery through increased motivation to ‘fight’.

For the mother, the baby comes to represent the motivation as well as the tool to cope and survive. Believing there is tangible cause for the timing of the cancer and their survival therefore helps participants integrate the overall experience into a new ‘life narrative’, to move forward and re-engage with their lives [22, p.21].

Theme 3: Experiencing a loss of being a mother

The participants experience that mothering their children becomes disrupted by numerous cancer treatment obligations, which distance them physically from their children, by incapacitating physical treatment effects, such as achiness and fatigue, along with accompanying distressing emotions, such as death anxiety and guilt, which comes to dominate their emotional lives. Research on mothering during illness corroborates these findings [24,27-30]. The illness prevents the mothers from caring for their children by literal and virtual separation from their infant [24,30]. This results in lower levels of ‘maternal preoccupations’ [31, p.933], and decreased frequency of bonding behaviours and signs of attachment. As the mother has diminished opportunity to develop and express her maternal identity, and less stimulation for maternal behaviour [31], she is compelled to disengage from her baby [32]. In a psychotherapy case study [12], authors described how a mother’s physical and psychological sensitivity and availability towards her infant was reduced due to her treatment obligations, resulting in a disrupted bonding process, and an inability to establish a stable emotional connection with the infant. The impact was likened to the mother’s abandonment of her child.

The findings show that aspects of the PABC experience interfere with the mother-patient’s relationship with her pregnancy, her infant and other children, her partner and herself, and that the reasons are manifold. In a study on motherhood and cancer [33] authors described a mother’s withdrawal from her infant and others as a consequence of feeling objectified as a cancer patient, with her maternal identity ignored and undermined by HCPs and friends and family. This caused confusion and isolated the mother, exacerbating her distress. Withdrawing psychologically and emotionally from the pregnancy or child(ren) could also be interpreted as a complex but unintentional measure taken to cope with death anxiety and protect the self [13,34]. The behaviour of withdrawing is accompanied by guilt (felt in the present) and a sense of loss of the relationship. The participants seem to feel that they have violated the good mother ideology, that their relationship with their baby (or other child) is damaged or lost, and that their children have lost out. The consequence is pain and self-blame. Guilt feelings in the present also link to the fact that the mother’s death ultimately did not occur, and therefore distancing themselves from their children was an unnecessary measure believed to have caused much hurt. The child becomes an emblem of her perceived failure as a mother, accentuating her negative self-evaluations and in particular her maternal guilt [35].

With time, the mother instinctively compares her performance as a mother between children, with the mothering of the other children judged as ‘uninterrupted’. To compensate her PABC child and alleviate her own maternal guilt feelings, the mother creates a ‘special relationship’ with her PABC child, which allows her to return to a status of ‘good’ mother. In the ‘special relationship’, the mother feels she had a superior connection with the child because they share a special life/death history, having ‘shared’ the illness and ‘fought’ together. This is the mother’s
one way of negotiating and reducing her maternal guilt towards her PABC child. Mothers have been found to ‘use different measures to deflect the bad mother image and thus reduce mama-guilt’, involving ‘neutralizing techniques’ such as constructing narratives that allow the mother to ‘remain attached to ‘good mothering” [35, p.317]. Similarly, studies have found mothers were able to ‘reframe the mother role’ to convey to researchers how they were ‘good’ mothers in spite of feelings of guilt and failure [24, p.1440]. In the construction of the ‘special relationship’, mothering the PABC child then becomes the mother’s new representation of her ability to mother, confirming to her that she is competent after all, and re-establishing her identity as a mother.

Implications for practice and research

This study demonstrates that the PABC population has psychological care and support needs which are over and above the care which is routinely offered by psycho-oncology and perinatal mental health services. Understanding the experience is the first step in helping practitioners identify women and families susceptible to long-term and severe distress, and consequently intervene to treat these patients proficiently and with tailored approaches. Psychological adjustment generates better outcomes for patients, better health and well-being, and higher quality of life [14]. Supportive care throughout this time can help women and their families cope and adjust, including addressing problems with emotional well-being, parent-infant relationship (bonding and attachment process and outcome) and systemic concerns [22]. We also suggest that approaches to psychological management are applied within a flexible structural format to accommodate illness and treatment effects, as well as parenting needs and responsibilities.

Emotional distress in breast cancer patients is under-recognised by HCPs [36]. As part of a multi-disciplinary team, psychologists can function efficiently as important mediators in the tension between patients and HCPs, at the decision-making stages of treatment planning and implementation and after. Armed with knowledge of the psychological implications, psychologists can help ensure that appropriate levels of patient involvement at all stages, and in decision-making, are effectuated [37]. This study ascertains that there is also scope for psychologists to support HCPs, including surgeons, midwives and nurses, with knowledge of the psychological implications of PABC that they may not have reflected on, and thereby help enable better ‘attuned’ communication with patients and families. HCPs’ and psychological practitioners’ knowledge about the PABC experience and knowledge-related psychological interventions could help patients’ coping and adjusting to life during treatment and after, as well as patients’ overall survival [15].

The experiences explored in this study transpire in the first year after diagnosis. Exploration of the longer-term experience is relevant to knowledge about adjustment. It would be useful to examine older children’s experiences of the impact on their relationship with parents and siblings, in particular whether there is perceived deprivation (of parental attention and support) in family relationships. It would also be important to investigate ‘attachment disturbances’ or ‘bonding disorders’ in addition to the impact on systemic dynamics and organisation. Finally, there is a need to ascertain which therapeutic approaches, psychological interventions and types of support will work for whom and in what context, with regards to method and timing, as well as effect. It will be necessary to test the acceptability and efficacy of psychological approaches and interventions, as to ensure these have the necessary evidence-base to be commissioned [38].

