Patients who decide to forgo Breast Cancer Treatment: Perspectives and Experiences of Cancer Professionals.

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ABSTRACT

Background: Breast cancer is highly treatable if caught early, yet there are increasing numbers of women who decline treatment entirely, or in favour of alternative therapies. Previous research has demonstrated that such decisions can be troubling for health professionals, creating an ethical dilemma in which the bioethical mandate to respect patient autonomy must be offset against duties to act in the patient’s best interest. Previous research has indicated that health professionals may find it difficult to accept and understand such decisions; however, this research has predominantly focused on the experiences of different health professionals in isolation.

Method: Qualitative, semi-structured interviews were carried out with eight oncology health professionals (Three oncologists, two breast surgeons and three clinical nurse specialists) to explore how health professionals understood and responded to these decisions. A critical realist epistemology was adopted and interviews were analysed using thematic analysis.

Results: Four overarching themes were identified including ‘Head-Heart Lag’, ‘Tug of War’ ‘You Can’t Win Them All’ and ‘The Power and Privilege of Unbiased Expertise’. Themes yielded insights into how professionals navigate their responsibilities towards patients who decline treatment and the values, frameworks and resources that influence this process.

Conclusion: Results indicated that health professionals’ responses were grounded in a commitment to evidence based practice, and that time and experience are important factors in professionals learning to accept a decision to decline breast cancer treatment. Findings are considered in the broader social context of contemporary healthcare and in relation to professional and patient needs. Recommendations are made for a more reflexive medical practice which transcends the constraints of the evidence-based paradigm and liberates health professionals to engage with the existential, as well as the medical within the clinical encounter.

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1.0. INTRODUCTION

1.1. Background

This research focuses on understanding the experiences of health professionals when working with individuals who decline conventional treatments for breast cancer. The introduction begins with a description of the current context of breast cancer care within the UK, outlining relevant literature and policy. I[1] will describe the nature and consequences of breast cancer treatments and consider the complexities of treatment-related decision making for patients.[2] I will then consider the ethical and conceptual frameworks which guide decision making and care delivery within general medicine and more specifically the National Health Service (NHS) before outlining the findings of a scoping review which gave rise to the aims and research questions.

Within qualitative research, it is generally accepted that the researcher's relationship with their subject is inextricably connected with the research (Dodgson, 2019). As such, I have aimed to remain conscious and attentive to the biases and assumptions that comprised my rationale for undertaking this research and influenced my thinking during the process. As most of my family work as health care professionals, I have grown up sympathising with the challenges of public health care, while implicitly learning to accept the absolute authority of science and medical institutions. Throughout my own career, I have learned to question taken for granted beliefs and appreciate that notions such as health and illness do not reflect infallible truths belonging to science or medicine, but constructs which are promulgated and reproduced through interactions between dominant systems and wider society (Hofmann, 2002). As my relationship with these concepts has evolved, I have come to recognise the immense power held by medical institutions in defining normative standards of

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[1] I have written parts of this thesis in the first person to reflect that this work reflects one interpretation, that is bound with my own experiences as opposed to an infallible truth.

[2] This term may be used at times throughout this thesis to describe individuals with cancer in line with nomenclature of healthcare provision

health (Peterson, 2012) and subsequently excluding that which may not be encompassed or explained by science.

While working in a psycho-oncology team within a national cancer centre, I noticed that individuals who declined conventional breast cancer treatments often created uncertainty and confusion within clinical teams and were sometimes referred to speak with counsellors or psychologists. It seemed that the psycho-oncology service was sometimes enlisted as a last resort when staff had been unsuccessful in overturning the seemingly unconventional choice to not undergo cancer treatment. In my own supervision with a consultant clinical psychologist, we reflected on these referrals and wondered what they might signify in terms of how physical health colleagues appraise, and respond to patients' decisions to decline treatment. We also wondered what these responses might communicate to patients, and the extent to which they felt their decisions were respected, or considered viable. My supervisor and I agreed that it would be valuable to pursue these questions within my doctoral research and I have approached this research from a position of respect and curiosity to understand the values and frameworks that are employed by health care professionals when working with individuals who decline treatment. In listening to health care professionals' accounts of working with patients who decline, I hope to bring their stories and challenges into the spotlight, while exploring the systems and frameworks that influence the positions they take towards those who decline treatment. In doing so, I hope to create possibilities for understanding the needs of health care professionals and to subsequently consider how they can be supported to respond to the needs of patients who decline breast cancer treatment.

2.0. BREAST CANCER

2.1. Incidence and Early Detection Policy

In the United Kingdom (UK), breast cancer is the most common female cancer, with approximately 55,000 women[3] and 370 men diagnosed every year (Breast Cancer Now, 2021). It is estimated that one in eight women will be diagnosed with breast cancer during their lifetime with age reflecting the most significant risk factor (Iyer & Ring, 2017) although aetiology reflects numerous, interacting factors including genetic, reproductive, hormonal and exogenous influences (Schoemaker et al., 2016). Although breast cancer prevalence has increased by 6% in the United Kingdom over the past decade (Iyer et al., 2017) mortality rates have steadily declined and 80% of women who are diagnosed with early breast cancer have a projected survival of 10 years or more (Iyer & Ring, 2017). Breast cancer outcomes are often associated with the disease stage upon diagnosis, which largely determines whether treatment is curative or palliative (Akram et al., 2017). A diagnosis of 'early breast cancer' in which disease is confined locally to breast tissue and axillary lymph glands is associated with better prognosis (Cancer Research UK, 2018) and several strategies have been employed within the UK in the past 30 years to increase early detection rates including the implementation of a national breast cancer screening program. In the United Kingdom, patients may be diagnosed with breast cancer either through the NHS Breast Screening Program or via GP referral to a specialist breast cancer clinic. Where referrals are deemed urgent by GPs, patients are generally seen within two weeks while routine referrals are seen as soon as possible (Breast Cancer Now, 2019). In many cases, women may be referred to One Stop clinics which aim to expedite the diagnostic process by providing physical examinations, scans and biopsies within a single appointment (Breast Cancer Now, 2019). The NHS Long Term Plan for Breast Cancer has articulated a vision for breast cancer diagnostics in the coming decade and committed to the proportion of cancers diagnosed at stages 1 and 2 increasing from 50% to 75% by 2028 (NHS, 2020). Strategies for realising this vision

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[3] Breast cancer will be discussed and considered as a female cancer in keeping with epidemiological convention, but with the acknowledgement that men are also affected by this disease.

include a lower threshold for GP referrals to cancer centres, use of risk-stratified screening and testing of family members where there is an increased genetic risk of cancer (NHS, 2020).

2.2. The Psychosocial Impact of Breast Cancer

A diagnosis of breast cancer represents a moment of ‘biographical disruption’ (Bury, 1982) in which expectations for normal life are suspended as the person is confronted by a future that will be irrevocably affected by cancer and its legacy. A breast cancer diagnosis can be a life-changing moment (Fu et al., 2008) in which relationships with the self, body and world are fundamentally changed (Books, 2002). While the literature suggests that most women cope with the demands of treatment (Ganz et al., 2002) for some, cancer-related distress may have significant implications for progression through care pathways, impacting physical health, quality of life and the ability to make decisions and adhere to treatment regimens (Irvine et al., 1991). The National Comprehensive Cancer Network defines distress as “a multifactorial unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment (Holland et al., 2013, p 233) and is included as the sixth vital sign to monitor in those with cancer. existing on a spectrum ranging from normal feelings of vulnerability to disabling emotional difficulties (Howell & Olsen, 2011).

The breast cancer experience is typically comprised of several, distinct stages (Hewitt et al., 2004). Diagnosis typically encompasses the period from initial detection of symptoms to confirmed diagnosis, and is often a period of fear and disbelief as women undergo various investigations to establish cancer stage, treatment options and likely prognosis (Ciria-Suarez et al., 2021). Research has indicated that 30-50% of women with breast cancer experience depression and anxiety following diagnosis, which may persist throughout treatment (Park et al., 2017). During this period the individual may be challenged to make critical decisions around subject matter of which they may have little knowledge or background, at a time when heightened emotions may preclude them from fully absorbing all that is communicated by health professionals (Hewitt et al., 2004).

Studies have indicated that women may become particularly sensitive to the non-verbal communication of medical personnel at this time, with qualities such as tone and body language being taken as indicators of prognosis or optimism around treatment and recovery (Ciria-Suarez et al., 2021).

The transition from initial diagnosis to treatment planning and delivery is marked by a new set of physical, social and emotional challenges (Arroyo et al., 2019). Treatment decision making is highly individual and may be influenced by factors which extend beyond the nature and behaviour of the cancer (Hewitt et al., 2004). For instance, while some women prioritize the preservation of healthy breast tissue, others may mitigate fears of recurrence by undergoing contralateral prophylactic mastectomy despite negligible survival benefits (Carlson, 2014a). The demands of cancer treatment often cause disruption in social, occupational and family life, creating additional challenges which may compound experiences of cancer-related emotional distress. For instance, Macmillan (2013) reported that in England, individuals who are diagnosed with cancer are approximately £600 worse off, due to loss of income through missed work and increased transport costs associated with medical appointments. Breast cancer treatments are often invasive and may be experienced as a violation of bodily integrity or one’s sense of ownership over their body. Indeed, Hama and Tate (2020) reported that 40% of women felt embarrassed at needing to be undressed during radiation therapy, expressing a preference to remain clothed and work with female therapists.

Advances in treatment and detection have arguably transformed representations of breast cancer as a terminal condition to one of a chronic nature with lasting physical and psychological consequences (Furrow et al., 2011). Cancer survivorship is a variable concept encompassing a multitude of experiences including diagnosis, primary treatment, management of metastatic disease, recurrence, long term survival or eventual death (Walsh, 2016). The transition from treatment to remission has been described as a tumultuous experience in which feelings of relief or gratitude are enmeshed with the realities of persistent physical symptoms and fears of recurrence (Knobf, 2015). The end of treatment can be a challenging transitional phase where there may be more space for psychological struggle as the individual becomes less occupied by the demands of treatment (Cappiello et al., 2007). Where treatment involves regular contact with health professionals, women may find themselves without important supports (Costanzo et al., 2007). Charmaz (1991) describes how individuals with chronic illness often need to renegotiate identities and self-image to accommodate new, embodied realities. The end of treatment may represent the beginning of this journey for many breast cancer survivors, whose embodied experiences may be irrevocably altered by treatments which result in long term changes to the body.

2.3. Breast Cancer Treatments and Side Effects

Breast cancer is becoming increasingly treatable due to advances in research and technology which have enhanced understanding of subtypes and responses to treatment modalities (Harbeck & Gnant, 2017). Treatment options are determined by the biology and behaviour of the cancer, and often reflect genetic and hormonal factors (Cappiello et al., 2007). Breast cancer treatment plans vary considerably depending on the above factors and may include primary, adjuvant, neoadjuvant and targeted therapies; however, due to space limitations, three main modalities of primary treatment namely, primary surgery, chemotherapy and radiotherapy will be considered.

2.3.1. Surgery

Breast surgery involving partial or complete loss of one or both breasts is a mainstay in breast cancer treatment and is often sufficient for treating early breast cancer. However, it carries risks of side effects such as asymmetry, scarring, alteration to breast and nipple sensation, a need for reconstruction or prosthesis, changes to limb mobility and lymphoedema (Cappiello et al., 2007). While mastectomy was once considered the standard, primary treatment for breast cancer (Gumus et al., 2010) it is increasingly recognised that breast conserving surgery combined with radiotherapy is equivalent to mastectomy in terms of survival (Martin et al., 2006) although surgical preferences have been shown to vary according to individual, clinical and systemic factors such as disease stage, desire to avoid radiotherapy and surgeon opinion and experience (Gu et al., 2019). Cross-sectional research has emphasised that factors pertaining to body image and sexuality are vitally important within treatment decision making and may differentiate treatment selection, with those who opt for breast-sparing procedures endorsing body image concerns to a greater degree (Kraus, 1999). For instance, Margolis et al.,(1989) reported that women who opted for lumpectomy against physicians' advice emphasised concerns around body image, loss of femininity and sexual desirability more so than fears of recurrence or mortality. While concerns around body image and sexual desirability appear to be important predictors of treatment choice, the links between surgery type and body image outcomes are less consistent. For instance, although the majority of cross-sectional work indicates that women who opt for procedures that promote the appearance and integrity of the breast (i.e. lumpectomy or mastectomy with reconstruction) tend to experience better body image than those who undergo mastectomy (Nano et al., 2005) longitudinal work has demonstrated that associations between surgical procedure and body image difficulties become less robust over time. Collins et al. (2011) compared body image disturbance among women who had either undergone mastectomy, breast-conserving surgery or mastectomy with reconstruction and noted that differences in body image had dissipated at the two-year mark.

While much of the longitudinal, empirical work attributes body image and adjustment post-surgery to individual factors such as self-esteem or resilience (Cappiello et al., 2007) other authors have highlighted how women's treatment choices are seldom neutral, but decisions that are deeply embedded in social and cultural contexts which determine the meaning that is bestowed upon breasts (Webb et al., 2019). In western societies, the breast is often taken as a symbol of femininity, sexuality, beauty and motherhood (Young, 2005) so it stands to reason that cancer-related change to breasts may be experienced as a threat or assault to these domains (Cappiello et al., 2007). Qualitative work has indicated that adjustment to bodily changes after surgery can be a function of the extent to which women internalise social norms and roles, and the personal meaning which they afford to breast loss. Koçan and Gürsoy (2016) interviewed a sample of Turkish women who had undergone mastectomy and observed that women's personal relationships with their changed bodies were entwined with their relationships and changes in social roles. The authors observed that women seemed to make sense of their experiences within the context of their relationships with others, which influenced their engagement with normal roles. Women who interpreted their experiences within a religious framework described an obligation to accept their fate and pursue normal routines, as their changed bodies represented a physical manifestation of their God's will. Participants seemed to experience more distress when breast loss signified an inability to adequately inhabit a previously valued role or attribute, such as sexual attractiveness or desirability within marital relationships. In such instances, women's distress was situated not only within their individual experience of breast loss, but also within others' changed behaviours or responses, which signified that the women were represented differently by others along dimensions of femininity and womanhood.

2.3.2.Radiotherapy

Radiotherapy is a procedure that involves the administration of high energy x rays to the tumour site and surrounding tissues, to destroy residual cancer cells in the breast, chest and lymph nodes following surgery (Shapiro & Recht, 2001). Approximately 50% of women are prescribed radiotherapy as part of their treatment program (Halkett et al., 2008) due to its efficacy in improving localized tumour control, reducing risk of recurrence and increasing life expectancy (Vinh-Hung & Verschraegen, 2004). Radiotherapy has transformed the management of breast cancer meaning that a significant proportion of women no longer need to undergo radical surgery; however, its prognostic benefits are not without physical, emotional and social costs (Schnur et al., 2009). Radiotherapy may be both a disruptive and intimidating treatment; it is typically administered daily over a number of weeks which may place considerable demands on women (Arenas et al., 2015). Radiation therapy delivery mirrors challenges associated with other imaging procedures in that motion must be minimised to effectively target the tumour while reducing radiation dose to adjacent tissue (Mayr et al., 2020) and has been described as stressful and uncomfortable (Cappiello et al., 2007; Holmes & Williamson, 2008). Evidence has suggested that radiation therapy can be a feared treatment where associations with nuclear accidents provoke concerns around the treatment's safety profile (Gillan et al., 2014). Shaverdian et al. (2018) observed that women's baseline perceptions of radiotherapy included concerns around damage to internal organs and the immune system, skin burning, and being unable to perform daily tasks, which in some cases, may contribute to individuals declining radiation therapy and breast-conserving surgery (McGuire et al., 2009).

Radiation therapy for breast cancer is associated with transient and lasting side effects. Fatigue is the most commonly reported side effect occurring in approximately 80% of patients (Dhruva et al., 2010) with 30% of women describing fatigue that ranges from severe to intolerable (Schnur et al., 2009). Fatigue is generally considered a temporary consequence of demanding treatment schedules coupled with the effects of radiation on healthy cells; (Dhruva et al., 2010) however, it is also likely that radiation therapy contributes to chronic cancer-related fatigue which persists after treatment has ended (Xiao & Torres, 2019). Radiation can damage soft tissues in a dose-dependent manner, hence the majority of women who undergo radiotherapy experience some degree of radiation dermatitis (Holmes & Williamson, 2008). Acute side effects of radiotherapy can emerge within days or weeks, and mainly include oedema, inflammation and desquamation of the skin (Kole et al., 2017) while delayed effects can emerge in the months or years after therapy, and mainly entail fibrosis and atrophy (Xiao & Torres, 2019) impacting the appearance of the breast. Lymphoedema that is persistent or periodic is another potentially chronic, side effect of radiation therapy and typically involves impaired arm mobility in addition to pain, heaviness and numbness (Hille-Betz et al., 2016). Pain and diminished strength often mean that women with lymphedema have difficulty performing everyday activities such as dressing and household chores (Hille-Betz et al., 2016) which can serve as a permanent reminder of cancer and a continuous obstacle to negotiate in resuming pre- cancer routines (Hille-Betz et al., 2016).

2.3.3 Chemotherapy

Chemotherapy is often prescribed within breast cancer treatment regimens as a means of reducing the risk of recurrence following primary surgery; (Choi et al., 2014) however, it is associated with a range of disabling side effects including nausea, vomiting, diarrhoea, weakness, fatigue, loss of appetite, and alopecia (Reich et al., 2008). The majority of chemotherapy-induced side effects are confined to the period in which the individual is receiving treatment; however, certain chemotherapeutic agents can cause permanent damage to ovarian tissues, which has been associated with difficulties such as hot flashes, osteoporosis, sexual dysfunction and in some instances, reduced fertility (Shapiro & Recht, 2001). Age, dosage and duration of adjuvant chemotherapy are the primary determinants of ovarian failure (Shapiro & Recht, 2001) with younger women generally being able to tolerate longer treatment courses without reaching permanent failure; (Presti et al., 2004) however, studies have suggested that this additional protection decreases quite sharply with age. Letourneau et al. (2012) observed that 9% of women with breast cancer experienced acute ovarian failure following chemotherapy, which increased to 55% in women who were 40 years old. The authors suggested that a focus on amenorrhea as a primary reproductive impairment in previous work may have obscured the full impact of chemotherapy which may further narrow the reproductive window by triggering early menopause, even in those whose menses return after treatment.

Chemotherapeutics, although a mainstay within breast cancer treatment, are also known for causing adverse, off-target effects in the central and peripheral nervous systems. ‘Chemobrain’ is a term that emerged to describe neurological symptoms which can develop during or after chemotherapy, manifesting in short term memory loss, concentration difficulties, word-finding difficulties and feelings of mental dullness (Umfress et al., 2021). While there is robust evidence of cognitive complaints among women with breast cancer who have undergone chemotherapy (Jim et al., 2012) there is debate around whether this reflects specific neurotoxic effects due to evidence of both pre-existing cognitive deficits (Vardy et al., 2008) and discrepancies between self-reported cognitive complaints and intact neuropsychological testing performance (Hutchinson et al., 2012). Imaging work has contributed to the debate around chemotherapy's potentially neurotoxic effects evidencing structural and functional differences between controls and women treated with chemotherapy; however, the causal role of neurotoxicity remains unresolved due to multiple potentially interacting factors such as anaesthesia, radiotherapy, and psychological morbidity (Jim et al., 2012). While the aetiological origins of chemobrain remain ambiguous, it is not an uncommon experience (van Dam et al., 1998) and can cause considerable disability within social and occupational functioning (Bender & Merriman, 2014).

Among chemotherapy-related side effects, alopecia is often considered one of the most feared and traumatic (Choi et al., 2014) and has been identified by some women as harder to endure than the loss of breasts (Freedman, 1994). Rosman (2004) observed that the experience of hair loss often signified a milestone within the individual's processing of their diagnosis, upon which the life-threatening nature of breast cancer was rendered visible. Alopecia is often assumed to be an inevitable but transient side effect that can be temporarily managed through wigs or other head coverings; (Lemieux et al., 2008) however, there is evidence to indicate that the estrangement to one's body which may accompany hair loss may persist, particularly when regrowth is of a different colour or texture. For instance, a prospective, longitudinal study examining self-concept and body image found that self-concept and body image were compromised during treatment and did not return to pre-treatment levels upon regrowth (Münstedt et al., 1997). Where alopecia represents a loss of vitality (Moreira & Canavarro, 2012) it may also serve as a visual reminder of cancer which may contribute to feelings of stigmatisation. In qualitative studies, women linked alopecia with a loss of privacy where hair loss was construed as a non-verbal disclosure of one's cancer status. Indeed, studies have demonstrated that measures taken to cope with hair loss such as scalp cooling procedures or wigs are utilised not only for the individual's benefit, but also for the preservation of the self within others' perceptions (Williams et al., 1999).

2.3.4. Limitations

Feminist theory highlights how research around breast cancer treatments and side effects has largely taken place in the context of gendered ideas about femininity and may reproduce patriarchal and heteronormative norms, by mirroring the scrutinising of women's bodies that takes place in wider society (Hille-Betz et al., 2016). Where research has focused on understanding links between treatment and body image according to masculine standards of beauty, the exploration of positive body-related experiences has arguably been neglected (Brunet et al., 2013). The exclusive focus on body image disturbance has been criticised, with researchers highlighting the importance of also understanding body positive image (Thornton & Lewis-Smith, 2021) to allow for a more nuanced account of women's varied experiences with their bodies. With that said, there is considerable evidence that side effects which impact women's wellbeing may influence appraisals of breast cancer treatments which will be considered in the following section, as such assessments have significant implications for treatment decisions and experiences of health services.

2.4. Quality versus Length of Life

Individuals diagnosed with breast cancer exist in a unique medical context in which they are required to make choices around treatments that carry significant risks of toxicity without guaranteed curative benefit (Meropol et al., 2008). Women diagnosed with breast cancer may be challenged to make decisions around treatments that are characterised by discomfort and disability, and based on probabilistic concepts pertaining to recurrence and survival. In this regard, the relative weight placed on quality and length of life represent critical values within the decision-making process (Meropol et al., 2008). QoL has been subjected to variable and expansive conceptualisations within the literature (Marquez et al., 2020). While there is general consensus that it encompasses functioning in physical, psychological, occupational and social domains, it is also acknowledged that it is highly subjective and therefore should be assessed with reference to the individual and their unique goals, values and preferences (Fayers & Machin, 2013). Implicit in this agreement is the recognition that patients have their own health-related metrics, which may not mirror the views of others such as healthcare professionals (O'Connor, 2004).

It is increasingly acknowledged that the patient's perspective is central when weighing the risks and benefits of treatment (Shrestha et al., 2019) and preferences for quality versus length of life have been shown to vary according to a wide range of factors. Rietjens et al. (2005) observed that individuals with histories of life-threatening illness were more likely to value life-prolonging treatments compared to the general population who prioritised quality of life. Similarly, studies have demonstrated that individuals tend to be more receptive to adjuvant treatments they have already experienced (Stiggelbout et al., 1996; Yellen et al., 1994) due to feeling less fearful of negative effects and more confident in coping abilities (Lindley et al.,1998). However, quality of life ratings in this sample were generally high, with moderate or severe side effects only reported by a minority of participants, hence such findings may not extend to all women with experience of adjuvant cancer therapies. While research has suggested that the extent to which a treatment is judged as beneficial in terms of increasing disease-free survival may differentiate preferences for quality versus length of life, in previous studies of women with breast cancer it was found that a 0.5-1% reduced risk of recurrence was considered sufficient to warrant adjuvant chemotherapy (Ravdin et al., 1998). Palda et al (1997) observed that 46% of breast cancer patients would elect to undergo post-operative radiotherapy, even with no stated benefit, while participants with smaller tumours were more likely to decline further treatment. Such findings are supported by research indicating that disease status or the severity of one's condition may predict willingness to undergo high-risk treatments (Gaskin et al., 1998) with patients generally being more likely to opt for such treatments relative to healthy individuals (Kiebert et al., 1994).

Treatment toxicity has also been identified as significant within quality versus length of life trade-off. O'Connor (1989) observed that preferences for toxic treatments decreased as the probability of survival dropped below 50% suggesting that individuals may only be willing to consider toxic treatments if they make a meaningful difference to survival prospects. Sociodemographic factors such as age and social circumstances have also been shown to influence the trade-off between quality and length of life with older individuals generally being less accepting of aggressive cancer therapies than younger patients; (Cappiello et al., 2007) however, this finding may be moderated by disease status; Malhotra et al. (2017) reported that patients over 60 were more inclined to endorse length of life over quality of life relative to adults over 60 in the general population. Finally, research has indicated that stakeholders such as family and healthcare professionals may hold important roles in influencing length versus quality of life preferences (Kim et al., 2021). Stiggelbout et al.(2007) examined the importance of significant others' opinions to women with breast cancer's adjuvant chemotherapy decision-making and found that the opinion of the treating specialist was considered the most important, followed by partners, children and other family members and friends.

The reviewed evidence indicates that cancer-related treatment decision-making is a highly individual process and the relative value placed on quality of life versus survival reflects a complex calculation in which health factors are considered against a unique psychosocial and cultural backdrop (van Kleffens et al., 2004). The prevailing zeitgeist surrounding medicine and healthcare may also constitute an important context for treatment decisions, which has recently been reflected in the increased use of complementary or alternative medicine, (Posadzki et al., 2013) which is said to have emerged in line with the postmodern epoch characterised by a sense of alienation from medical structures, a rejection of scientific authority and increased consumerism and desire for choice around health and wellbeing (O'Callaghan & Jordan, 2003). Complementary and alternative medicine (CAM) may represent a challenging landscape for oncology professionals to navigate as it operates outside the biomedical paradigm encompassing approaches to "diagnosis, treatment or prevention which complement mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual frameworks of medicine" (Ernst, 2000, p.1133). As CAM use has become increasingly common among women with breast cancer (Shen et al., 2002) healthcare professionals have needed to consider their ethical obligations towards patients and how to discharge their duties in relation to treatments that operate outside of their expertise. In many instances, such discussion is grounded in bioethical principles, with particular emphasis on concepts like autonomy and informed consent.

2.5. Autonomy, Consent and Complementary and Alternative Medicine

A patient-centred approach that allows individuals the power to manage their own health and make informed decisions is increasingly recognized as a pivotal component of high-quality health provision (Martinez et al., 2016). In contrast to the historical physician-dominated paradigm, patient-centred care strives to elevate patient autonomy through engaging patients as active participants in decision-making (Epstein & Street, 2011). Patient autonomy is conceptualized as the right to make informed decisions without undue influence or pressure from others and is enacted within healthcare through informed consent procedures, in which treatment options are outlined and the costs and benefits explained (Cassileth et al., 1980). Informed consent is typically situated in the wider context of evidence-based practice (EBP), which refers to the integration of the best available research evidence with clinical expertise and patient values (Masic et al., 2008). The process of EBP involves an awareness of various levels of evidence underlying an intervention and evaluating that evidence according to the patient or specific clinical encounter (Christiansen & Lou, 2001). The nature of medical decision-making is such that many patients will lack the knowledge or training required to critically evaluate the ever-evolving medical literature (Martinez et al., 2015). As such, the physician plays an important role in facilitating patient autonomy by exploring the patient’s circumstances and presenting treatment choices in the context of medical evidence and the patient’s values and preferences (Martinez et al., 2015).

The use of complementary and alternative medicine within oncology arguably poses a challenge for EBP and patient autonomy. This is particularly applicable when considering treatment modalities whose effects cannot be explained or evaluated within the dominant scientific paradigm (Wilkinson, 2014). Indeed, critics of complementary and alternative approaches have queried the quality of evidence purporting to demonstrate efficacy, emphasising a need for scientific evidence to justify CAM treatments (Ben, 2008). While the NHS has embraced some complementary approaches to support quality of life and symptom management (Egan et al., 2012) the integration of complementary and conventional approaches remains controversial (Rosenthal & Dean-Clower, 2005) and has raised several issues around CAM use and the balancing of bioethical principles.

CAM for the most part is an unregulated industry with potential for benefits and risks to women with breast cancer, who are particularly high utilizers of CAM therapies (Zörgő & Mkhitaryan, 2020). Respect for patient autonomy requires that the individual's values and preferences are privileged; however, this may prove challenging when a preference for empirically unsupported alternative therapies are in conflict with the principles of beneficence and non-maleficence which require health professionals to act in the best interest of the patient and prevent harm. Cancer professionals report numerous concerns around CAM use, including the lack of an established evidence base, risk of interactions with anti-cancer therapies (Keene et al., 2019) risks of non-disclosure and unsupervised CAM use (Rosenthal & Dean-Clower, 2005) and perhaps most significantly, using CAM in place of evidence-supported interventions.

Although evidence suggests that complementary therapies can improve quality of life (Latte-Naor & Mao, 2019) CAM users are at a higher risk of waiving recommended biomedical treatments by declining to initiate or discontinuing treatment (Greenlee et al., 2016; Zörgő et al., 2020) which significantly elevates the risk of disease progression, recurrence and morbidity (Johnson et al., 2018). The death of Apple co-founder Steve Jobs who died of a rare pancreatic cancer in 2011 may speak to the dilemma that health care providers navigate when patients opt for alternative approaches. While the decision to decline surgery was an autonomous choice, Job's biographer informed the media that he regretted the decision to refuse surgery and undergo alternative herbal treatments, particularly as his health declined (Potter, 2011)**.** Similar concerns have been raised around the ethics of CAM delivery and the potential for exploitation and harm, given CAM users tend to self-fund treatments (Song et al., 2020) with some fundraising to cover the costs of CAM treatments provided abroad in specialist centres (Song et al., 2020).

Knowledge of such risks may create an uncomfortable tension between the professional commitment to EBP and respect for patient autonomy, which are likely to require careful navigation. A patient's decision to pursue alternative approaches and more specifically to decline curative or life-sustaining cancer treatment may constitute a troubling anomaly for cancer professionals (Kacen et al., 2005) and place them in an ethically nebulous position where paternalism and a desire to prevent harm must be carefully balanced. This will be considered in the following section to provide an empirical context for this research.

3.0. SCOPING REVIEW

A scoping review was undertaken to map the literature pertaining to treatment refusal and health professionals' experiences of working with individuals who decline breast cancer treatment. Systematic literature searches were carried out in the period between June 2020-December 2021 while the study and research questions were being both developed and refined, to set the empirical context for the study. Given the relative dearth of literature pertaining to this subject, no constraints were imposed on the time frame from which selected articles were drawn from.

3.1. Search strategy

The following research questions guided the literature review:

- What factors underpin treatment refusal?
- How do cancer professionals make sense of a decision to forgo conventional breast cancer treatment?
- How do cancer professionals respond to a decision to forgo conventional breast cancer treatment?
- What influences cancer professionals' responses to the decision to forgo conventional breast cancer treatment?

- How do cancer professionals experience working with patients who decline treatment, personally and professionally?

The following databases were searched: Psychinfo, PsychArticles, CINAHL, Academic Search Complete and Science Direct, with no limits on date or country. The search terminology used in varied combinations was: (*treatment refusal) AND (breast cancer* OR breast neoplasms OR oncology OR cancer OR bioethics OR patient-professional relationships OR physician attitudes or nurses' attitudes).

3.2. Inclusion criteria

Qualitative and quantitative articles published in English in peer-reviewed journals which considered the refusal of cancer treatment or focused on health professionals' impressions of cancer treatment refusal or attitudes towards individuals who decline cancer treatments were included. Reflective papers, case reports and professional guidelines which considered the refusal of cancer treatment from a bioethical standpoint or offered guidance for health professionals were also included.

3.3. Exclusion criteria

Papers which were not written in English and which examined treatment refusal from a solely medical standpoint (i.e. pathology, disease progression etc.) as opposed to examining health professionals' relationships with this phenomenon were excluded. Papers which focused on the ethics of treatment refusal outside of the oncology context (e.g. mental health, acute settings) were also excluded.

3.4. Search Results

The search strategy initially identified a total of 1311 publications (109 from PsychInfo and Psych Articles, 487 from CINAHL Plus, 196 from Science Direct and 519 from Academic Search Complete) whose titles and abstracts were reviewed against the above criteria to identify 14 core publications. Manual searching of the reference lists of relevant publications revealed three more publications which were included within the final scoping review (see Appendix A and B).

3.5. Forgoing Cancer Treatment

Early breast cancer is highly treatable; however, there are recorded cases in which individuals have declined treatment entirely (Frenkel, 2013) or in favour of therapies that are categorised as alternative medicine (Verhoef & White, 2002). Although reliable estimates of cancer treatment refusal rates are not currently available (Verhoef et al., 2008) certain studies have demonstrated instances in which 3% of patients have declined all treatment (Velanovich et al., 2002) and 6-14% have declined adjuvant treatment either partially or completely (De Csepel et al., 2000; Neugut et al., 2012; Saquib et al., 2012). Despite the obvious risks of declining cancer treatment, this issue is poorly understood and most research has focused on characterising individuals who are most likely to decline treatment or reject medical advice on the basis of demographic criteria. For instance, Restrepo et al. (2019) identified that women from marginalised ethnic groups and who lacked private medical insurance were more likely to decline breast cancer surgery than white women, while Gaitanidis et al. (2018) reported that older age, divorce/separation or single relationship status were associated with the refusal of breast cancer-directed surgery.

These findings have been expanded upon within qualitative work which has taken a more fine-grained analysis of treatment refusal and identified a range of contextual, psychological and social factors that may contribute to that choice. Goldberg (1983) suggested that the decision to decline cancer treatment may not always reflect a fully reasoned choice but a consequence of psychological, interpersonal, psychiatric or medical systems issues. Goldberg cautions health professionals against prematurely accepting an individual’s preference to forgo treatment, suggesting that exploration and resolution of relevant issues such as the psychological meaning of cancer, earlier experiences of the medical system and family myths around cancer may help the individual to accept treatment. This conceptualisation of a choice to decline as an emotional reaction or psychological disturbance is present within some of the anecdotal literature in which oncology professionals have reflected on experiences of working with patients who decline cancer treatment. Carlson, (2014b) suggested that declining treatment often emanates from exhaustion, depression, or wishing to avoid burdening loved ones, while Sindhu, (2019) recalled a patient who expressed regret at their initial choice to decline therapy, which they attributed to the fear and shock of diagnosis and being offered treatments with significant risks of side effects.

While themes of distress, family issues and previous experiences of health services are echoed within the qualitative literature, this work arguably considers treatment refusal as a purposeful choice as opposed to a decision that is excessively biased by emotion. Verhoef et al. (2002) observed that some participants made the personal choice to forgo cancer treatments in favour of alternative approaches based on their negative experiences of mainstream medicine, or experiences of watching a loved one suffer through cancer treatment. The authors reasoned that these experiences had led participants to turn away from biomedicine, in some cases before even being diagnosed with cancer, and to pursue alternative paradigms for understanding health and illness. Where individuals believed that their cancer reflected personal struggles rather than representing an exclusively biological phenomenon, they privileged alternative approaches that accommodated their beliefs and emphasised a holistic approach to mind-body healing as opposed to disease management. Similarly, Citrin et al. (2012) observed that women with breast cancer who declined cancer treatment differed from women who accepted treatment with respect to their perception of medical treatments, and believed that chemotherapy and radiotherapy were risky interventions that are more harmful than helpful. In this study, women who declined treatment believed that they could treat cancer with lifestyle approaches such as diet, exercise and supplements. However, rather than reflecting a psychological response to previous negative experiences, Verhoef et al. (2002) reasoned that the choice to decline conventional treatment constituted a self-affirming act that corresponded to participants’ views of themselves and the world in the context of their life stories.

Women's individual philosophies on life and death also emerged as pertinent within further studies exploring the decision to decline cancer treatment. Huijer and van Leeuwen (2000) conducted a small, qualitative pilot study (n=3) which examined women's reasons for declining chemotherapy for breast and ovarian cancer. Decision-making was an elaborate process in which women deliberated on the pros and cons of chemotherapy while integrating their unique personal circumstances, the opinions of others and attitudes towards living and dying. Some participants had an open attitude towards death, acknowledging they had lived well and did not wish to excessively suffer through treatment, while others referenced caring commitments or financial obligations which meant that they could not afford to be disabled by treatment side effects. Personal values and holding onto things that give life meaning have also been seen to inform women's decision to decline treatment. Van Kleffens et al. (2005) reported that participants employed values-oriented rationality within their decision-making, deciding to forgo treatments that might prevent them from carrying out valued roles and activities. In this study, many participants believed that oncological treatment was not compatible with a good quality of life and over 50% chose not to be treated because they believed that treatment would lead to side effects or induce symptoms. Some patients indicated they would prefer to sacrifice longevity than live a prolonged, but compromised life due to treatment.

3.6. The Sociology of Treatment Refusal

Where research has predominantly focused on understanding individual reasons for declining cancer treatment, the sociological context in which treatments are declined has arguably been overlooked. Radley and Payne (2009) emphasise how health systems are grounded in socially constructed ideas and practices concerning the right to life. The desire to extend or preserve life is characteristic of western culture (Pijnenburg & Leget, 2007) and is the implicit goal of medical research concerned with counteracting diseases of ageing (Pijnenburg & Leget, 2007). It has been suggested that the life prolongation mission is at least partially attributable to the wider reluctance in western society to contemplate and accept death; (Moore & Williamson, 2003) however, an inevitable consequence of this collective goal is disruption of the natural dying process, such that 80% of people now die in hospitals and nursing homes while being cared for by individuals who value life preservation (Barton, 1991). Radley et al. (2009) argue that to expedite one's death (by declining curative treatment) could be seen by many (particularly health professionals whose business is predominantly life preservation) as a form of negligence in relation to life itself. The authors argue that in a society that wishes to preserve life such acts may represent moral transgressions that breach the norms and values to which many appeal.

According to Penson et al. (2005) "For many, cancer is synonymous with death and fearing death is a rational response" (p.160). Implicit in this statement are expectations around reasonable or acceptable responses to cancer and death, with fear and subsequent efforts directed at life prolongation (namely medical treatment) reflecting a rational response. As previously discussed, issues of rationality are of critical importance within bioethics with reason and rationality representing the vehicles through which patient autonomy is realised (Martinez et al., 2015). Indeed, contemporary health care policy which advocates for greater choice within cancer care (Department of Health., 2007) is situated within a rational cognitive framework in which the provision of appropriate, accessible and suitable information is considered sufficient to allow patients to contemplate treatment choices, make decisions and express preferences about them (Radley et al., 2009). Brock and Wartman (1990) describe an irrational decision as one that meets the patient's goals and values less effectively than other available options. If fear and a desire to avoid death are considered the rational response to cancer diagnosis then it follows that a decision to decline cancer treatment should be evaluated as irrational. A patient's decision to decline cancer treatment is likely to challenge health professionals, by threatening the scientific and ethical frameworks that orient their work and decision-making, while simultaneously violating wider social norms around the avoidance of death and prolongation of life. Verhoef et al. (2002) reported that patients' communication and relationships with cancer specialists were a contributing factor to their ultimate decision to forgo cancer treatment, and highlighted instances in which physicians responded judgementally to patients' decisions. Such evidence speaks to the difficulties that health professionals may experience both in understanding a decision to decline and responding in a way which is helpful to the patient.

3.7. Responses of Health Professionals to Patients Who Decline Cancer Treatment

Little is known about how health professionals regard a patient's choice to decline cancer treatments that are potentially curative (Verhoef et al., 2008). Where research into this issue has taken place, it has been mostly qualitative and focused on the experiences of physicians as opposed to surgeons or nurses. van Kleffens and van Leeuwen (2005) evaluated how oncologists and general practitioners understood a patient's decision to decline treatment and found that physicians tended to emphasise a goal-oriented medical perspective and so the decision to decline treatment was often considered irrational, particularly when the proposed treatment was curative. It was observed that physicians were better able to empathise with the value-oriented rationality of patients in cases where the declined treatment was palliative. In a separate study based on the same interviews, the authors observed that the extent to which physicians were guided by ethical principles varied as a function of treatment goals, and physicians were more likely to attempt to persuade patients to reconsider when the recommended treatment was curative (van Kleffens et al., 2004). In this study, the physician's acceptance of the patient's decision was a critical factor in determining their attitude towards the patient and contributed to patients feeling respected and free to make their own decisions. A similar study that explored the experiences of medical and radiation oncologists found that physicians dichotomised patients and their decisions distinguishing between curable and non-curable disease, rational and irrational treatment decisions and patients who took a passive or an active role in decision-making (Madjar et al., 2007). In this study physicians spoke about the trade-off between the benefits and side effects of treatment, seeing a spectrum upon which the decision to decline treatment was more or less acceptable. While the physicians did not consider patients incompetent, they did question the rationality of decisions and were accepting of the patient's right to choose, but more so when the disease was no longer responding to medical treatment. Although physicians referenced patient autonomy, they also acknowledged that most patients preferred to make decisions within a model of benevolent paternalism. Patients who were more active in decision-making were seen as different and were often discussed as difficult, or irrational patients who required extra time.