Limitations of this study

This sample was large and there was considerable variation in the ‘time passed’ from diagnosis until interview (see Table 1), potentially affecting the quality and accuracy of memories. Similarly, participants varied in length of time spent being pregnant with the diagnosis (from diagnosis until
giving birth), from a few days to 35 weeks. Two participants were diagnosed shortly after having given birth. This may influence experienced stress levels, specifically worry about the well-being of the fetus. Furthermore, participants’ individual cancer diagnoses differed widely in terms of type and grade, and subsequently treatment type and length provided to participants was not the same.

**Conclusion**

This study argued that PABC involves unique psychological challenges with long-term consequences for patients and families. The phenomenology of PABC is complex, has substantial relational and psychological implications, and primarily concerns an experience of coping and loss during the first year following diagnosis. The experience can severely impact on a mother’s attachment to her infant, and on other close relationships. Women in this study felt that they lost mothering ability and opportunity, and that there was a lack of understanding and support from others including some family members and HCPs.

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The authors wish to thank the participants who shared their stories in this study. This article formed part of a thesis submitted in fulfillment of the requirements for the degree of Professional Doctorate in Counselling Psychology. No conflicts of interest are declared.
Journal References

23. Vos MS, De Haes, JCJM. Denial in cancer patients, an explorative review. Psycho-Oncology.
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Time since diagnosis</th>
<th>PABC pregnancy no./total no. of children</th>
<th>WEEKS of gestation @ diagnosis &amp; when giving birth</th>
<th>Social class Self-reported</th>
<th>Ethnic origin/race Self-reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Katie</td>
<td>44</td>
<td>11 yrs 9 months</td>
<td>2/2</td>
<td>16/32</td>
<td>High working/ Low middle class</td>
<td>White British</td>
</tr>
<tr>
<td>Lorna</td>
<td>38</td>
<td>2 yrs 9 months</td>
<td>1/1</td>
<td>30/34</td>
<td>Middle class</td>
<td>White British</td>
</tr>
<tr>
<td>Chrissy</td>
<td>37</td>
<td>2 yrs 2 months</td>
<td>3/3</td>
<td>28/35</td>
<td>Working class</td>
<td>British</td>
</tr>
<tr>
<td>Jane</td>
<td>38</td>
<td>4 yrs 11 months</td>
<td>2/2</td>
<td>22/34</td>
<td>Working class</td>
<td>White British</td>
</tr>
<tr>
<td>Nadine</td>
<td>32</td>
<td>4 yrs</td>
<td>1/1</td>
<td>-/40</td>
<td>Don’t know</td>
<td>White</td>
</tr>
<tr>
<td>Corinne</td>
<td>48</td>
<td>12 yrs 6 months</td>
<td>2/2</td>
<td>5/40</td>
<td>Don’t know</td>
<td>White English</td>
</tr>
<tr>
<td>Rebecca</td>
<td>37</td>
<td>7 months</td>
<td>2/2</td>
<td>-/39</td>
<td>Middle class</td>
<td>Welsh</td>
</tr>
<tr>
<td>Anna</td>
<td>38</td>
<td>11 months</td>
<td>2/3 (twins)</td>
<td>24/35</td>
<td>Middle class</td>
<td>White British</td>
</tr>
<tr>
<td>Daisy</td>
<td>33</td>
<td>5 yrs 9 months</td>
<td>2/3</td>
<td>12/33</td>
<td>Working class</td>
<td>White British</td>
</tr>
<tr>
<td>Rita</td>
<td>37</td>
<td>1 yr 6 months</td>
<td>4/4</td>
<td>11/40</td>
<td>Middle class</td>
<td>White British</td>
</tr>
<tr>
<td>Linda</td>
<td>33</td>
<td>4 yrs 9 months</td>
<td>1/1 (pregn.)</td>
<td>30/35</td>
<td>Working class</td>
<td>White</td>
</tr>
</tbody>
</table>
Table 2. Main Findings: Super-ordinate themes and sub-themes

<table>
<thead>
<tr>
<th>Super-ordinate theme</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A maternal protective drive</td>
</tr>
<tr>
<td></td>
<td>1b. ‘I let them fight it out’</td>
</tr>
<tr>
<td></td>
<td>The experience of a conflict between obstetrics and oncology</td>
</tr>
<tr>
<td>2. My baby saved me</td>
<td>2a. ‘I could have been dead a long time ago’</td>
</tr>
<tr>
<td></td>
<td>Coping and surviving in a physical sense</td>
</tr>
<tr>
<td></td>
<td>2b. ‘You have to keep going for this baby’</td>
</tr>
<tr>
<td></td>
<td>Coping psychologically by keeping a focus</td>
</tr>
<tr>
<td>3. The loss of being a mother</td>
<td>3a. ‘We didn’t go to any baby groups’</td>
</tr>
<tr>
<td></td>
<td>Loss of new mother-infant engagement and behaviour</td>
</tr>
<tr>
<td></td>
<td>3b. ‘That year should have been all lovely’</td>
</tr>
<tr>
<td></td>
<td>Bonding and attachment - disrupted by circumstances</td>
</tr>
<tr>
<td></td>
<td>3c. ‘I think I kind of withdrew from him’</td>
</tr>
<tr>
<td></td>
<td>Protective distancing myself from baby (and from others)</td>
</tr>
</tbody>
</table>