Madjar et al., (2007) also observed that physicians described their experiences of working with these patients as difficult in the interpersonal sense. The decision to decline reflected a stark departure from the norm and created a sense of helplessness and uncertainty in terms of how to proceed. Patients who declined treatment evoked fear in physicians who worried about doing their best for the patient and felt a sense of failure at being unable to convince patients to reconsider. Patients who declined curative treatment tended to stay with the physicians, who continued to reflect on what had prevented them from fully understanding the patient and persuading them to reconsider. The authors suggested that the physician's tendency to evaluate treatment decisions in terms of rationality may contribute to feelings of uncertainty and concern, limiting physicians' ability to respond with sensitivity and understanding. For instance, patients with curable cancer who chose to forgo treatment were seen as making irrational decisions, which justified the professional feeling upset and trying to persuade the patient to change his or her mind. Dhotre et al. (2016) observed similar emotional and behavioural responses among nurses who cared for patients who chose to prematurely discontinue chemotherapy. Nurses described their attachments to patients which meant that painful emotions were experienced when patients decided to discontinue. These feelings compelled the nurses to try and persuade patients to continue and like the physicians, nurses felt a sense of personal responsibility and failure when patients did not continue. Barton (1991) acknowledged that the patient's right to decline treatment is supported by a legal precedent, but suggested that this may be difficult for nurses to accept due to an ethic of care and a sense of advanced knowledge and experience which creates a sense of knowing what is best for the patient. While Dhotre et al. (2016) reported that nurses were able to understand patients' decisions, they still struggled to balance their responsibilities for patients' care with respect for the patient's right to decide and felt responsible for removing all barriers to finishing chemotherapy by educating patients, helping to control treatment side effects, offering counselling and exploring financial options.

3.8. Professional Guidance around Treatment Refusal

The aforementioned research demonstrates that a decision to decline treatment may be troubling for cancer specialists; however, professionals' interactions with patients may be implicated within the patient's decision-making (Van Kleffens et al., 2005). Citrin et al. (2012) found that women who refused conventional treatment mentioned that a better first experience with their physicians may have made impacted the treatment path they ultimately chose, while Kim et al. (2021) reported that women who felt pressured into decisions by physicians experienced more decisional regret. Interestingly, Kim et al. (2021) reported that women who accepted treatment felt more pressured by doctors, with those who declined treatment reporting that they felt able to trust doctors because they were open to their preferences. Although cancer professionals may find conversations around treatment refusal challenging, Goldberg, (1983) recommended that physicians should not neglect patient ideas and beliefs around treatments, as understanding patient values and preferences is an important part of respecting autonomy. Goldberg also argues that a decision to decline treatment should only be accepted once a systematic exploration of internal and external factors has taken place, as declining treatment may often reflect circumstantial factors that may be modifiable. These recommendations are echoed within the guidelines issued by the French Society for Psycho-Oncology, which encourage a systematic analysis of the patient's decision, as patients may be opposed to some aspect of treatment as opposed to treatment as a whole and may be open to alternative modalities (Dauchy et al., 2017). These guidelines emphasise that maintaining a relationship based on providing care and progressing the initial refusal toward consideration of treatments that may be acceptable to the patient. The authors emphasise that premature discharge or fully breaking off the relationship should be avoided as this would ultimately deprive the patient of all care.

Giorgi and Bascioni (2012) warn that a patient who declines treatment may often assume that this choice terminates their relationship with cancer services; however, patients who declined conventional treatment indicated that they valued ongoing follow up care from oncology services, provided that they felt supported in their health beliefs (Kim et al., 2021; Verhoef et al., 2008). Keeping the door open has emerged as an important theme within guidance around the management of treatment refusal. In guidelines for communicating with patients who decline conventional treatments, Zörgő and Mkhitaryan (2020) emphasise that severing all contact not only decreases the chances of patients reconsidering their decisions, but may also increase the risk of safety issues. They suggest that cancer teams allow sufficient time for treatment decision-making and recommend a break between diagnostic and treatment-related consultations, as the emotional turmoil of diagnosis may lead patients to feel pressured to comply with health professionals' recommendations (Verhoef et al., 2002). Sensitive and approach oriented communication is emphasised as primary within the management of treatment refusals and the authors advise that health professionals avoid condemning patients' decisions or the use of scare tactics, which may invoke resentment and distrust in the professional-patient relationship. Verhoef et al, (2008) conclude that the decision to decline treatment does not necessarily signify distrust of the medical system or displeasure with the care received, but can reflect intensely personal factors. Through exploring treatment preferences and honouring the uniqueness of patients, cancer specialists can embody the ethos of autonomy and patient centred care and transform 'problem' patients into partners in care (Frenkel, 2013).

3.9. Critical Evaluation

Results of the scoping review generally indicated that while physicians and nurses recognised the patient's right to decline treatment, they struggled to accept the decision as a reasonable alternative to treatment. However, there is also recent contradictory evidence in which individuals who declined conventional cancer treatment described their doctors as open and supportive of their choices (Kim et al., 2021). At present, the literature pertaining to health professionals’ perspectives on treatment refusal is heavily comprised of anecdotal, opinion pieces that provide a limited framework for the integration and interpretation of contradictory findings. The evidence base for health professionals’ experiences of working with patients who decline treatment has been limited to four empirical studies which considered physician perspectives, and a single study that explored the experiences of nurses. Although results demonstrated overlap, opportunities for understanding discipline-specific contributions to health professionals’ experiences of treatment refusal are similarly limited by the extant literature. Moreover, at the time of this research, the experiences of breast surgeons have not been explored, even though surgery is indicated in the management of all invasive breast cancers (Restrepo et al., 2019). The patient’s care pathway is predominantly determined by the nature of their cancer and the local infrastructure. While the patient’s treatment recommendations will largely determine which health professionals they encounter throughout their journey, most patients will have some form of contact with surgeons, as assessment and diagnosis within One Stop clinics are typically overseen by surgical teams and breast care nurses (Breast Cancer Care, 2014). Moreover, tumour resection often represents the first port of call in breast cancer management with patients generally feeling more willing to accept surgery than adjuvant treatment (Kim et al., 2021). In this regard, a refusal of surgery may be construed as a more explicit expedition of death and the omission of surgeons’ perspectives may represent an important gap in the literature.

The included studies have predominantly taken place in the USA and Western Europe; however, the unique context of NHS cancer care may have implications for how professionals engage with patients who decline treatment, given national cancer targets (NHS, 2020). The pressures that oncology services contend with may limit the time available for exploring patient values and circumstances, despite this being indicated in guidance pertaining to the professional management of treatment refusal. Doyal (1995) argued that differential value afforded to certain types of knowledge within EBP can create a context in which women’s experiences and values are marginalised despite this knowledge being central to women’s decisions to decline cancer treatment

(Citrin et al., 2012; Huijer & van Leeuwen, 2000; Kim et al., 2021). Doyal's (1995) reflections highlight the importance of understanding the perspectives of health care professionals who may plausibly take up different positions in relation to patients and their decisions. For instance, Barton (1991) suggests that nurses are uniquely positioned to resist medical paternalism and function as patient advocates, due to their proximity to patients and holistic perspective of healthcare. In the United Kingdom, breast care nurses are likely to be similarly positioned to advocate for patients within their capacity as key workers (Amir et al. 2004). Breast care nurses offer continuity of care for women with breast cancer as they typically accompany patients through each stage of the care pathway, often joining surgical colleagues within diagnostic consultations and providing information and support both during and after treatment (Breast Cancer Care, 2014). Breast care nurses serve as the primary point of contact for patients within the system by supporting patients to understand their treatments and liaising with consultants should patients experience any problems or have concerns about any aspect of care or treatment (Luck et al., 2017). Breast care nurses provide both emotional and practical support, conducting holistic needs assessments (Briggs et al., 2020) and advising on non-clinical matters such as childcare or financial options following cancer diagnosis.

The extant literature has indicated that health professionals recognise, but may struggle to engage with beliefs or philosophies that depart from medical science (Madjar et al., 2007). While these studies have provided important insights into the frameworks that influence health professionals' responses to treatment refusal, this body of research is small and has examined physicians' and nurses' experiences in isolation. Research that considers the perspectives of various health professionals will provide a more nuanced insight into how health professionals understand and respond to treatment refusal not just as individual professionals, but as members of an MDT. These insights are important to understand factors that may influence how breast care teams respond to patients who decline treatment.

3.10. Rationale

This study will make a novel contribution to the literature by exploring the experiences of NHS oncology professionals, who have worked with patients who declined conventional breast cancer treatment. It is hoped that by exploring the positions of different cancer professionals, this research can understand ways in which NHS cancer professionals understand and respond to women's decisions and explore how professionals navigate commitments to EBP and patient-centred care that emphasises patient values.

3.10.1. Aims

This study aims to explore the experiences of breast surgeons, medical oncologists and clinical nurse specialists when working with women who decline conventional breast cancer treatments and to understand how the different perspectives of these professionals can be understood and integrated within patient-centred care. Previous research has indicated that health professionals may struggle to accept a patient's decision to decline treatment; (e.g. Madjar et al., 2007; Dhoetre et al., 2016) however, respecting patients' beliefs and decisions is an important facet of patient centred care and has emerged as impactful in research examining factors that contribute to trust within patient-professional relationships (Kim et al., 2021; van Kleffens et al., 2004). Through exploring the commonalities and discrepancies within different professionals' experiences of working with women who decline breast cancer treatment, this study may identify both collective and specific support/training requirements, and therefore highlight ways in which health professionals can be supported to meet the needs of all patients, including those who decline breast cancer treatment. This study will explore this by qualitatively interviewing surgeons, medical oncologists and clinical nurse specialists about their experiences of working with women who have declined breast cancer treatment.

3.10.2. Research Questions

The following research questions will be explored through interviews with cancer professionals

- How do cancer professionals understand a patient's decision to forgo conventional breast cancer treatment?
- How do cancer professionals respond to women who decline breast cancer treatment?
- What guides or informs cancer professionals' responses to women who decline breast cancer treatment?
- How do cancer professionals experience working with breast cancer patients who decline treatment, personally and professionally?

4.0. METHODS

In this chapter, I will outline the critical realist stance of the study and consider relationships between this epistemological stance and the study's research questions and methodology. Following this, I will describe the processes and procedures of carrying out this research and the approach to analysis.

4.1. Epistemology

Epistemology is the branch of philosophy concerned with the nature of 'knowledge' and the establishment of criteria for evaluating claims that something is known (Ashcroft, 2004). In detailing one's view of the world and reality, epistemological assumptions provide the context for all research activity, determining the conceptualisation of the research subject, the methods of inquiry through which knowledge is pursued and the lens through which data is interpreted and presented. As such, it is imperative that epistemological assumptions are rendered explicit from the outset (Bradshaw et al., 2017).

The model of evidence-based medicine (EBM) that informs healthcare provision can arguably be taken as a system of knowledge in which differential status is afforded to specific types of empirical evidence such as randomised controlled trials and meta-analyses. This approach endeavours to uncover the true nature of phenomena through eliminating bias, controlling for extraneous influences and statistically integrating data to arrive at the universal, scientifically discovered truth. Inherent in this approach is the realist assumption that an objective reality exists which can be discovered through the methods of science (Goldenberg, 2006). Post-positivist critics have argued that the pursuit of objectivity within clinical research serves to obscure the inevitably subjective dimensions of human inquiry, as the relative privilege afforded to different types of evidence may formalise a tendency to overlook concepts that elude description by the scientific method (Schwartz & Wiggins, 1985). Goldenberg (2006) warns that to neglect context and subjective knowledge increases the risk of technocratic healthcare provision which cannot engage with the subjectivity of patient experience and therefore undermines patient centred care.

Critical realism has been proffered as a philosophical framework that can accommodate the subjective forms of knowledge that may be oppressed, overlooked or obscured by conventional methods of scientific inquiry (Nairn, 2012). Ontologically speaking, critical realism can acknowledge the material reality of biological phenomena like cancer; however, it is epistemologically relativist in recognising that such phenomena take place in socio-cultural contexts in which we construct and bestow meaning upon concepts like health and disease (Bhaskar, 2010). The meaning bestowed upon such realities irrevocably influences the material and subjective experiences of diseases such as cancer and is therefore inseparable from it. Marks (2009) suggested that there is disparity between research conducted in healthcare and what is important to patients, which may be reflected in the growing popularity of alternative approaches (Goldberg, 2006). This research is interested in subjective aspects of clinical practice which are not accounted for by the EBM framework, hence a critical realist position will be held throughout.

4.2. Design

I chose a qualitative design which sought to explore professionals' experiences through semi-structured interviews. I chose to analyse the data using thematic analysis due to its flexibility and theoretical openness, and because it mapped onto my critical realist position and hopes to provide a contextualised account of professionals experiences (Braun & Clarke, 2006). Although this research was concerned with understanding the experiences of healthcare professionals, I was also conscious that this study is the first (at the time of completion) that has attempted to juxtapose the experiences of different healthcare professionals. For this reason, I decided that thematic analysis was more suitable than qualitative approaches that are more idiographic in nature (e.g. Interpretative phenomenological analysis). I chose to analyse interviews using thematic analysis as it could support consideration of points of convergence and discrepancy within the experiences of different healthcare professionals.

4.3. Ethics

Ethical approval was granted by the University of East London's (UEL) Ethics Committee (Appendix C). All participants were issued with a Participant Information Leaflet (Appendix D) in advance of interviews and encouraged to read it carefully so queries could be answered before commencing interviews. All participants gave written consent (Appendix E) and I highlighted the right to withdraw at any time without reason or consequence. Confidentiality and instances in which this might be broken were also explained. I considered the sensitivity of this research and interview questions at all stages; however, I agreed with my supervisor that the interview was unlikely to cause undue distress given that staff were likely to encounter and engage with existential issues as part of their professional roles. Throughout the research, I endeavoured to cultivate a context in which participants were protected from harm and could benefit from our discussions. I was careful to monitor for distress throughout and asked participants to reflect on how it felt to speak about patients who decline treatment. Many participants expressed their interest in the research and requested that I share the results once the project was completed. A debrief session was offered after the interview as an opportunity for participants to speak about any issues raised. All participants received my contact details and I encouraged them to contact me should they wish to discuss the research. A debrief leaflet was provided which identified supports available to participants (see Appendix F)

4.4. Recruitment and Participants

Participants formed an eight person convenience sample that was recruited via social media, and word of mouth. Advertisements were published on the websites of the UK Oncology Nurses Society, the Association of Cancer Physicians and the Association of Breast Surgery (see Appendix G for an example) however, no participants were recruited through this pathway. One oncologist was recruited via Twitter and requested to pass my contact information onto a nursing colleague whom they felt would be interested in participating. The six remaining participants (two oncologists, two nurses and two surgeons) were recruited with the support of an ex supervisor; a consultant clinical psychologist whom I had previously worked with in a psycho-oncology service within a major cancer centre (see section 1.1). This professional works alongside clinical staff who had previously expressed concern around treatment refusal among patients with breast cancer and signposted interested participants to the study by sharing my contact details. Interviews took place remotely via Microsoft Teams. I communicated with participants through my university email and sent meeting invitations once a time had been agreed via email. Participants consented to meetings being recorded for transcription purposes and were aware that recordings would be destroyed once the thesis was complete. Pseudonyms were used to retain confidentiality and anonymity and demographic information is not included as a proportion of participants work in the same cancer centre.

Table 1

Participants' professions

Pseudonym	Self-reported Profession
Edward	Consultant Oncologist specialising in Breast Cancer
Angela	Consultant Medical Oncologist in Breast Cancer
Theresa	Clinical Oncology Consultant
Sophia	Consultant Breast Oncoplastic Surgeon
Andrea	Consultant Surgeon
Lucy	Clinical Nurse Specialist Oncology
Athena	Breast Cancer Clinical Nurse Specialist
Catherine	Breast Clinical Nurse Specialist

4.5. Interviews and transcription

Semi-structured interviews were guided by the interview schedule (Appendix H) which was used flexibly and in response to material generated in discussion with participants. I was conscious that several participants were colleagues and may feel a degree of self-consciousness if asked to reflect on other professionals' responses to treatment refusal and was therefore careful to emphasise confidentiality and to highlight that identifiable information would be removed and that pseudonyms would be used within the interviews and analysis. Questions were intended to be curious and encouraging of elaboration. Transcriptions were generated by Microsoft Teams which I went through while listing to video recordings to ensure accuracy and to remove all identifiable information. The 'Jefferson-lite' transcription protocol was used (Potter & Wetherell, 1987) which is a simplified version of the original Jefferson transcription system (Jefferson, 1984). Interviews were transcribed at the semantic level, as opposed to emphasising extralinguistic features such as intonation and emphasis. This felt sufficient given that I aimed to analyse at the level of participants' spoken words. Punctuation was added to transcripts to improve readability, while being careful to ensure that participants' intended meaning remained. An extract from a Transcript can be found in Appendix K.

4.6. Analysis and Materials

Qualitative data was analysed using reflexive, thematic analysis to identify patterns and themes. *Reflexive* thematic analysis is distinctive in its position towards the analytic process and departs from reliability approaches, which construe coding as an exercise in finding evidence for pre-existing themes (Boyatzis, 1998). Reflexive thematic analysis is a fundamentally interpretive approach in which coding and theme development are generative exercises, based on the researcher's subjective engagement with the data, as mediated by their beliefs and experiences (Braun & Clarke, 2019). In keeping with my epistemological assumptions, I endeavoured to explore the subjectivities of participants' experiences during analysis, while acknowledging that my own context and familiarity with the extant literature may come to bear on my interpretation of participants' words and meanings. I used NVivo qualitative analysis software and uploaded anonymised transcripts to NVivo, which allows users to generate codes in reference to passages from transcripts. NVivo supports the analytical process by allowing the researcher to easily link codes and passages of text, while also supporting the researcher to remain reflexive and externalise the reasoning behind codes within code summaries. This program allows the researcher to group and organise codes into themes and sub-themes. I was guided by Braun and Clarke's (2020) recommendations while using NVivo and undertook the following steps.

1. I took transcription as the beginning of the analytical process (Byrne, 2021) and used this stage as an opportunity to revisit video recordings and to include gestures or mannerisms that may not have been missed during interviews. I familiarised myself with the data by reviewing transcripts several times and noting my initial thoughts or ideas.
2. I generated initial codes using NVivo qualitative analysis software taking one transcript at a time. I coded extensively in the first instance, as per Braun and Clarke's (2013) recommendations and coded at latent and semantic levels (Byrne, 2021). I was careful to acknowledge my biases and assumptions within code summaries. Re-reading transcripts and refining codes helped me to notice instances in which my assumptions were activated and to make these explicit
3. Following the coding of interviews, I proceeded to connect related codes. At this point the overlap between certain codes became apparent and it was possible to refine and reduce the number of codes, whilst retaining the semantic level of analysis.
4. Using NVivo I began to group related codes and consider organising concepts, thereby beginning the process of mapping potential themes. This process was also supplemented by the familiarisation notes I had made during interviews and throughout the coding processes.
5. Once I arrived at candidate themes, I reviewed transcripts and considered the coherence of the themes, how they fit together, and the extent to which they encapsulated the data.
6. I then wrote summaries for themes and subthemes, trialling names and titles that best captured their content.
7. I maintained an analytic position while writing the report and continued to tweak the analysis as I became more immersed in themes and the story they told.

4.7. Reflexivity

Willig (2013) recognises two distinctive forms of reflexivity which come to bear on the process of qualitative research. Personal reflexivity involves engaging with ways in which the researcher shapes the research through personal beliefs, values and experiences, in addition to ways in which the researcher is impacted by their subject and interactions with participants and data. Comparatively, epistemological reflexivity is concerned with a conscious probing of ways in which the research paradigm may determine and limit what can be found. Epistemological reflexivity requires the researcher to engage with assumptions around the nature of knowledge and how knowledge is accessed. Both personal and epistemological reflexivity have been integral to this study given my own relationship with the work (see section 1.1) and the epistemological assumptions that underpin EBM which guides contemporary healthcare delivery (Ashcroft, 2004). I have endeavoured to remain reflexive by using a reflective diary (see Appendix N) in addition to articulating a rationale for decision-making throughout the research process. Using the diary helped me to develop a deeper understanding of the data and to situate my interpretations within the wider social, political and cultural context.

5.0. RESULTS

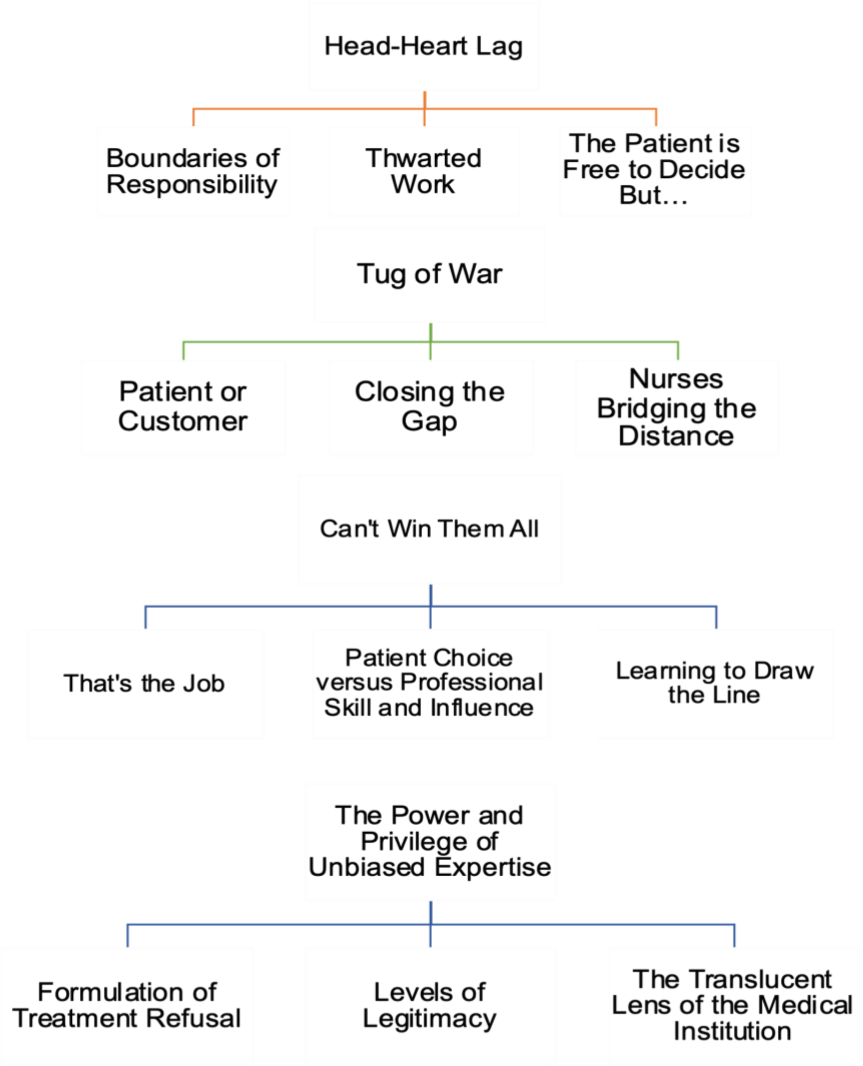
This chapter presents the findings of the analysis. It will begin by presenting the overall thematic map and discussing each theme and sub-theme. Participant quotes are denoted in italics and will be used throughout with the pseudonyms identified in Table 1.

5.1. Thematic Map

Overall, four themes and twelve subthemes were identified across the eight transcripts which are depicted in Figure 1.

Figure 1

Thematic Map of Health Professionals Experiences of Working with Women who Decline Breast Cancer Treatment



5.2. Theme 1: Head-Heart Lag

The first theme captured areas of tension within professional identities as participants reconciled their commitments to the bioethical principles that underscore healthcare provision, against a desire to fulfil their overarching purpose as healthcare professionals. The participants recognised their professional obligation to respect the patient's choice; however, this responsibility seemed to obstruct the vocational aspects of the role that emanate from the seemingly noble commitment to curing disease and prolonging life. A patient's decision to decline breast cancer treatment was seen to thwart the life prolongation mission of healthcare professionals, forcing them to engage with the patient's mortality, whose salience was pronounced as their decision meant that death was almost certain. The inability to prevent or delay the patient's demise elicited uncomfortable, conflicted feelings that were defended against by intellectually revisiting the ethical frameworks that underpin professional conduct and the boundaries of one's responsibilities and duties. While this seemed to guide the participants' practice and decision-making, the professionals were unwilling to completely disengage from their fundamental hope of patients surviving cancer and spoke about practices and infrastructures that are designed to support patients to reconsider.

5.2.1.Subtheme 1: The Boundaries of Responsibility

Throughout transcripts, participants reflected on their commitments and duties towards patients who decline treatment and considered activities that comprised part of their clinical roles to greater and lesser degrees. Professionals recognised their first duty to the patient's care and treatment, which exceeded their wider responsibilities to the NHS and cancer targets.

we are always told, "Oh, someone's going to breach. That's going to cost the Trust x thousand pounds," or something like that. But, okay, we'll work around what we can do, but at the end of the day, if you got a decision…a clinical decision, that's going to trump most things (Theresa: Oncologist).

At the same time, professional responsibilities were also discussed as existing outside of the patient and their needs or desires. For consultants, providing the best, evidence-based treatments was a fundamental part of their role and an ethical obligation that persisted even when patients did not wish to receive that treatment. The following quotes from Angela and Edward suggest that patients who decline treatment sometimes push the boundaries in their expectations of professionals; however, both were resolute in their roles and highlighted aspects of their practice that functioned to reinstate the oncologist's purpose, reminding patients that the professional's job is to advise on treatments in which they have experience and expertise.

I would I would stand firm on the recommendations and and and and then it would be, yeah, so they, that they will recognize that that's my, that's why they've come to see me. You know to for me to give them the advice (Angela: Oncologist).

Ehmm, I am very clear with patients that I am not supervising or endorsing and I will make it very clear to them and I will often write to the person who is prescribing their therapies and saying this is your responsibility (Edward: Oncologist).

Professionals spoke to the value of shared decision-making and were mostly open to the idea that cancer treatment is not always the best thing for the patient. For the most part, participants accepted that some patients would make decisions that did not make sense to the professional mind; however, they did feel a responsibility to ensure that patients understood the implications of their decision-making, and emphasised their responsibility to educate patients and ensure that they understood the implications of their choices.

as long as I felt that I had discharged my duty to explain it fully, to correct any misunderstandings and that that patient was fully involved in shared decision-making, I think I've reached a point where I'm happy with that…if I can make sure I've corrected any misunderstandings or at least challenged misunderstandings, made a case which I thought gave the patient the best *opportunity to make the right choice for them and accepting that the right choice for there may not be a wise choice* (Edward: Oncologist).

There appeared to be variation in the extent to which health professionals felt capable of, or compelled to engage with the patient's emotional suffering, with the following quotes suggesting that some professionals were prepared to look beyond the patient's medical situation, while others preferred to remain boundaried and to enlist colleagues as a means of providing the patient with emotional support.

We've got some of the surgeons that are incredibly, sort of look at somebody as, as a whole, take into account their emotional situation, their family situation, everything. And then we've got some that are much more sort of just medically focused if you like, surgically focused (Lucy: CNS).

They don't want to, you know, it's not somewhere they want to go, um, with patients. And I've even had it where a patient started a conversation with somebody. And they've actually said, 'Oh, hang on. Let me get [name] for you because, um, she's probably a better person to talk to.' And they literally will pull me into this conversation because they don't want to have it, and they'll walk away (Catherine: CNS).

5.2.2. Subtheme 2: Thwarted Work

Patients who declined treatment seemed to obstruct two fundamental aspects of participants' work; to defer death through the management of disease and to help sick and vulnerable patients. It was apparent throughout interviews, however, that these goals represented more than participants merely doing their jobs. It seemed that these aspects of professionals' work were connected to higher moralistic values, which meant that participants were left feeling conflicted despite being able to accept patients' decisions in the academic sense.

Throughout interviews, it was evident that professionals were moved by their patient's plight and held very genuine feelings of care and concern for them. The participants emphasised that encouraging patients to have treatment stemmed from wanting the best for the person as opposed to egotistical efforts at furthering a professional agenda. At the same time, Sophia recognised that a decision to decline cancer treatment was also a rejection of heath professionals' most basic and immediate purpose, and inadvertently denied professionals of the virtuous feelings that stemmed from engaging in work that is personally meaningful.

it goes against every principle, um, that we have er started and we trained and we believe in…all the recommendations and all the discussion and all the, um, persistence to go with the recommended treatments come out of care and out of love and affection towards them…err, so, it's, it's a moment of, er, um, cancellation of all the noble feelings (Sophia: Surgeon)

It was evident throughout interviews that participants considered the decision to decline treatment as a wasted opportunity for patients to live a life without cancer. This was particularly difficult for participants to digest when patients were young women with good prognoses or women with families who were seen as having a lot to live for.

many of these women are really still quite young actually, you know so they're fit, able people, uhm and so you know but, but many might have gone to have more advanced disease and metastatic disease, which is by then incurable (Angela: Oncologist).

It was just so it's certainly hard to you know if she agreed to earlier, we could have prolonged her life and she could be with her children (Athena: CNS).

For some participants, a decision to decline lifesaving treatment was so incomprehensible, that it could only be understood as emanating from some form of personal or systemic shortcoming. The MDT and colleagues represented a way for participants to protect themselves from such feelings, in that plans and decisions were validated by and shared with colleagues. The following quote illustrates the lingering frustration that persists for Athena despite the support of her colleagues, which seemed to emanate from a maternalistic desire to help patients. Her words speak to the conflict that she continued to experience, despite the patient being ostensibly comfortable with their choice.

I suppose I really struggle with feeling that is there more that we could have done or how sad it is…whereas I know with my colleagues it's like, it's their choice you have, you know you just have to accept it…but obviously, you're kind of restricted and actually you know they're not upset… but they're quite happy to stick with that and that's quite I find that hard to understand (Athena: CNS).

5.2.3. Subtheme 3: The Patient is Free to Decide But…

Although participants felt saddened by patients' decisions, they also appreciated that it was the patient's decision to make, and understood the importance of patients feeling comfortable in their choices. Participants were aware that patients who decline treatment often enter into relationships with health professionals on the defensive, so participants were conscious to emphasise this during interactions with patients to avoid appearing judgemental.

trying to you know make them feel that they don't have to be on the defensive, that their, that their view is their view and they're perfectly entitled to have it (Edward: Oncologist)

And if that is a decision that is to refuse treatment, and you…that's what you believe is the right thing, then, that's up to them (Theresa: Oncologist).

While participants respected certain patients' desire to pursue alternative treatments that aligned with their lifestyles and health beliefs, they preferred for patients to pursue these alongside conventional treatments and took exception at alternative practitioners who were seen as misleading and exploiting vulnerable women. This type of scenario was described as an ethical dilemma which needed to be navigated carefully to avoid losing the patient.

And I welcome people to try it alongside what we're doing but it's, sometimes we feel that they're taken advantage of because they're in a very, they can be in a vulnerable state, so they're desperate to try anything to make them better (Athena: Oncologist)

And as the conversation, um, went on, I don't know. I just became quite uneasy about things, but I couldn't really say that. So, afterwards, I just said, 'How was the appointment?' You know, 'How did it go? And was it useful?' Et cetera, et cetera. And yeah, sure enough, he's going to put her on all these weird and wacky things. It's going to cost her an absolute fortune (Catherine: CNS).

A number of participants referenced the Mental Capacity Act as an invaluable source of guidance in these situations, insofar as it explicitly stipulates that patients have the right to make decisions that may seem bizarre or unwise. It seemed that the Capacity Act absolved professionals like Edward of any personal responsibility for changing the patient's mind. He likened women declining breast cancer treatment to Jehovah's Witnesses refusing blood transfusions, noting that it felt simpler to handle the latter because of explicit guidelines and protocols.

But the the good thing about the Capacity Act was, and it was a light bulb moment for me, is it that decision does not have to be wise (Edward: Oncologist).

The Jehovah's Witnesses have a register of surgeons who will accept that risk and operate on that patient. What we don't do is sit for two hours trying to persuade them that the witnesses are wrong about, about blood transfusion (Edward: Oncologist).

While participants understood the statutory duty to accept seemingly unwise decisions, they continued to hold out hope that patients would eventually accept treatment and were willing to go to great lengths to facilitate this. Participants were sensitive to the patient's situation and there was evidence of professionals tolerating antagonism which was understood as the patient's reaction to their circumstances, despite being personally upsetting. The following quote from Angela highlights a pressure to remain composed during tense consultations, to avoid deterring the patient

Yeah, but you know they're frightened uhm you know, again, we, this is just, you know what we what we do so it is different…I would hate it if if if one of them said well, I'm not coming back because she was rude to me and she said if I didn't take her, if I didn't take her treatment she wasn't going to see me (Angela: Oncologist).

Participants aimed to keep the door open for patients as long as possible and described infrastructures and personal practices that were designed to encourage patients to return. Breast care nurses were described as being responsible for following up with patients in the days after consultations to check in and answer any questions. Participants emphasised that they would always try to encourage the patient to come back for a second appointment and were careful not to pressure the person, but to let them know that they were always welcome to return.

And I'll say look, "I will offer you this appointment. Does that feel OK to you? If when the appointment comes around, you feel you don't want to see me, just ring up, postpone it, but don't cancel" I say, "don't cancel it, "it's always good to have your, you know your options open (Edward: Oncologist).

Participants understood that cultural differences often prohibited connection with certain women who declined treatment, and nurses, in particular, expressed concerns about failing these patients. It seemed that nurses' concerns reflected a worry that patients were not getting the care they needed, as opposed to insecurities around personal competence, as these participants emphasised the value of going 'outside of the system' and enlisting stakeholders who could better connect with patients and understand their needs. Nurses in larger hospitals were exceedingly grateful for the support of chaplains who could ‘speak the patient’s language’ by understanding and accommodating their psycho-spiritual needs.

oh yeah, like we’ve got a chaplain, you know, a West African chaplain…one of the things we have tried in the past which has been helpful is for them to speak to our spiritual care team…And then that can be really helpful…And that’s on a couple, at least two or three occasions, that absolutely turned some people around and they've agreed to have treatments (Athena: CNS).

5.3. Theme 2: Tug of War

The second theme captured participants’ experiences of understanding and responding to patients’ decisions. Participants spoke to the dynamic re-positioning within relationships as patients enacted their preferences and professionals manoeuvred to lessen the disconnect with patients whose goals, values and frameworks for understanding cancer fell outside the conventions of contemporary healthcare. Professionals attempted to close the gap by stepping into the patient’s world or trying to convert patients to their way of thinking. Nurses appeared to be critical players in this endeavour, as their job structure and close relationships with patients allowed them to offer support that recognised the person as an individual. Developing close relationships with patients was discussed as a vocational dimension of the nursing profession, rather than a strategy for influencing patients; however, the recognition of patient preferences was discussed as a medium through which professionals’ objectives can be translated into a message that patients can take up.

5.3.1. Subtheme 1: Patient or Customer

Women who decline breast cancer treatment were noteworthy for participants as they subverted the traditional patient-professional dynamic by declining to defer to professionals’ knowledge and experience. While professionals were generally accustomed to patients coming to them in a state of ‘unknowing’ and relying on them for information and advice, women who declined treatment were distinctive in their independence and self-reliance.

I think they feel quite empowered that they have done all that research themselves. And they feel like they're coming with a lot knowledge to it, but they might not do (Athena: CNS)

Participants noted that this patient group are often forthright in their treatment preferences, with a clear sense of the care they wish to receive. Such patients were often cynical of contemporary cancer management practices, which they considered outdated and inattentive to wider determinants of health. Participants recognised that some patients are more comfortable with the idea of holistic approaches which were seen as promoting health and wellbeing, as opposed to toxic treatments whose ethics and efficacy were considered dubious. Some participants suggested that patients' dissatisfaction with treatments available on the NHS provoked distrust of professionals who deliver them, who were considered ambassadors of the status quo.

she wanted them to be funded by the NHS, and she's very angry that we cannot fund, um, treatments like caffeine injections and, um, vitamin injections and some hyperbaric or oxygen therapy and things that I haven't heard before (Sophia: Surgeon)

But there's a lot, some people would say it's all funded by the big pharma companies, they don't want you know, that's all the distrust maybe and all that side of things as well and we are pushing our agenda. And we don't acknowledge kind of alternative therapies enough (Athena: CNS)

This patient group was generally perceived as proactive and capable in terms of articulating their preferences and enacting their will, by seeking second opinions or paying for alternative therapies. While professionals did not take offence at patients going their own way, there was a sense of irritation at those who wanted 'to order off menu' and who used professionals' time and expertise to explore treatments that are not delivered in NHS cancer services.

Because my experience is that even if they do not want the therapy, they will often have a huge amount of questions about their disease. They will often want *to interrogate our knowledge base about their disease, and they'll often want to use us to sense check the therapies that they are pursuing. If they're pursuing complementary therapies or quasi-quasi scientific alternative therapies and that to do that sincerely takes a lot of time* (Edward: Oncologist)

While participants wanted to be as supportive and accommodating as possible, the consultants recognised that they cannot support patients who do not want treatment indefinitely. In these instances, professionals adopted a more authoritative stance, acknowledging that the patient’s right to choose is delimited by the system.

If I am the second consultant, they have declined treatment, have you had a consultation with one of my colleagues and they, I can see that they can consent, er, they have mental capacity… um, I am frank with them and, um, I’m explaining that we, we don’t have anything more to offer (Sophia: Surgeon).

5.3.2. Subtheme 2: Closing the Gap

Women who decline treatment often felt beyond reach for participants who spoke to a culture clash in which disparity between the goals and beliefs of patients and professionals impeded understanding and connection. Participants lamented the rise of a post-factual, conspiracy based culture which rendered their usual tools of logic and evidence less impactful. When patients’ decisions were grounded in belief systems that are incompatible with medical science, participants were forced to draw on alternative skillsets to try and speak the language of the patient, or to undermine alternative beliefs that kept patients outside the reach of professionals.

In the following quote, Lucy reflects on professionals’ position within the healthcare system and considers the implications for concepts of health and disease, which are assumed to be universal, but yet are not shared by all patients. Edward’s words perhaps speak to a similar disconnect emanating from an anti-establishment culture which divides those who sit within dominant institutions and those who resist them.

I think my understanding and what the accepted understanding in here, sort of, you know, you do the correct research, just even sort of talking about what cancer is at that basic level. I think we assume everybody agrees with it. And they don't (Lucy: CNS).

Why would a person be an anti-vax? I don't understand that. Why would a person think that chemotherapy is a toxic, a deliberate plot? (Edward: Oncologist)

The rejection of treatments that are validated by research and the consensus of the medical institution was exceedingly difficult for professionals to understand, and was at times perceived as a threat to good practice, prompting some participants to characterise patients as irrational.

*You know, it just makes no sense, but we can't let- I can't let that, um, influence how I treat them because, you know, it's obviously something in their mind that's stopping them (*Andrea: Surgeon).

The holding of different perspectives was sometimes discussed as contributing to a fundamental disconnect, which was regrettable for Edward, who worried that difficulties in understanding may prevent professionals from getting alongside patients.

I'd entrenched myself in a position where I was no longer able to, the patient just had lost sight of me and I'd lost sight of the patient (Edward: Oncologist).

most health care professionals try to use empathy as part of their skill set and when you cannot understand how someone has cognitively arrived at a point where they don't believe in or don't wish to have that therapy. And so it's very difficult to walk in their shoes (Edward: Oncologist)

Participants had various strategies for engaging patients who declined treatment which included appeals to reason, emotion and the relationship with the patient. Consultants adopted a multi-pronged approach, at times using facts and evidence to make a case for treatment or to challenge beliefs or misconceptions.

and sometimes, just the presentation of facts and data might mean that they can understand it in a better way and can pick a better decision (Theresa: Oncologist).

Some people will come to your way of thinking pretty quickly. They may need to go and think about it. They may work, but when they see the data when they understand the risk and hopefully when you've challenged or corrected some false beliefs (Edward: Oncologist).

While consultants felt obliged to lead with science and facts, they recognised that it was important to build trust with patients by demonstrating openness and sensitivity. Offering follow up appointments was discussed as a tangible expression of collaborative practice that helped professionals to nurture relationships with patients by allowing them to take things at their own pace.

So, um, I think that the patients who decided to—they change their minds, um, they felt that they were heard… they were not laughed at, they were not rejected, they were not—they didn't, they didn't feel as been, er, the outcast and the weirdos… so, it was, it was the, building the trust between us (Sophia: Surgeon)

you want to try and take the tension out of that and one of the ways the tension is to give them the time and space (Edward: Oncologist).

5.3.3. Subtheme 3: Nurses Bridging the Distance

While consultants were motivated to build relationships with patients, they noted that busy clinics did not allow unlimited time for the dialogue and discussion that some patients desired. In contrast, the nature of the breast care nurse role was discussed as allowing nurses to really get to know patients and understand their needs in ways that sometimes supported patients to accept treatment. During interviews, nurses spoke to their genuine investment in patients and were greatly concerned by the limiting impacts of the system and professionals' socialisation, fearing that the different worldviews of professionals and patients might contribute to the marginalisation of certain women.

I think we maybe we approach it from such a kind of you know our clinical standpoint and also cultural view and what we think so I can't understand why you won't have it… I suppose we get such a diverse population coming through us as well. And it's, yeah. It's just that we're, we're not hitting the right notes I guess for some people. (Athena: CNS).

Nurses were sensitive to power dynamics within interactions with consultants and eager to act as patient advocates, or as a receptacle for that which patients could not share with consultants.

I think we have the luxury here of often being able to…if we feel, you know, there's sort of things that are unsaid or the patient hasn't been able to ask the surgeons or, you know, just…you just feel that there's more to it. Then we often just sort of say, 'Why don't we go and have a chat' (Lucy: CNS)

Consultants similarly valued the work of nurses who were seen as better placed to support patients with the emotional aspects of cancer and to 'interpret' for patients so that consultants' meaning could be conveyed in a way that makes sense to patients.

they're more likely to crumble with them than they are with me. Um, and, I mean, it would probably more likely to do with me than with my male colleagues, but, um, more so with the nurses (Andrea: Surgeon)

So it's about their understanding of what we've said and they will then be able to say, well, actually, that's not what she meant or or this is what she said, and they'll say, you know, if they, if they've taken something in a different context or understood it differently (Angela: Oncologist).

The nurses’ role was distinctive in its emphasis on holistic care; however, Athena highlights how providing care that extends beyond illness and medical needs may reflect a means of supporting patients to engage with medical treatment.

…so, part of my training is very much sort of, yeah, looking holistic care, interpersonal skills, all of that sort of thing that was sort of key to it…So, yeah, I think it is fundamental to nursing (Lucy: CNS).

If it’s other things that we think might be influencing their decision so things like housing or childcare, is there anything else that we can maybe help with I suppose, so we would try and maybe tap into those bits as well, um and kind of see them as the whole holistic picture rather than just treatment (Athena: CNS).

5.4. Theme 3: Can’t Win Them All

The third overarching theme saw participants’ emotional responses break through the professional veneer, as participants reconciled their limitations and reflected on their disappointment and the inevitable sadness of oncology. Experience and seniority seemed to help professionals realize that part of the work is making peace with factors that are beyond personal control, although this felt precarious when human life was at stake. The ability to accept patients’ decisions seemed to evolve with experience, as professionals grapple with the extent to which they can influence patient decision-making. Professionals were seen to re-evaluate hopes for work with this patient group, striving to connect with patients and to cultivate conditions in which the patient can safely make the right decision for them.

5.4.1. Subtheme 1: That’s the Job

Although participants identified with a vocational desire to help and cure patients, they understood that this was not always the reality of the job. Participants recognised that they were situated in a system that could not feasibly meet the needs and demands of everyone, which sometimes resulted in death and loss.

So in my job patients die all the time. I had had a medical student with me this morning and he wants to be a surgeon and he was like, well, "how can you do oncology when people die and I take the view that I didn't give them cancer? They are going to die (Edward: Oncologist).

Participants spoke to the pressures of contemporary healthcare and obstacles that needed to be navigated while trying to look after patients. Although these challenges were often personally stressful for participants there was a sense of resignation to this and an acceptance that they had to 'get on with it.'

Yes. But we could always benefit from having more time to do it. So, I think it's, it's difficult for some patients. They need so much support. But it means that we haven't then got time to sort of support others and the sort of quieter ones that go under the radar almost…you know, we have got some of the consultants that are a bit more sort of…I guess sort of open and, you know, look at holistic care a little bit more. But I think, yeah, a lot of them just need to…time is short, and they need to crack on and get sort of treatment organised (Lucy: CNS)

Participants spoke to a process of patients coming to terms with their diagnoses and treatment recommendations, which the cancer did not always allow for. Participants spoke to the frustration of needing to start from scratch when patients reached a point of being able to accept treatment. This was not due to concerns around wasted time and resources, but that the cancer had often taken a non-curative form by that point. Although this was immensely disappointing, participants did not blame patients and recognised that they then needed to work within the options available to the patient.

But of course, our heart sinks when we see that uhm and it's always very disappointing (Angela: Oncologist).

I mean, you just deal with what you're faced with at the time. There's no sort of blame or review of what's happened in the past. They may bring it up, um, but you have to just deal with what's face…facing you right then. (Theresa: Oncologist).

Participants spoke of their human responses to the work and acknowledged that witnessing the decline and deterioration of patients was painful, particularly when there was personal resonance. There was a sense, however, that professionals should not indulge in these human responses as oncology in its nature is often sad. Participants seemed to accept that sadness was a part of their job and something that they coped with by trying to focus on those who they could help.

Um, and of course, you see the young patients, you see the pregnant patients, or people that…that you might, um, you know, just have similar connections within their lives to me, and then…then it makes it so much harder. So, yeah, I think it is…it's, yeah. But then, that's oncology (Theresa: Oncologist).

Um, I suppose we can't let ourselves get upset by it because we have such a volume of patients that we just have to keep going with the ones who are here (Andrea: Surgeon).

5.4.2.Subtheme 2: Patient Choice versus Professional Skill and Influence

Participants seemed to exhibit mixed feelings in terms of the extent to which they could influence the patient's decision-making. While they recognised that their skills and expertise could not negate the particularities of the patient's context and rationale for declining treatment, nor did they suggest that their contributions were completely redundant.

Theresa reflected that consultations with patients who wish to decline treatment became easier for her with time, suggesting that she'd developed strategies for offsetting the initial surprise evoked by patients who decline treatment. She noted that skills in 'reading the patient' are an important part of supporting the patient in decision-making and recognising if patients might be declining treatment because of emotional or information processing difficulties.

…with more experience, do you…and feeling better able to handle the con- …the consultations, you do notice kind of a…patterns in terms of how it goes, maybe, if, you know, if somebody enters or comes to the consultation, maybe, feeling a certain way, can you sometimes have a sense of how it might go, given that you've been doing it a while and you're more used to these patients (Theresa: Oncologist)

the consultation that they have, to start with, with one doctor might be a time that they've just finished their surgery and they're in shock about the…the results, of that they have after their surgery. And so, that they're not really listening at all. And then, you give…you have another chance to speak to them and they're a bit more, um, calm and they can take in the, the facts (Theresa: Oncologist).

Participants recognised the potential impact of proper communication and a trusting relationship, and some enlisted the support of colleagues to reduce the possibility of patients' declining due to a personal misstep or miscalculation.

in that case, yes, I would ask, um them to have a consultation with another colleague of mine because there's this possibility that the outcome is such because, um, we, we don't have the optimal communication and, um, er, the outcome could be different with, er, with the colleague (Sophia: Surgeon).

At the same time, participants also recognised that their skills were no match for deep-seated feelings and beliefs, which did not lend themselves to cancer treatment. Professionals identified a particular cohort of patients who arrived at consultations having already made their decision and with whom it was pointless to engage in debate or persuasion.

So these people have led with a very powerful story, a very powerful narrative in their own life-that chemotherapy is not helpful or useful thing, and it it's that, that *narrative is so powerfully anchored that me telling them this is a different cancer and not all chemotherapy is the same and that times have changed, and technologies have changed, and supportive medicines have changed, will not be enough to shift that very deeply rooted, anchored narrative* (Edward: Oncologist).

Participants accepted that persuading patients to have treatment was not always within the remit of their professional skill and scope; however, they still felt motivated to support these patients and to prioritise aspects of the patient's experience that they could reasonably influence, such as enabling the patient to feel respected and understood.

And you know, I've had that a couple of times and it's been very pleasing where the patient said "well, thank you for that consultation. That's not what I was expecting, I'll go away and think about what you said" and that that for me feels like a really big win (Edward: Oncologist).

5.4.3. Subtheme 3: Learning to Draw the Line

It seemed that professionals' ability to tolerate patients declining treatment evolved with time and experience, as they developed more nuanced understandings of what it means to support patients. Theresa recognised the pressure health professionals experience to do all they can for patients and described a process of learning to step back and recognise when this is not in the patient's best interest

Um, I mean, there's still also, uh…uh…an immense pressure on doctors to…that we've put on ourselves to…to…to feel that, oh, you must be doing everything…I think it is just getting more experienced and, uh, realising that…just understanding the…the population, um, and seeing from experience that…that actually, if they've made up their minds, there's…there's nothing you can do. And, um, I guess, it's just feeling sort of, um, the knowledge that your…that your…that you've done what you can, um, and just accepting that, really (Theresa: Oncologist)

Athena identified this as a learning curve, noting that the pressures to do all one can are often felt more intensely by those who are less experienced or familiar with the oncology environment.

And it's probably, within the team, there's probably a kind of gen-, I don't know, maybe not half and half but there are certainly some people that are just a bit more like yes…we just need to accept this and they will come to us for help if that's what they want and then those who are less experienced who still try to kind of push a bit more, perhaps and less accepting. It's probably experience so just seeing it and realising where, how much you can influence things and where you can't (Athena: CNS).

Participants expressed a willingness to persevere with patients who were on the fence, or who were declining due to personal circumstances but recognised that there comes a point when the only thing left to do is respect the patient's decision.

I think it depends how open the patient is about it, what else they've got going on, you know. If it's somebody with a chaotic life sort of social situation as well, and there may be other reasons that they've missed and whatever, then, you know, you may sort of persevere for longer (Lucy: CNS)

but so they know the whole truth and, um, if they feel comfortable with that decision, I accept it and, um, I'd say if you change your mind, we're going to be here for you, um, we'll be very happy to see you again. But there's no point to, um, keep on discussing and repeating the same things from both sides, and, er, many patients, er, accept this (Sophia: Surgeon).

Developing the ability to accept the patient's decision to decline treatment was discussed as a means of avoiding burnout, as evidenced by Edward who talked about needing to change his standpoint towards these patients for the sake of his own wellbeing.

I think the the crucial change in standpoint that's helped me not be psychologically damaged by these or psychologically injured or burnt out or emotionally distressed by these consultations, is to reach the understanding that it's not about me making this patient make the best decision for their cancer. It's about making sure that that patient has made the best decision for them (Edward: Oncologist).

It seemed that working with patients who declined treatment amounted to a shifting of the goalposts in terms of professionals' hopes for the work. The following quote from Lucy perhaps illustrates a process of deriving alternative meaning in the work with patients who decline treatment-namely the gratification of connecting with and understanding the patient.

So, it's not a failure that we haven't got them to have their surgery or whatever it is. I think it's, it's a failure that I feel, yes, that I haven't been able to just get under the surface a bit more to find out, but, yeah…I think if I could get somebody talking and just explaining what they believe, what is important to them, what they want to do and achieve, then I feel like I've made a real sort of breakthrough (Lucy: CNS).

5.5. Theme Four: The Power and Privilege of Unbiased Expertise

Professionals had insight into factors that underpin decisions to decline breast cancer treatment, but the ability to truly regard these decisions as legitimate was limited by the epistemic privileging of beliefs and practices that emanate from the medical institution, whose ideological basis was obscured due to associations with science. The neutrality of science driven practice legitimised professionals and their recommendations, permitting them to evaluate the rationality of patient choices without referencing the power they hold as purveyors of the scientific evidence, or engaging with the expectations this engenders for patient-professional exchanges. While the interplay between medicine and personal identities was not explicitly referenced, professionals exhibited a sense of ownership over scientific pursuits and frustration at 'bad science' being used to justify treatment refusal.

5.5.1. Subtheme 1: Formulation of Treatment Refusal

Participants shared nuanced and developed hypotheses as to women's reasons for declining treatment which reflected psychological, circumstantial and cultural factors. Participants acknowledged the shock and terror of diagnosis, which propelled some patients into a state of mental collapse in which they were incapable of contemplating treatment. Participants unanimously recognised that breast cancer diagnosis is a psychological assault on many patients' sense of self and the idea of treatments that would jeopardise appearances or lifestyles was intolerable.

I think it's the whole idea of losing their breast. Um, and, I mean, we offer immediate breast reconstruction to a lot of our patients here, but some of them don't even- they don't even get to that stage of considering it, you know, they- for a lot of them it's a step too far. It just- It's- it's too much part of who they are (Andrea: Surgeon).

While diagnosis caused some patients to shut down, professionals identified another cohort who appeared to cope with the destabilisation of diagnosis by holding onto control and refusing to submit to professionals and their treatments. Refusing treatment was an act of resistance in which patients retaliated against a disease which was life-threatening, not only in the mortal sense, but also in terms of the patient's way of life. Edward reflected on a breast cancer diagnosis being particularly challenging for health conscious patients, whose lifestyles were supposedly designed to keep disease at bay. For these patients, the threat of cancer was compounded by the prospect of treatments that were antithetical to their beliefs and way of living, insofar as they were considered unnatural and unhealthy in of themselves. Paradoxically, patients were described as becoming more committed to health beliefs and lifestyles, needing to retain one's sense of self and to regain control by responding to cancer in self-affirming ways.

How could they have got cancer when they're taking such good care of themselves?...if you care and you've been super careful about all of those things and then you get diagnosed with breast cancer, that's a massive injury to your sense of self, to your ego… And so what have you got left where you've got this belief that you can put it right? You weren't able to prevent it? Well, maybe I can now put it right by overcompensating a lot of these things (Edward: Oncologist).

Participants identified that some patients were able to decline treatment due to their relationships with life and death. Certain patients prioritised their quality of life over longevity, viewing death as a natural part of life that did not need to be fought with treatments that would likely lead to suffering. A proportion of women also declined due to factors associated with their individual contexts, such as personal circumstances which complicated the process of undergoing treatment. Culture and religion were major factors that were described as concurrently influencing women's decisions. For women of certain ethnicities, the stigma of cancer was an insurmountable obstacle to treatment, as acceptance of both the diagnosis and treatment would 'out' the person to their community. Participants noticed that the religious beliefs of this patient group were recruited to justify decisions.

for some people that maybe come from more of an African-Caribbean background, there is more of a cultural influence um as to why people might not want to do it, where it's breast cancer is, um, seen as being a real stigma and really negative and bad luck almost as it were amongst that family group. So, there's a real reluctance definitely then for anything that would kind of acknowledge that and then cause them to be really noticeable amongst that, their social group that they were having that treatment or have that diagnosis. So as part of that and into that also comes the religious element as well. So, sometimes there's a strong belief that actually, God will cure it and they don't need any interference from us and they will pray and get their way through that way (Athena: CNS).

5.5.2. Subtheme 2: Levels of Legitimacy

Participants appraised the rationales of women who declined treatment along a spectrum of permissibility, that evaluated decisions on the basis of conformity and performance of ideals like logic and rationality. Throughout interviews, participants made repeated references to the research evidence supporting conventional treatments, which was construed as an objective endorsement that validated the suitability of these measures for helping patients to survive cancer. The availability of evidence that ‘backed up’ professionals’ recommendations eliminated any risk of bias or personal agenda, which added weight to professionals’ recommendations and brought the trustworthiness of alternative practices into question.

clarifying that it’s all based on research and is something that is a proven way of treating and making something better whereas we don’t have the information to say, show basically we could say we’ve – and we do say so lots of people have tried this in the past and it doesn’t work… So we have research data to back up what we're suggesting, whereas usually with complementary therapy, the research data is not there (Angela: Oncologist).

While logic and rationality were indispensable features of sound, intelligible reasoning for participants, they recognised that some patients made choices from belief frameworks that were not structured on such principles. While professionals’ commitment to reason and rationality prevented them from fully understanding or endorsing such choices, they were able to recognise that these women brought different values to their decision-making. Some participants like Lucy were disconcerted by the inability to join up with patients in their thinking, as they wished to truly understand and connect with the patient, while others like Edward recognised that it was not the professional’s place to interfere with or cast aspersions on patients’ beliefs.

when it’s based on a faith or something like that, I think that, that’s really difficult to argue with… so, I think that’s, that’s the…the difference that I think we *probably could be doing more. And could have better understanding, and…you know?* (Lucy: CNS).

We accept that that's their religious belief and and let them hold that belief, and then we work around that…that is a that is a philosophical construct, that is, without my experience and knowledge. So so a belief system that patients engaged in and it is not for me to challenge it (Edward: Oncologist).

In contrast, professionals were less tolerant of decisions that were felt to masquerade at being based on scientific principles, or patients who were seen to have failed in successfully utilising logic to inform their reasoning. While objective evidence was regularly cited as grounds for decision-making, professionals emphasised that not all evidence is created equal, which patients did not always identify when conducting their own research.

when a patient comes to me with scientific, scientific in inverted commas papers they've published off the Internet saying, "oh, this is I've, this shows that this works" and I look at it, and I look at it and say, well, this is a paper from 1973 that was done on some cell lines in petri dishes, it's never progressed any further and I am sharing with you the results of a 6000 patient study that was done two years ago. These are not the same. (Edward: Oncologist).

Professionals understood that patients searched the internet in an attempt to gain control of their situations but felt that this research was more of a hindrance than a help, as internet searches cannot present results in order of scientific authority.

5.5.3. Subtheme 3: The Translucent Lens of the Medical Institution

At times, participants' experiences of working with women who declined treatment seemed to be filtered through the lens of the norms, goals and conventions that they inherited in their capacity as professionals within a system interested in healing sick patients. Participants had accumulated experiences of working with patients who subscribed to this model, and who met the expectations of the system by engaging with professionals and treatments in ways that validated the system’s purpose. Spending a career working with patients who engaged in expected and predictable ways seemed to reify the beliefs and goals of professionals, further adding to the sense that patients who declined treatment were atypical.

that's different to most patients 'cause most patients will come in knowing they're in trouble and they're coming in to find out how they can be helped (Edward: Oncologist).

the first week I started here, um, there were people refusing treatment, um, and yeah, it was…it came as a quite a surprise to me because it was very different from previous hospitals that I’ve worked in (Theresa: Oncologist)

Participants frequently referenced the research and evidence, almost as if to depersonalise their recommendations, yet there were echoes of higher moralistic values around life preservation in their reasoning, which may have been personal, or internalisation of the medical institution’s higher purpose.

I think the thing I find difficult to sort of understand is the patient’s willingness to sort of decline treatment for primary breast cancer where we’re looking at cure… but then will agree once their cancer has spread, and then it’s just palliative treatment. I don’t mind…I think, for me, I’d do it the other way around (Lucy: CNS).

Professionals felt it was their duty to guide and treat patients in line with the evidence which was taken to represent the objective truth. While professionals accepted the patient’s right to their beliefs, there was a sense that these beliefs could not live up to professionals’ evidence which was pure, uncontaminated and indisputable.

Um, and, um, I also say that for all this, er, different mumbo jumbo they, they, they present but, um. there’s no scientific evidence, er, to prove that they work, *um, but of course, they are free to, um, believe what suits them more. This would not stop me from recommending what is appropriate* (Sophia: Surgeon).

There was a sense that professionals were better positioned than patients to read and deliver the scientific evidence, by virtue of their training and position within a multi-disciplinary team, whose support added further weight to the accuracy of the evidence. While the research was often regarded as an objective endorsement of treatments that existed outside of professionals, in the following quote, Edward highlights that truth held within evidence is not always available for everyone, belonging more to the professional than the layperson.

Um, we all know them as they mostly come from the MDM recommendations. So, um, the, not exactly the interpretation, it's not a matter of interpretation (Sophia: Surgeon).

You need you need some degree of scientific understanding, and that's what really irritates me… because that, because they they're using my game, they're playing my game-science and coming up with the wrong answers. (Edward: Oncologist).

While professionals emphasised the patient's entitlement to their beliefs and choices, their position as purveyors of the evidence operated as a form of power in which professionals would inevitably know better than patients who did not have that same access. While some participants made reference to the lingering effects of medical paternalism, the professionals were generally spared from engaging with the power they hold, as it emanated from the neutral entity that is research and scientific evidence.

6.0. DISCUSSION

6.1. Overview

In this chapter, I return to the results and consider them in relation to the pre-existing literature and this study's main objectives; namely to explore participants' experiences of working with women who decline breast cancer treatment in order to understand the unmet needs of both professionals and patients. I have explicitly considered findings within the broader social and healthcare context to illuminate the epistemic assumptions of healthcare culture, which inevitably influence the judgements of healthcare professionals and therefore the experiences of patients whose health beliefs and decisions are situated in other contexts. I offer a critical appraisal of the methodology and make recommendations for future research and practice. I have endeavoured to remain critical throughout and make explicit links to my own position in a concluding, reflective section. In line with the critical-realist ethos, I have endeavoured to draw links between the findings and various theoretical paradigms, recognising that the current analysis reflects an interpretation as opposed to a definitive 'correct' account of participants' experiences.

6.2. Summary of Findings

Findings indicated that the experience of working with women who decline cancer treatment is exceptionally personal, with participants espousing individual hopes and objectives for working with these patients. A patient's decision to decline treatment seemed to be a troubling anomaly that disrupted the traditional model of healthcare provision and necessitated a recalibration of professionals' fundamental desire to help sick and vulnerable patients. Patients' apparent rejection of professionals' services and expertise created a disconnect between patients and professionals, in which it seemed difficult for each to understand the other, or to feel able to make themselves understood. This distance was discussed in terms of contextual differences between patients and professionals which seemed to amount to different, and sometimes incompatible perspectives on cancer and its treatment. Findings showed that participants invoked various strategies for bridging this distance, with some aimed at bringing patients around to professionals' ways of thinking and others oriented towards trying to better understand the patient and their context to arrive at a different understanding of patient needs.

Results indicated that acceptance was a personal journey that professionals undertook throughout their careers, which became easier with time and experience, as they became more realistic about the limits of their influence and the inevitability of death within a cancer setting. This process appeared to be moderated by profession and the extent/nature of the relationship with the patient. All participants recognised patient autonomy, but consultant surgeons and oncologists appeared more secure in delimiting their responsibilities with reference to bioethical commitments. Consultants recognised the value of trust and rapport within the patient-professional relationship, but placed greater emphasis on the patient's right to decide and their duty to support patients in this through the provision of sufficient information and education. The emotional or interpersonal work was delegated to nurses, who were committed to building close relationships with patients and providing holistic support that extended beyond the medical. Nurses' commitment to knowing and understanding patients seemed to underpin a sense of estrangement from women who declined conventional treatments, which was deeply uncomfortable and led to worries of failure, and concerns of women being marginalised by the status quo of healthcare. While participants varied in their sense of personal investment in patient decisions, all professionals were united in their commitment to caring for and supporting patients, and subsequent concern and frustration at vulnerable patients being exploited by alternative therapy providers.

Results indicated that professionals' socialisation within a system that prides itself on scientism had a considerable impact on evaluations of patient choices. While professionals could recognise that patients had complex, nuanced reasons for declining cancer treatment, their ability to forecast patient outcomes by virtue of training and experience, empowered professionals to judge these decisions as irrational. Patients' decisions were considered more or less acceptable depending on the reasoning and beliefs that underpinned them.

While professionals questioned the rationality of patients who drew upon faith as opposed to evidence supported treatments, they were able to respect this entirely different belief system and acknowledged that it was indeed their professional responsibility to do so. In contrast, professionals had great difficulty in accepting decisions to pursue non-proven cancer treatments. While professionals accepted patients' desire to use identity-confirming alternative practices throughout their cancer journey, they struggled to understand how patients who wished to survive cancer could justify relying on treatments that lack a reliable evidence base.

6.3. Findings in Relation to Literature

This section will consider key findings and how they inform understanding of health professionals' experiences of working with women who decline breast cancer treatment. I will make links with the broader literature as appropriate and highlight outstanding issues.

6.3.1. Evaluations of Treatment Refusal

Previous studies examining health professionals' assessments of treatment refusal emphasised reason and rationality as criteria by which professionals evaluated patients' decisions. van Kleffens et al. (2005) suggested that incompatibilities between the goal-oriented reasoning of clinicians and the value- oriented reasoning of patients were such that professionals judged patients' decisions as irrational. Comparatively, this study found that professionals strived to demonstrate openness and tolerance to patient values, recognising this as a professional obligation. Professionals did not necessarily share in patients' values and belief systems, yet they acknowledged that patients were entitled to their beliefs and generally tried to demonstrate respect for this. It seemed that professionals viewed choices as irrational when patients were seen to pursue suboptimal means to their ends, which was sometimes the case for patients who relied on faith, and the belief that their God would deliver them from cancer. While professionals judged these choices as ineffective in terms of realising the patient's goals, they also recognised a professional imperative to respect these beliefs, referring to equality and anti-discrimination law. In these scenarios, professionals were challenged to offset their obligation to inform and educate patients against their duty to respect protected characteristics. These conversations were challenging and some participants identified that they did not feel sufficiently skilled for these discussions. Comparatively, professionals seemed to struggle more with decisions that occurred within belief systems that bore resemblance to that of professionals, such as alternative interventions with presumed physiological effects. Particularly frustrating for professionals was the fact that decisions to pursue alternative therapies were perceived as involving misapplication of valued scientific principles. Professionals admonished the use of alternative therapies in substitute of conventional treatments as the former lacked a comparable evidence base, Again, while professionals showed insight and openness into the psychological factors underpinning such decisions, they were seen as illogical and an ineffective means of goal attainment.

6.3.2 Responses to Treatment Refusal

Previous studies such as van Kleffens et al. (2004) identified that professional responses to treatment refusal were moderated by treatment goals, with physicians making a greater effort to persuade patients who were eligible for curative treatment. In this study, participants seemed to reserve their persuasive efforts for participants who expressed ambivalence or who were seen to decline treatment due to modifiable circumstances. They did not emphasise a distinction between patients who declined curative versus non-curative treatment, but did demonstrate understanding for women who chose to decline treatment on the grounds of wanting to avoid suffering. A decision to reduce one’s lifespan and to live on one’s terms appeared reasonable to participants; however, they emphasised their obligation to ensure that patients fully understood the implications of their decisions. It seemed that professionals could tolerate decisions that would ultimately amount to death provided they felt they had discharged their responsibilities correctly**.** The theme *Head-Heart Lag* captured the tension between professionals’ understanding of their responsibility towards patients who decline treatment in the intellectual sense, and their initial, instinctive responses to women declining treatment. Hardman and Hutchinson (2021) describe the ethical as that which becomes clear to us by the everyday perspectives that we develop as individuals living with one another in society. It appeared that professional commitment to patient autonomy was in competition with the fundamental ethical values inherited from wider society (Radley et al., 2009) which are perhaps more felt, than known. It seemed that this ‘sense’ of treatment refusal being wrong or unnatural undermined certain participants’ security in the patient’s right to choose, which manifested in an imperative to keep the door open for patients, which was also seen as an ethical obligation.

This study was largely concerned with comparing the experiences and responses of professionals from different disciplines. While findings did indicate some discrepancies between the responses of consultants and nurses, seniority and experience were also important contributors to professional responses. Madjar et al. (2007) found that patients who declined treatment sometimes evoked a sense of helplessness in physicians and concerns at having failed the patient. Consultants acknowledged the possibility that patients could decline due to professional misdoing and recognised the value of nurses being present within consultations or colleagues providing a second consultation to mitigate this risk. However, these measures seemed to reflect consultants doing their due diligence, as opposed to genuinely believing that they were the root of patients’ treatment refusal. To the contrary, several consultants spoke to the process of making peace with the patient’s right to decide throughout their careers. The theme *Can’t Win Them All* depicted what is perhaps a lifelong process of professionals developing a tolerance for the inevitable pain and grief of oncology. While professionals identified curing sick patients as their raison d'être, assuming personal responsibility for patient choices was discussed as a characteristic of junior, or perhaps less experienced professionals, who were less accustomed to the oncology environment and driven by their vocational desire to see patients survive. Participants in this study seemed to be at different stages in this process with some internalising patients’ decisions as personal failures and others identifying that the goals of professionals in the business of life prolongation do not always reflect the best interests of the patient. While bioethical principles were often cited as the intellectual framework in which professionals' practice could be justified and defended, it also seemed that professionals developed a different type of intuition throughout their careers, which helped them sense what patients needed, and whether that was for professionals to respect their decisions and let them go. The result seemed to be the establishment of new criteria for the evaluation of their personal practice in which professionals placed emphasis on the interpersonal dimensions of their work including connecting with the patient and supporting them to feel respected and understood.

As suggested by Dhotre et al. (2016) the journey towards acceptance was more challenging for nurses, and consultants in this sample mentioned needing to manage the expectations of nurses and junior doctors in respect of patient decisions. Both consultants and nurses in this sample identified that nurses may experience a stronger vocational desire to see patients survive and thrive, as the nature of the role is such that nurses often spend a lot of time with patients, accompanying them through various stages of a very personal and intimate life journey. It seemed that developing close relationships was of central importance to nurses, which was described as taking precedence over convincing patients to make particular decisions. Again, this appeared to evolve over time, with one nurse identifying that colleagues more experienced than she seemed to experience greater ease in accepting the patient's decision. Although it was painful for nurses to acknowledge that these women were likely to die, there was honour in simply standing by the patient and offering support that reflected the patient's needs and wishes.

6.3.3. Constraints on Patient Centred Care

Patient centred care that respects the individual's beliefs, values and preferences is a cornerstone of NHS health provision (Richards et al., 2015). Previous guidelines hypothesised that cancer professionals avoid conversations around treatment refusal due to uncertainty around the management of such cases, and caution against withdrawing care prematurely on the grounds that a failure to explore patient preferences prevents the full delivery of patient centred care (Dauchy et al., 2017). These recommendations highlight that maintaining supportive relationships with patients who initially decline treatment may create a context in which treatments that are more acceptable to the patient can be considered. Indeed, results of the current study tie in with wider findings demonstrating that patients appreciate having opportunities to share their values and preferences with professionals, provided those beliefs are respected (Kim et al., 2021; van Kleffens et al., 2004). Results of the current study suggested that participants saw value in exploring patients' beliefs and that patients expressed their surprise and appreciation at health professionals being open to their perspectives. However, there was also evidence that some participants evaded explorations of patient beliefs, acknowledging that the patient was entitled to their beliefs and that it was not for the professional to query or challenge. It seemed that professionals avoided such discussions due to fears of being perceived as challenging or judgemental. Indeed, it is possible that professionals could not help feeling slightly judgmental of that which they could not understand, with several participants identifying that they could respect patients' beliefs without necessarily understanding or endorsing them. While consultants expressed interest in understanding patients' beliefs as a means of understanding their opposition to conventional treatment, this was discussed from the standpoint of wanting to correct misconceptions and facilitate the discharging of educational and information sharing responsibilities. It is likely that consultants' reticence to overly engage with patients' contexts and beliefs may reflect different levels of influence which will be discussed below.

6.3.3.1 Limited resources: All participants spoke to the immediate pressures of busy clinics, noting that those who decline, or who are ambivalent about treatment often disrupt normal proceedings. Madjar et al. (2007) reported that physicians described those who were not immediately amenable to medical recommendations as difficult patients who required extra time. In this study, patients who required extra time were not necessarily described as being difficult or irrational; however, there was a sense of frustration at patients using clinical resources outside of their intended purposes and for in-depth discussion of alternative therapies. Participants also noted that clinics were intended for patients undergoing treatment and that they could not allow patients to use consultations as a deliberative space indefinitely. The nurses in this study identified a particular cohort of women who required a lot of support and reassurance from their doctors, but noted that clinic design did not always permit expansive dialogue as consultants need to ensure that patients fully understand the diagnosis and treatment recommendations within the time allotment. This reflects other work examining oncologists' accounts of barriers to psychosocial communication (Fagerlind et al., 2013). Participants in this study also identified concerns about being incapable of addressing identified problems as a barrier to such communication, suggesting a lack of confidence in one's ability to support patients outside of their medical needs. While consultants in the current study did not explicitly doubt their capacity to be a source of 'holistic' support for patients, there was a sense that nurses were better positioned to deliver this, perhaps due to their assumed interpersonal competence, their access to resources such as financial and housing assistance, or the expectation that patients would simply feel more comfortable receiving such support from nurses.

The perception of the breast care nurse role as expansive and wide-ranging (Jones et al., 2010) is interesting when juxtaposed with that of the surgeon and oncologist, which are inevitably narrower, given their specialist nature. While consultants in the current study identified that they operated from a place of care and compassion, this did not manifest in a desire to support patients in multiple life domains as was the case with nurses, but rather within the enactment of a specialist role in which they imparted their clinical experience and expertise. Indeed, this may have underpinned consultants' sense of frustration with patients who used consultations to explore alternative therapies, and who were perhaps perceived as pressing consultants to offer support outside of their specific designation. Insofar as consultants' skills are considered more specialist, and therefore less readily available, it stands to reason that they may negotiate their responsibilities on the basis of what they provide that other colleagues do not. While consultants understood the value of exploring patient beliefs, they perhaps felt it necessary to prioritise education and information sharing in a time-limited context that does not necessarily cater for all dimensions of patient need.

6.3.3.2. The socialisation and training of professionals: The theme *The Power and Privilege of Unbiased Expertise* evidenced how conceptions of expertise and therefore of professional responsibilities and priorities, were heavily bound up in values that characterise science and the medical institution such as objectivity, impartiality and rationality. Professionals were emphatic in their responsibility to relay the facts and the evidence which invariably reflected the professional's answer to the patient's problem. The objectivity of the evidence seemed to obscure the idea of professionals and patients holding particular perspectives within interactions, as professionals' opinions were substantiated by evidence while patients' positions were based on conjecture. Indeed, during interviews participants did not identify as proponents of a certain school of thought, but purveyors of the objective truth which existed outside of them within the data of clinical trials. This observation represents a vulnerability identified by Hardman et al. (2021) whereby the training and socialisation of health professionals operate to obfuscate the value base of seemingly objective evidence, and therefore the inevitable links between the medical and the personal. The authors acknowledge that data and values are irrevocably interwoven, with values that are grounded in wider socio-political contexts often determining that which is treated as medical fact. Indeed, while participants acknowledged contextual aspects of service provision such as bureaucratic, socio-political constraints (like NHS targets) the research evidence was generally discussed as impenetrable and without agenda. Moreover, there was a sense that patients who acknowledged the wider context and queried the integrity of the evidence base were considered radical, or perhaps not sufficiently skilled in reading the evidence.

The predilection to separate the medical and the personal may also be reflected in nurses' observations that some consultants tended not to engage with the patient's wider psychosocial context, preferring to focus on that which they considered their designation-namely the medical. Delimiting professional responsibility to the mechanical correction of malfunctioning bodies has previously been discussed as a means of health professionals (particularly surgeons) gaining emotional distance from the person upon which they operate to cope with the immense responsibility of human life; (Brown, 2016) however, it has also been argued to reflect the lingering effects of Cartesian dualism and the separation of the physical and mental (Mehta, 2011). The overhang of dualism can be similarly identified within the EBM paradigm, which has persisted in its privileging of controlled, impartial evidence despite increased calls for professionals to make diagnoses in biopsychosocial terms which are personal to the patient, and so cannot be impartial (Evans, 2003). Evans (2003) argues that the devaluation of evidence which exists at the lower levels of the hierarchy serves to reproduce scientific rationalism as the epistemological framework in which patient centred care is delivered, despite being predominantly concerned with a single dimension of patient health. Evans (2003) argues that the medical institution's commitment to rationalism amounts to patient centred care remaining a conceptual ideal as opposed to a practical reality, as the scope of its aims are limited to that which can only be addressed and understood with logic and reason, which may not encapsulate the experiences and worldviews of patients. Carel and Kidd (2014) warned that the uncritical privileging of a medical perspective can translate into epistemic injustice with tangible and deleterious implications for patients, if the emphasis on gathering medical information precludes listening for, or hearing other important information within patient testimony. Indeed, such arguments map onto the current findings and nurses' concerns of certain women being marginalised by the status quo of contemporary healthcare.

Foucault (1961) lamented the modern physicians' abandonment of their moral role, suggesting that they instead undertook the position of the "enlightened scientific entrepreneur" (Gold, 1985, p. 663). While professionals in the current sample engaged with the moral and ethical aspects of their role, these too seemed to be grounded in rationalist foundations. Indeed, the ability to relegate one's emotional responses with reference to bioethical principles was a skill that clinicians seemed to acquire throughout their careers. Ethical responsibilities towards patients were similarly viewed in the intellectual sense and construed as the imperative to recognise patients' autonomy by supporting them in shared decision-making that is facilitated through education and information sharing, as opposed to being concerned with the social or relational dimensions of decision-making. Saunders (2000) makes the point that science requires personal participation in knowledge, implying a sense of personal identification with the knowledge base to which one is affiliated. It seemed that participants' membership within an institution predicated on rationalism and objectivity precluded this identification, and served to obscure the epistemic privilege that professionals enjoy as members of a dominant institution. This was discussed as being problematic when working with patients whose contrary beliefs and value systems provoked distrust and suspicion of the medical institution which will now be considered.

6.3.4. Distrust and Disillusionment

Participants discussed women's distrust and dissatisfaction with conventional, western medicine as a significant factor within women's decisions to decline breast cancer treatment. The theme *Tug of War* saw participants reflect on efforts to mitigate the sense of estrangement from women, who were either suspicious of professionals and their treatments, or whose models of health and illness did not align with that of scientific medicine. Participants' reflections suggested that some women resented needing to submit to health professionals within the public healthcare system, believing that better and safer treatments exist that transcend the outdated archaism of the medical institution. Such distrust in the medical institution has been discussed as a retaliation against the dubious history of scientific medicine and its treatment of women and people of the global majority (Shahvisi, 2019). The social power of the medical institution has rendered it prone to historical, moral failures and women's trust in conventional medicine continues to be challenged by systemic discrimination and medicine's failure in meeting the differential needs of women's bodies. For instance, gendered inequalities are widely documented within medical research and clinical encounters (Annandale & Hunt, 2000) with physicians diminishing or discrediting women's reports of pain, or inappropriately attributing pain to mental health issues (Hoffmann & Tarzian, 2001). Women's health problems are also more likely to be attributed to psychological, as opposed to physical, causes. For instance, Hamberg et al. (2004) found that women with irritable bowel syndrome were more likely to be offered sedatives and lifestyle advice, compared to men who were more likely to be offered X-ray imaging.

Participants reflected that certain women who declined treatment felt lost to them. Indeed, Meyer and Ward (2008) note that trust in the expertise of healthcare professionals has declined in recent decades, with questions of trustworthiness being raised in international media, when musician Kylie Minogue urged women to trust their intuition after doctors' initial failure to diagnose her breast cancer. The advent of alternative medicine is thought to reflect the evolution of feminist ideologies that push back against the power of dominant, patriarchal, institutions that oppress the voices and interests of minorities (Astin, 1998). Alternative therapies are assumed to espouse qualities that are emblematic of normative femininity, such as being caring and gentle, taking emotions seriously, and seeking to care for, as opposed to cure (Shahvisi, 2019). The holistic approach is thought to appeal to women because it legitimises the relationality that is considered stereotypically feminine, while also validating notions of self-care which subvert the nurturer stereotype and encourage women to prioritise their own wellbeing (Sointu & Woodhead, 2008).

There is an abundance of research indicating that alternative medicine use is associated with poor experiences of conventional healthcare ranging from iatrogenic effects of long-term medication use to dissatisfaction with the doctor-patient relationship (Shahvisi, 2019). Importantly, alternative medicine is often described by users as being more personalised which is a positive aspect of the experience and likely to underscore preferences for such therapies. For instance, Jacobs et al. (1998) reported that homoeopaths in the United States spent twice as long with patients as medical doctors, suggesting that alternative practitioners could potentially provide the additional time and support that was untenable for professionals in the current study, due to resource and time constraints.

Participants in the current study also identified another form of distrust that was considered specifically cultural, and reflected difficulties among women of certain ethnicities in trusting health professionals and western medicine. Professionals described chaplaincy as particularly valuable for working with women of West African heritage whom they otherwise would have struggled to connect with. While there is an undisputed history of medical racism and abuses against individuals of the global majority internationally (Jacobs et al., 1998) fear and distrust of the medical institution in West Africa has been specifically discussed in relation to the 2013-2016 Ebola virus epidemic, when medical power was yielded against communities in the outlawing of culturally valued burial rituals (Furman, 2020). An anthropologist working in Guinea during the epidemic shared the following testimony from an interviewee, who speaks to the sense of powerless and fear experienced at the hands of professionals who by all accounts intended to help and heal "We are afraid of the disease, but are also afraid of all those who come to us to make us aware of it, track contacts or take away the ill" (Anoko, 2014, p.11). Professionals in this study reported immense difficulties in cultivating relationships in which West African women could 'open up' and communicate their rationales for declining treatment. While research has demonstrated that issues such as the first language of the patient and healthcare provider can impact perceptions of trustworthiness (Sheppard et al., 2016) it is also possible that nurses' observations of patients' guardedness could reflect broader difficulties, and the traumatic experiences that teach patients to feel unsafe in the care of western health professionals.

6.4. Clinical Implications

Results indicated that participants in the current study were aware of the limitations of certain practices, but were unsure of how such issues could be overcome. The following section will consider contemporary frameworks for healthcare provision that have been discussed as a means of overcoming some of the issues that participants discussed during interviews.

6.4.1. Support for Health Professionals

Encouragingly, the COVID-19 pandemic has directed attention to the needs of healthcare professionals which is important context given the distress and dissonance reported by participants, with results indicating that professionals can experience uncertainty and turmoil related to patients' decisions to decline treatment, which they may not feel justified in expressing, due to perceptions that sadness and loss are something to be endured in oncology settings. While NHS England has taken steps in recent years to implement support structures to promote the health and wellbeing of staff (*Support for Healthcare Staff - NHS Resolution*, n.d.) there seemed to be a marked lack of official support for professionals in this sample. For instance, there was a lack of official guidelines and protocols for managing treatment refusal, with participants referencing colleagues as a main source of ad hoc support in terms of agreeing to work with patients in substitute of the professional who was experiencing difficulties, offering alternative forms of support such as spiritual care, or from a learning standpoint and observing how other colleagues navigated such situations. It was noteworthy that participants did not appear to have access to any form of reflective or supervisory spaces, particularly given the heavily interpersonal dimensions of the work, and the embeddedness of clinical supervision in professions such as social work and psychology. Results demonstrated that patients who decline treatment can trigger uncertainty and insecurity, that may become easier to manage with time; however, it is highly likely that the health professionals' wellbeing may be compromised within this process of acclimatisation. Supervision and reflective practice may represent a means of offsetting these risks by providing space for health professionals to safely experience emotions which are 'part of the job' but a reality nonetheless. Such spaces may also provide a means for MDT health professionals to collectively consider individual approaches to treatment refusal and what those mean for patient care. Beyond supporting staff in the exceptionally challenging work of supporting cancer patients, reflective practice and supervision may also represent a means of supporting health care professionals to develop the reflexive skills described by (Charon, 2001).

6.4.2. Narrative Medicine and Competence

Dieppe et al. (2002) contended that it can seem as though the NHS is overheating through chaotic attempts to accommodate patient centred care, while practising EBM and evaluating the effectiveness and efficiency of its activity. While patient centred care and EBM that integrates patient values (Kelly et al., 2015) are in theory, complementary practices, current results speak to the difficulties in honouring both charges within breast cancer care. A noteworthy finding was that consultants privileged principles of rationality within their delivery of patient centred care, prioritising their duties to support shared decision-making. However, there is evidence that women with breast cancer want relationships in which they can communicate about emotional issues with doctors (Wright et al., 2004). Hardman et al. (2021) argue that medical professionals' specialist knowledge can sometimes result in clinical situations being regarded in exclusively biological terms, which side-line the human elements of the exchange. The field of narrative medicine has been proffered in response to the shortcomings of this tendency, defined as a medicine that is imbued with respect for the narrative dimensions of illness and caregiving (Charon, 2001). This framework privileges the relational and technical aspects of the clinician's skillset noting that an exclusively scientific medicine cannot help the patients to navigate lived aspects of illness such as grief for the loss of health or deriving meaning from suffering. Charon (2001) contends that physicians' scientific and technical abilities need to be matched by their ability to listen to patients' narratives, understand and honour their meanings and to be moved to act on the patient's behalf.

As a helping enterprise, medicine is necessarily grounded in the intersubjective and interpersonal, yet the rationalism of medicine often invokes a medical practice of ‘detached concern’ (Fox & Lief, 1963). This was evident in the current participants’ attempts to limit their emotional responses to patient decisions, acknowledging that vulnerable feelings could not be allowed to interfere with the work. Narrative medicine strives to invert this and to develop clinicians that bring their humanity and reflexivity to the clinical encounter, recognising that skills in telling and listening to stories of illness are becoming increasingly important in an economic climate that constrains the time available for dialogue. In such contexts, Charon argues, it is imperative that medical training privileges skills which can support professionals to nurture empathic, therapeutic relationships alongside the development of technical skills and knowledge. While narrative medicine arguably emphasises attributes which all clinicians possess-namely the ability to be human, it is important to note that narrative competence represents a departure from the certainty and security of scientific knowledge. Bearing witness to stories of illness and realising that there are no clear solutions to patients’ existential questions requires immense courage and generosity (Weine, 1996). However, Charon argues that acts of witnessing support the clinician to effectively progress through the stereotypically medical tasks of diagnosis and treatment, and is therefore irrevocably entwined in the delivery of effective care.

Narrative medicine arguably proposes an ideal of care that could still function to support women who decline cancer treatment; however, its efficacy and uptake is contingent on professionals’ perceptions of their roles and responsibilities. For instance, Evans (2003) queries whether the clinician should be confined to evidence-based interventions and leave the existential aspects to someone more suitably qualified. I would argue that patients’ lived experiences are not delimited by the professionals they see. In making a case for the promotion of narrative competence I do no suggest that health professionals should also serve as counsellors, chaplains or psychologists but rather for a culture that permits and supports professionals to privilege the relationship with the patient due to its intrinsic value, and not just as a means to an end. In this way, narrative competence may provide a means for professionals to be alongside patients in all aspects of their illness experience.

6.4.3. Cultural Competence

Nurses' observations of the benefits of chaplaincy and spiritual care underscore the idea that professionals cannot and should not be expected to undertake responsibility for all aspects of patients' psychosocial wellbeing. While distrust in the medical institution remains, resources like spiritual care and peer support that sit outside of the medical system may be particularly helpful for patients (Taleghani et al., 2012). However, nurses' appreciation of chaplaincy and spiritual care also reflected their broader concerns and confidence in working with cultural difference, with particular reference in this instance to ethnicity. Indeed such concerns are valid given evidence that women of the global majority in the UK are more likely to present with more advanced cancers and to be missed in breast screenings (Brennan, 2017). Cultural competence has been extensively discussed as a framework for promoting inclusive practice and generally refers to the capacity of systems, agencies and practitioners to respond to the unique needs of populations whose cultures vary from that which might be considered dominant (Cross, 1989). In practice, cultural competence is vaguely defined and poorly understood, which has generated confusion and controversy around the construct, with many questioning its utility or ability to address structural problems and inequalities (George, 2015).

Proficiency-based conceptualisations of cultural competence are evident within cultural diversity training programmes which have been implemented with some success in the UK, whereby health professionals have reported increased awareness, confidence and ability to care for minoritized populations (Chevannes, 2002). Similarly in the USA, cultural competence training has been associated with increased satisfaction among patients of the global majority (Govere & Govere, 2016). Research into the psychosocial impact of breast cancer diagnosis and treatment in black and south Asian women in the UK has indicated that such training may indeed improve women's experiences of breast cancer care, highlighting cultural values that health professionals might not necessarily consider, such as expectations around modesty that could increase feelings of discomfort around medical examination (Patel-Kerai et al., 2016).

Although undeniably influential, the notion of cultural competence has been a source of contention, in part due to recognition that it is not possible to be truly competent in another's culture, and concerns that it reflects a top-down approach in which individuals who are often highly educated and privileged determine the content and criteria by which competence in a marginalised group's culture is evaluated (Greene-Moton & Minkler, 2020). Moreover, it has also been argued that training which increases professionals' familiarity with the norms and values of marginalised groups does little to address the structures which perpetuate the subjugation of minorities (Danso, 2018). It has been suggested that multicultural medical education must extend beyond traditional conceptions of competency as knowledge and skills, towards a critical consciousness in which awareness of the self, others and the world drives a commitment to addressing issues of societal relevance in healthcare (Kumagai & Lypson, 2009). I would argue that both cultural competence and critical consciousness are indispensable strategies for addressing health inequalities, which perhaps reflect short and long term solutions. In the short-term, cultural competence may facilitate care provision that respects the particularities of various cultures, which when combined with critical consciousness, can be seen as an entry point for transforming health systems from the inside out. Such efforts will inevitably need to look beyond individuals and consider how health systems can be designed with the interests of oppressed groups embedded within.

6.5. Future Research

This research has provided insights into ways in which health professionals understand women's reasons for declining cancer, and has shed light on how participants of various professions delimit and discharge their duties towards patients. However, healthcare provision occurs within relationships between patients and providers, hence exploring the experiences of women who decline treatment will be essential to fully contextualise and understand the implications of current findings. For instance, the current study indicated that consultants subscribe to a rationalist model of patient centred care whereas nurses' vocational instincts prompted an extension of care into psychosocial realms. Previous authors identified the risk of assuming that patients who decline treatment do not want support (Giorgi & Bascioni, 2012) and current results indicated that women may eventually feel able to accept conventional treatment if they feel respected and understood. Research into the support preferences of women who decline treatment may illuminate this group's healthcare needs and perhaps inform understanding of the utility of concepts such as patient centred care in its current form. This work has expanded on the previous literature by highlighting the operations of intersectionality (Crenshaw, 2016) within treatment refusal and the risk of women who are already marginalised within healthcare declining treatment. Future research into cultural barriers to contemporary healthcare arguably represents an essential element of the critical consciousness strategy referenced above; however, such work would need to be undertaken in collaboration with target populations through co-production or in partnership with community leaders.

Previous research has indicated that differential preferences for quality of life and longevity are also moderated by patient circumstances, with family and dependents typically constituting a predictive factor in terms of a preference for a longer life (Kim et al., 2021; Stiggelbout et al., 2007). At points, it was evident that participants' evaluations of patients' decisions also reflected gendered ideas about women's responsibilities to families or children which made it harder for participants to understand and accept patients' positions. Participants did not reference patients' interpersonal circumstances as a moderator of responses towards women who decline; however, it is possible that discomfort at the idea of mothers declining lifesaving treatment could impact professional conduct and demeanour. Research examining health professionals' responses to treatment refusal in the context of male cancers, or those which affect both genders would be useful to disentangle the contribution of gender roles to health professionals' responses to treatment refusal.

Finally, both previous research and current findings indicate that trust within the patient-professional relationship is an important factor in women feeling respected by healthcare professionals and free to make their own decisions;

(Kim et al., 2021; van Kleffens et al., 2004) however, this study cannot discern how this is cultivated beyond the self-report of participants in the current sample. While it is unlikely that establishing trusting relationships can be reduced down to specific guidelines or instructions, an ethnographic approach in which the live interactions of healthcare professionals and women who decline treatment may allow for a more detailed understanding of behaviours which support or inhibit trusting relationships. Co-producing such research alongside women who have declined medical treatments may represent a useful means of establishing the criteria by which such interactions can be assessed and analysed.

6.6. Critical Evaluation

As with all research, this study must be considered in the context of its strengths and limitations. A strength of this study is that it has created opportunities for understanding ways in which contemporary breast care teams respond to women who decline breast cancer treatment, particularly in terms of eliciting surgeons’ perspectives given that this profession has been neglected in the extant literature. Given previous work in this area, it was deemed appropriate to conduct individual interviews with professionals of various disciplines to parse out the commonalities and discrepancies in responses. While it was useful to explore professionals’ sense of their multidisciplinary colleagues’ perspectives, such data is inevitably speculative meaning that the individual interview format did not permit full understanding of team operations and dynamics. A focus group approach in which all professionals could collectively speak to their experiences of treatment refusal may have yielded different results and provided a stronger sense of overlapping and contrasting areas; however, this poses particular issues in terms of recruitment and the need to consider power dynamics among professionals working in the same teams.

In a similar vein, it is important to acknowledge the implications of sampling and selection for results. All participants participated on a voluntary basis with many expressing that they had agreed to do so because treatment refusal was an area of professional concern and interest. As previously identified (see section 1.1.) this study was partially motivated by my experiences of working in a psycho-oncology team in which colleagues felt concerned that the likability of women who declined treatment may have been impacting their care. While current results indicated that professionals often understood antagonism as a manifestation of the fear and shock of cancer, the views of current participants cannot necessarily be assumed to reflect the perspectives of health professionals across the board, particularly given the consensus around gender bias and discrimination within medical training and healthcare provision (Crenshaw, 2016). Participants were gracious in volunteering their time for interviews, which was sometimes challenging given work commitments and clinics running overtime. A survey based study examining health professionals' attitudes towards women who decline cancer may represent an opportunity for future work to gather more data and establish a 'bird's eye view.'

The sample size of eight interviews is acceptable according to Weiss, (1995) however, this could be viewed as relatively small, particularly as the sample represented individuals of different professions. I would have liked to continue interviewing to further explore whether professional responses were moderated by discipline, but unfortunately, this was not possible within the time constraints of the thesis. It is also important to note the demographic constellation of this sample as all participants but one identified as female and were of European heritage. The ethnic homogeneity of the current sample is not in keeping with recent NHS workforce statistics (Milner et al., 2020) and therefore caution should be exercised when taking current findings to inform our understanding of responses to treatment refusal within the wider NHS. The homogeneity of the current sample is, however, interesting when considered against reported difficulties in working with women of certain cultures and ethnicities. It is possible that a more diverse sample would have yielded different insights into this phenomenon, but it is unclear whether sample composition reflected issues of a homogenous workforce, racialised staff not feeling motivated to participate in the study or a mere coincidence. In a study of the psychosocial impact of breast cancer diagnosis and treatment in Black and south Asian women, Patel (2013) called for recruitment programmes that reflect the diversity of local communities, which may indeed go some distance in terms of improving equity of access, and is also applicable to research aimed at improving healthcare provision. However, it is also important that racialised staff are not automatically expected to engage in the additional labour of furthering the anti-racist healthcare agenda. As mentioned in section 5.5.2. this work must reflect the long term goal of NHS healthcare, which is shared by all.

I was acutely aware of my own positioning within this research process, which was particularly apparent when transcribing interviews, as watching recorded interviews allowed me to assess my own contributions to interviews from the outside. At points, I was aware that I had veered away from the specific questions identified in my interview protocol when I was surprised by participants’ stories or became distracted by my own curiosity. However, on reflection, I can recognise this as a valuable side effect of research that is interactional and that can open up opportunities for previously unconsidered lines of enquiry. I have reflected on how participants may have perceived me as a relatively young white woman and the assumptions that they may have held about me and my reasons for conducting this research. I have considered the impact of my context as a trainee health professional and what that meant for my conversations with participants and what they felt comfortable sharing. While questions included in the interview schedule were intended to be as neutral and non-directive as possible, I was conscious that both myself and the participants are likely to be heavily socialised by the cultures of our respective professions, which is likely to have shaped the questions I asked, and what they shared in their answers.

6.6.1 Quality Assessment

The notion of quality in qualitative research is contentious as the inherent subjectivity of qualitative work does not necessarily lend itself to the establishment of formal evaluative criteria that can be applied to all forms of qualitative research as standard. There are several frameworks for assessing the quality of qualitative research in psychology; however, as space limitations do not permit consideration of each, I will outline Yardley's (2000) criteria and consider their implications the quality of this study.

1. *Sensitivity to context:* Qualitative research highlights the importance of context, both in terms of the researcher and their personal relationship with the subject and the wider socio-cultural context in which the research is taking place. Throughout this thesis I have attempted to provide a context for the research questions, acknowledging conventions of breast cancer care in the UK and situating treatment refusal as a phenomenon within a wider socio-political context that is characterised by disenchantment with dominant institutions and women's desire to have more autonomy and choice within healthcare. I stipulated my context and motivations for undertaking this research from the outset and used a reflective diary (see Appendix N) and field notes throughout this work. This, in addition to regular supervision, has helped me to externalise my own thoughts and assumptions and consider how they have impacted on findings.
2. *Commitment and rigour*: This study was designed and conducted over a three year period during which time I was fully immersed in the topic, by conducting a scoping literature review and having regular discussions with both my research supervisor and a psycho-oncology associate who supported the development of this project. The research questions were developed over a year-long period after several iterations that were refined and revised through detailed engagement with the extant literature base. Having the support of an academic supervisor and a clinical supervisor who is situated in a psycho-oncology context allowed me to design a study that was theoretically viable and operationally feasible, Frequent supervision was also provided during the execution of this study which provided invaluable opportunities to refine my interviewing technique and continuously hold the study's aims and objectives in mind.
3. *Transparency and coherence:* Reflexivity within qualitative work refers to a process of interrogating one's own context and monitoring how our beliefs, values and assumptions play out in the research process.

Reflexivity enhances the quality of research by allowing the researcher to name their influences and consider how these will shape all aspects of the research from initial engagement with the literature to developing research questions and reporting results. I have been conscious of the beliefs and experiences which have come to bear on this research, including a sense of affinity with medical professions to which my family members belong, juxtaposed with my own values around challenging the oppressive structures of dominant institutions. I have shared my previous experiences of working in psycho-oncology to give both the reader and participants a sense of how I came to be interested in this topic and have written parts of this thesis in the first person at points when it was important to emphasise my opinions and beliefs. Similarly, I have been explicit about the recruitment strategy used for this study and acknowledged the implications of interviewing participants who may have been aware that colleagues were also participating in the study. Finally, I have documented all stages in the development and refinement of the analysis (see Appendix M and O).

4. *Impact and importance*: Discussions with my supervisor and clinicians working within a pyscho-oncology setting ensured that the value of this study was continuously reviewed against the theoretical and practical requirements of the thesis. In the discussion chapter, I have endeavoured to communicate the relevance of findings and to offer tangible short and long term suggestions with regards to current findings and how they may inform the development of clinical practice and future research. I have been careful to acknowledge the wider context of this research, including the philosophical orientation that characterises science and the medical institution and not to insinuate that clinical recommendations reflect the shortcomings of individual health professionals. I have agreed to return to the services where participants work to disseminate findings, and hope to later publish the study to support the process of research contributing to knowledge and informing professional practice and policy.

6.7. Reflection

At the beginning of this research process, I was conscious of the assumptions and judgements that I held about health professionals, perhaps due to my own context, and perception that my profession was sometimes devalued by those whom I would expect to be proponents of the ‘harder sciences’. Having received teaching in philosophy of science I noticed a sense of infuriation at the single-mindedness of a health system which only recognises specific forms of evidence. However, I also acknowledged my privilege in receiving this teaching and my frustration was juxtaposed with respect for the work of health professionals, and an appreciation of their need to immerse themselves in the clinical situation as opposed to the philosophical literature.

Reflecting back on the earlier stages of data collection, I realise that a part of me was expecting participants to embody their stereotypes and to present as dispassionate practitioners who worked with bodies and not people. I realised that I was carrying the concerns of those who were supporting me in the research, and was anticipating to meet with participants who emulated their stereotypes. I could not have been more wrong. Throughout interviews, I was struck by the level of thought and concern that professionals expressed for their patients and their detailed analyses of patients’ reasons for declining treatment. I noticed that professionals’ concerns took different forms, often according to discipline and varied perceptions of responsibilities towards patients. I noticed that I felt more affinity with nurses, who seemed to bring the emotional parts of themselves into their work to a greater extent.

I realised that I held an image of health professionals as beaten down by the demands of NHS working, and was moved to listen to the accounts of health professionals who were very clearly driven by their commitment to patients. During the analysis, I noticed feelings of guilt as I implicated professionals’ socialisation within the current findings, as I did want to do a disservice to the participants who were very obviously committed to their patients, as evidenced in their willingness to go outside of their usual roles and participate in this research. In the latter stages of the research, I have felt overwhelmed by the seemingly impenetrable nature of conventions within the medical institution and wondered how these findings could amount to better experiences for women who decline breast cancer treatment. However, it has been encouraging to explore a literature concerned with expanding the boundaries of medical practice and patient care. Having met with the current sample of health professionals, I feel similarly restored in the knowledge that there are individuals who are both aware, and concerned by their professional limitations and who I believe would be committed to taking forward change that could benefit the patients they serve.

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8.0. APPENDICES

Appendix A: Summary Table to Scoping Review Papers

Table 1

Summary table of Scoping Review Papers

Authors	Title	Country	Sample	Method	Key Findings
Citrin et al.(2012)	Beliefs and Perceptions of Women with Newly Diagnosed Breast Cancer Who Refused Conventional Treatment in Favour of Alternative Therapies	USA	30 women with breast cancer who accepted treatment and 30 who declined	Qualitative Interviews	Those who declined believed that chemotherapy and radiotherapy were riskier and less beneficial (compared to those who accepted) Those who declined treatment believed they could heal themselves naturally from cancer with holistic methods Participants identified that a better first experience with their physicians might have made a difference to their treatment choices. They may have been more likely to accept conventional treatment if they had felt that their physicians were caring, understood their fears and communicated hope, and allowed them time to adjust to the news of diagnosis before starting treatment.

Van Kleffens & Van Leeuwen (2005)	Physicians' Evaluations of Patients' Decisions to Refuse Oncological Treatment	The Netherlands	30 cancer patients, 16 physicians (oncologists and GPs)	Qualitative Interviews	Physicians mainly use goal oriented reasoning whereas patients mostly used value oriented reasoning, except in the case of non-curative treatment refusal in which physicians give more emphasis to value oriented rationality. The physician's acceptance was crucial to his or her attitude towards the patient. It contributed to the patient's sense of being free to decide, being understood and respected, and thus to a better physician–patient relationship
Carlson (2014)	Understanding the Emotions of Patients Who Refuse Treatment	USA	N/A	Academic/reflective Essay	Clinical care guidelines are not always appropriate in situations that call for personalized care. Decision making is influenced by multiple factors that extend beyond the disease and its stage. Important to explore emotions or factors that drive decisions
Huijer & Van Leeuwen (2000)	Personal values and cancer treatment refusal	The Netherlands	3 oncologists and 3 patients with advanced breast and ovarian cancer who had prior experience of chemotherapy	Interviews (Grounded theory) Pilot study explores the moral reasons patients have for refusing chemotherapy, the ways oncologists respond, and how physicians and	4 categories identified 1. Weighing the pros and cons of chemotherapy: instances in which the cons outweighed the pros were interpreted as a rational and reasonable grounds for declining treatment 2. The patient's context-limited exploration of patients' contexts by oncologists 3. Good reasons-patients needed to have 'good reasons' (i.e. reasons that made medical

				patients communicate about them.	4. sense) for their decision to be considered rational 5. Communication on treatment refusals.
Frenkel (2013)	Refusing Treatment	USA/Israel	Family physician who integrates complementary approaches within practice	Academic/reflective essay	Patients who decline conventional treatment are sometimes experienced as ‘difficult’ Reported cases in which oncologists have advised that there was no reason for the patient to continue seeing them if the patient was not going to have chemotherapy Patients may decline treatment due to fear of side effects, uncertainty about effectiveness, hopelessness, helplessness, loss of control, mental health difficulties, dysfunction in the health care system, and, above all, issues surrounding communication and the patient–physician relationship It may not always be easy for clinicians to deal with these type of patients as they deviate from the norm and challenge current evidence
Verhoef et al. (2008)	Declining conventional cancer treatment and using complementary and alternative medicine: a problem or a challenge?	Canada	29 Prostate Cancer Patients 33 breast cancer patients	Qualitative interviews examining how cancer patients made decisions about declining conventional treatment and pursuing	Patients make informed choices based on personal experience, scientific evidence, medical literature, anecdotal information) Important for individuals to find a treatment consistent with health beliefs-having control and a healing orientation was considered important

				alternative treatment	Beliefs about conventional medicine, cancer and alternative approaches informed decision making. Physical, emotional, spiritual, and whole-person outcomes of treatment were all considered important indicators of treatment success. Participants indicated that they valued the ongoing follow-up care from their oncologists provided that they felt supported in their health beliefs. Participants preferred to take an active role and to make the final decision after seriously considering the opinions of their doctors
Verhoef & White (2002)	Factors in making the decision to forgo conventional cancer treatment	Canada	31 individuals with various cancers. 12 refused all conventional treatment, 13 refused most or some of the treatments recommended, and 6 discontinued conventional treatment.	Qualitative study using focus groups and interviews	Factors associated with the decision to decline treatment included 1. Knowing someone who suffered through cancer treatment, but was not cured 2. Experiences of diagnosis: the shock and fear of diagnosis made it difficult for participants to consider undergoing toxic treatments with significant side effects. Participants also referenced feeling rushed or pressured as part of their motivation for pursuing alternatives. 3. Participants experiences of doctors were also influential within decision making; some participants felt that doctors used ‘scare tactics’ to convince them to accept conventional treatment 4. A need for control and believing that alternative treatments would positively influence the disease trajectory contributed to decision making

Zörgő & Mkhitaryan (2020)	Factors underlying the use of non-conventional medicine and forgoing biomedical treatment among patients with cancer – Recommendations for doctor-patient communication	Hungary	N/A	Literature review and Recommendations for Doctor-Patient communication	Patients are increasingly forgoing biomedicine in favour of non-conventional treatment modalities The use of complementary or alternative medicine may reflect preferences for natural cures and beliefs of illness causation The use of alternative medicine may constitute a point of tension in the doctor-patient relationship. Both parties may be reluctant to discuss the issue. It is important that medical professionals are open to these discussion and encourage patients to discuss their alternative medicine use. Physicians should avoid using scare tactics or condemning the patient's decision. It is important to explore the patient's reasons for declining treatment
Goldberg (1983)	Systematic Understanding of Cancer Patients who Refuse Treatment	USA	N/A	Academic/reflective essay	Treatment refusal may reflect a transitional point in the individual's cancer journey and an underlying management problem: Treatment refusal may reflect interpersonal, intrapsychic and systemic factors. Clinicians should take care to avoid immediately accepting the person's decision or questioning their competence.

					Physicians should not shy away from conversations around patient ideas, beliefs around treatments. Treatment refusal should only be accepted when a systematic exploration of internal and external factors has taken place.
Madjar et al. (2007)	Telling Their Stories, Telling Our Stories: Physicians' Experiences With Patients Who Decide to Forgo or Stop Treatment for Cancer	Israel and Australia	12 medical and radiation oncologists	Qualitative Interviews	Patients who “refuse” curative treatment disturb the accepted rules of the doctor-patient relationship Doctors constructed narratives in terms of the nature of the disease, the nature of the patient’s decision, and personal characteristics of the patient. Physicians talked about the trade-off between benefits and side effects of treatment, seeing a continuum along which the decision to decline treatment is more or less acceptable. Physicians are accepting of the patient’s right to choose, but, only when the disease is no longer responding to medical treatment Physicians did not consider patients incompetent but did speak to the rationality of decisions Where physicians beliefs are supported by evidence and science they are considered rational and patients who disagree, by default are irrational Personal Characteristics of the Patient: Passive Versus Active, Younger Versus Older, “Normal” Versus Deviant

					Patients’ decisions creating uncertainty for oncologists Physicians experienced a sense of helplessness when the consultation does not follow the usual format Failure to convince the patient was described as a professional failing in one’s goals Patients’ decisions as a cause for concern or fear-fear of failing to do the best they can for patients-fear of families accusing doctors of malpractice or not doing everything they can Physicians mostly believed that having treatment was the right thing for the patient and felt their role was to support the patient towards making that decision.
Faivre et al.(2017)	Clinical practice guidelines of the French Association for Supportive Care in Cancer and the French Society for Psycho-oncology: refusal of treatment by adults afflicted with cancer	France	Task Force gathered by The French Association for Supportive Care in Cancer and the French Society for Psycho-oncology	Consensus methodology to draft guidelines	Guidelines: 1. Develop awareness of and explore factors associated with refusal-some may be modifiable e.g. financial hardship 2. Understand the complexity of the refusal; identify the modalities that are unacceptable to patients as patients may be opposed to some aspect of treatment as opposed to treatment as a whole 3. Systematically analyse the refusal to promote progression from disagreement toward a consensual decision. It is important to build a relationship and conduct an analysis of the

			The national task force (34 healthcare professionals) and the national review group (52 healthcare professionals comprised of doctors (medical oncology, radiotherapy, surgical oncology, anesthesia-resuscitation, palliative medicine, pain medicine, and psychiatry), psychologists, nurses, and lawyers.		conditions without judgment or pressure. Aim to have a dialogue around the meaning of the decision, even if this strays beyond medical logic 4. Devise procedures to address refusal of treatment which safeguards stakeholders in situations of sustained disagreement 5. Where appropriate utilise ethical consultation; gather multiple perspectives through MDT consultation. The key issue is to maintain a relationship, to continue providing care where possible and strive to progress the refusal toward an agreement regarding the delivery of a treatment that may be different from what was initially proposed but acceptable to the patient. Maintaining the relationship is critical to avoid relationship breakdown which would deprive the patient of all care.
Dhoetre et al. (2016)	Oncology Nurses' Experiences With Patients Who Choose to Discontinue Cancer Chemotherapy	USA (South Carolina)	7 Oncology nurses	Hermeneutic Phenomenology	Nurses experienced strong feelings when patients chose to prematurely discontinue chemotherapy. Nurses struggled with patients choices to forgo curative therapy and attempted to 'talk patients out of decisions' Nurses develop attachments to patients

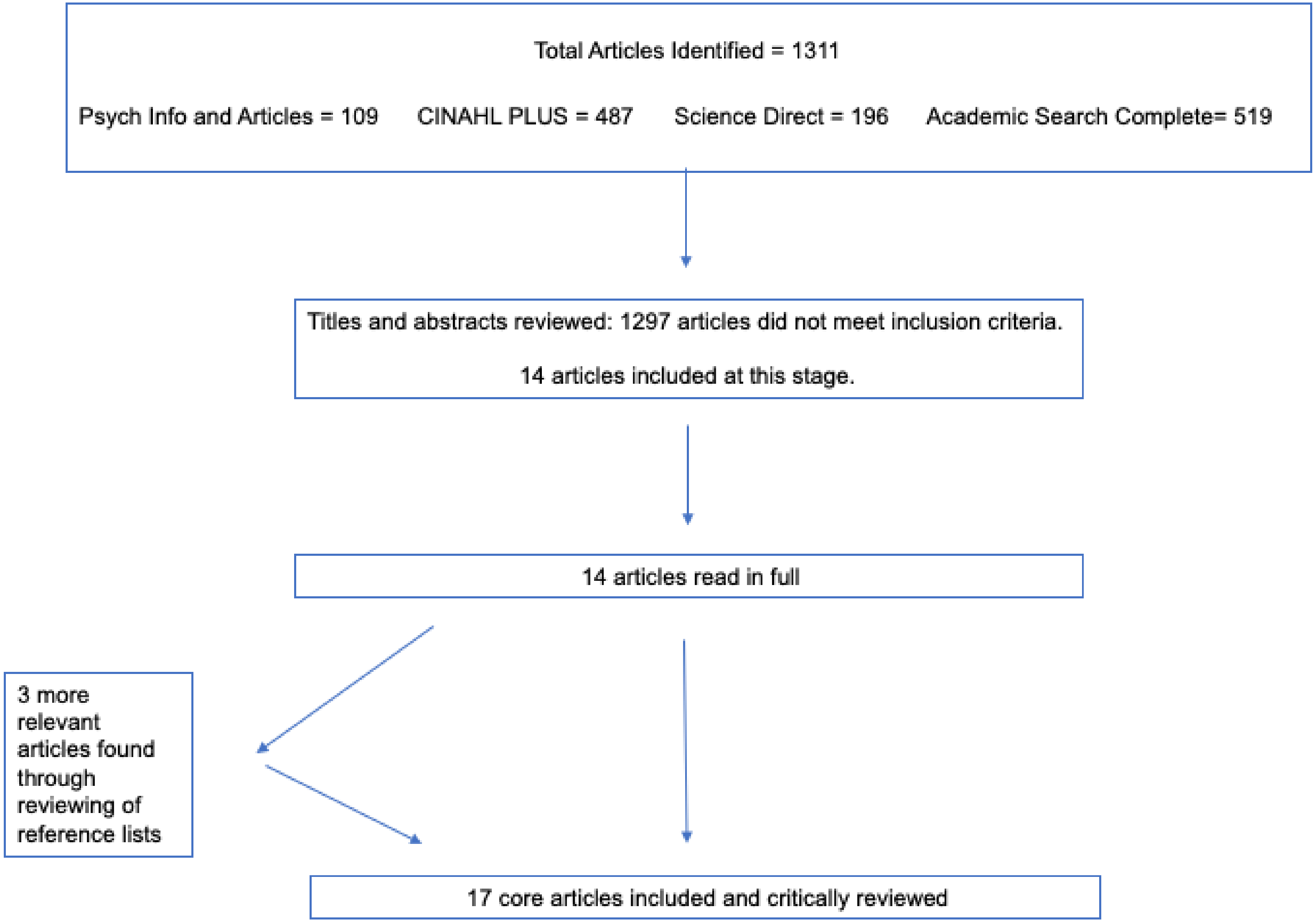
					Nurses' struggled to balance their responsibility for their patients' care with the respect they had for patients' individual decisions. Nurses sense of responsibility to remove all barriers to completing therapy by educating patients, helping to control treatment side effects, exploring financial options, and offering counselling. Some nurses felt a sense of failing or personal responsibility for not being able to convince patients to continue Nurses understood patients decisions in the context of patients feeling that chemotherapy dominated their life and prevented them from engaging in their lives as 'themselves' Nurses noticed that some patients who discontinued treatment had a difficult time accepting their diagnoses or were angry or anxious about going through treatment
Giorgi & Bascion (2012)	Doc I don't want your poison	Italy	N/A	Academic/reflective essay	Patients often assume that a choice to forgo terminates the relationship with the oncologist Emotional support from physicians is the most consistent long-term determinant of patient-physician trust amongst women with breast cancer The authors' patient decided to try oncologic therapy before ultimately discontinuing however the

					authors believed this was due to openness and respect within the patient-professional relationship It is important to maintain a trusting relationship with patients, even when treatment recommendations are dismissed for reasons which physicians don't agree with A compassionate approach is critical to help patients face their disease
Van Kleffens et al. (2004)	The Medical Practice of Patient Autonomy and Cancer Treatment refusals: a patients' and physicians' perspective.	T The Netherlands	30 cancer patients who had refused treatment, 16 physicians (oncologists and GPs)	Qualitative Interviews	Patient decisions do not always rely on the medical information about disease and treatment options, but are rather inspired by patients' own experiences or those of close others. However the medical information and the physician influence patients' experiences of being free and/or of having a choice. Results showed that the extent to which physicians pressure patients to be treated depends on the medical distinction between a curative and a non-curative treatment goal. Physicians respect for patient autonomy varied according to treatment goals
Barton (1991)	Advocacy: Nursing's role in supporting the Patient's Right to Refuse Treatment	USA	N/A	Academic paper	The process of death is prolonged where individuals receive end of life care in medical settings from persons who value the preservation of life

					Nursing practice should be guided by a philosophy of care that preserves patients’ self determination Patient advocacy can foster patient autonomy however there can often be conflict between the principles of autonomy and beneficence The patients’ right to refuse treatment is supported by a legal precedent which may be difficult for nurses to accept given advanced knowledge and experience which may create a sense of knowing what is best for the patient Advocacy involves ensuring that patients understand the implications of certain treatments and act as a sounding board to assist the patient in fully reasoning about choices
Radley & Payne (2009)	A Sociological Commentary on the Refusal of Treatment by Patients with Cancer.	United Kingdom	N/A	Academic paper	Declining treatment needs to be understood in terms of patients' relationship to medicine The emergence of competing ideologies provides the possibility for alternative value sets in which the meaning of life can be assessed. Apparent acts of ‘ individual defiance’ are couched in a society whose relationship with medical authority is evolving
Sindhu (2019)	Honesty in Medicine—An Approach to Patients With Cancer	USA	N/A	Academic/reflective paper	Interactions with patients who decline cancer treatment can be exceptionally difficult for health practitioners

	Who Initially Reject Conventional Treatment.				It can be distressing when patients decline treatment and return with advanced disease Physicians can question whether anything could have been done to change their minds Important to avoid assigning blame to patients and ensure that patients are made to feel deserving of care.
Kim et al (2020)	"I Made All Decisions Myself": Breast Cancer Treatment Decision-Making by Receivers and Decliners	USA	7 women with breast cancer (4 receivers, 3 decliners)	Inductive content analysis through semi-structured interviews	Receivers reported that doctors and family members influenced their decision-making. Decliners perceived their doctors as supportive and reported that the experience of family and friends, the results of Oncotest, and concerns about side effects influenced their decision-making. Both receivers and decliners felt they had made their decisions themselves, however receivers felt negatively about doctors' advice Receivers also described the the decision-making process as lacking and reported discomfort with the treatment process

Appendix B: PRISMA diagram of Scoping Review Search Strategy



Total Articles Identified = 1311

Psych Info and Articles = 109

CINAHL PLUS = 487

Science Direct = 196

Academic Search Complete= 519

Titles and abstracts reviewed: 1297 articles did not meet inclusion criteria.

14 articles included at this stage.

14 articles read in full

3 more relevant articles found through reviewing of reference lists

17 core articles included and critically reviewed

Appendix C: Ethics Application and Approval Letter

UNIVERSITY OF EAST LONDON
School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS
(Updated October 2019)

FOR BSc RESEARCH
FOR MSc/MA RESEARCH
FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

1. Completing the application

1.1 Before completing this application please familiarise yourself with the British Psychological Society's Code of Ethics and Conduct (2018) and the UEL Code of Practice for Research Ethics (2015-16). Please tick to confirm that you have read and understood these ☐ es:

1.2 Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will then look over your application.

1.3 When your application demonstrates sound ethical protocol, your supervisor will submit it for review. By submitting the application, the supervisor is confirming that they have reviewed all parts of this application, and consider it of sufficient quality for submission to the SREC committee for review. It is the responsibility of students to check that the supervisor has checked the application and sent it for review.

1.4 Your supervisor will let you know the outcome of your application. Recruitment and data collection must NOT commence until your ethics application has been approved, along with other research ethics approvals that may be necessary (see section 8).

1.5 Please tick to confirm that the following appendices have been completed. Note: templates for these are included at the end of the form.

- The participant invitation letter ☐

☐

- The participant consent form

- The participant debrief letter ☐

1.6 The following attachments should be included if appropriate. In each case, please tick to either confirm that you have included the relevant attachment, or confirm that it is not required for this application.

- A participant advert, i.e., any text (e.g., email) or document (e.g., poster) designed to recruit potential participants.

  Included ☐ or

  Not required (because no participation adverts will be used) ☐

- A general risk assessment form for research conducted off campus (see section 6).

  Included ☐ or

  Not required (because the research takes place solely on campus or online) ☐

- A country-specific risk assessment form for research conducted abroad (see section 6).

  Included ☐ or

  Not required (because the researcher will be based solely in the UK) ☐

- A Disclosure and Barring Service (DBS) certificate (see section 7).

  Included ☐ or

  Not required (because the research does not involve children aged 16 or under or vulnerable adults) ☐

- Ethical clearance or permission from an external organisation (see section 8).

  Included ☐ or

  Not required (because no external organisations are involved in the research) ☐

- Original and/or pre-existing questionnaire(s) and test(s) you intend to use.

  Included ☐ or

  Not required (because you are not using pre-existing questionnaires or tests) ☐

- Interview questions for qualitative studies.

  Included ☐ or

  Not required (because you are not conducting qualitative interviews) ☐

- Visual material(s) you intend showing participants.

  Included ☐ or

  Not required (because you are not using any visual materials) ☐

2. Your details

1.7 Your name: Jennifer Lennon

1.8 Your supervisor's name: Dr Kenneth Gannon

1.9 Title of your programme: Professional Doctorate in Clinical Psychology

1.10 UEL assignment submission date (stating both the initial date and the resit date): May 2022

3. Your research

Please give as much detail as necessary for a reviewer to be able to fully understand the nature and details of your proposed research.

1.11 The title of your study: Patients who decide to forgo Breast Cancer treatment: Perspectives and Experiences of Cancer Professionals.

1.12 Your research question: The decision to forgo conventional cancer treatment is associated with increased risk of disease progression and morbidity, yet there is a distinct, albeit predominantly anecdotal evidence base that documents cases in which breast cancer patients decline conventional treatment. A decision to decline treatment is likely to be contentious for medical teams, as this choice represents a sharp departure from medical convention and may challenge the scientific and ethical frameworks that orient cancer professionals. The proposed research hopes to explore the ways in which various cancer professionals experience and understand breast cancer patients who decline conventional cancer treatment.

The research questions are therefore:

1) How do cancer professionals attempt to understand and account for the decision to forgo breast cancer treatment.

2) How do cancer professionals make sense of a patients’ decision to forgo treatment and experience these patients on a personal and professional level.

1.13 Design of the research: Purposive sampling, qualitative interviews

1.14 Participants: Clinical nurse specialists, medical and clinical oncologists, surgeons and psychologists who work in a psycho-oncology setting and provide support to both patients and health care professionals.

1.15 Recruitment: The researcher has identified two provisional recruitment strategies, should there be difficulties in receiving NHS Research and Development approval, due to the prioritisation of COVID-19 related research during the pandemic.

If possible, health professionals may be recruited from a London NHS Trust as the researcher has a contact in this organisation who is willing to support the research and recruitment. If this approach proves viable applications for HRA and Trust R&D approval will be submitted in addition to the application for UEL ethical approval.

If this option ceases to be viable, the researcher will recruit from professional organisations such as the UK Nurses Oncology Society, the Association of Breast Surgeons, the National Association of Clinical Nurse Specialists, the Association of Cancer Physicians, The Royal College of Radiologists, The Royal College of Physicians, The Royal College of Surgeons and The British Psychological Society, Division of Clinical Psychology.

The research will also be advertised on social media via personal professional contacts. Dedicated Twitter, Facebook and Instagram pages outlining the study will be developed for the purpose of recruitment. These accounts will be created using the researcher’s UEL email and will be deactivated once recruitment has finished.

1.16 Measures, materials or equipment: As it is currently necessary to observe social distancing due to COVID-19, interviews will be conducted remotely via Microsoft Teams; a digital platform in which virtual meetings can take place. Microsoft Teams includes recording and transcription functions, hence additional recording equipment will not be required.

1.17 Data collection: Data will be collected via semi-structured interviews of 60 minutes, which will be conducted remotely via Microsoft Teams. Descriptive demographic data will also be collected to characterize the sample. The strategy for demographic data collection may vary depending on recruitment pathways. To minimise risk of identification within a specialist NHS service, the collection of demographic information will be limited to the professional's clinical specialism, gender and age within a specified range (e.g. 25-30, 31-40 etc.) and years of experience within a specified time range (1-5, 6-10 etc.) If participants are recruited from national, professional organisations, more detailed demographic data will be collected such as specific age, years of experience, years in current post, geographic location and hospital type (i.e. national, regional, district hospital).

1.18 Data analysis: Data will be analysed using Thematic Analysis (Braun and Clarke, 2006).

4. Confidentiality and security

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

1.19 Will participants data be gathered anonymously? Participants will be assigned a pseudonym for use within transcripts, thesis extracts and subsequent publications. Only the researcher will be aware of participants' identities. Any demographic information (i.e. age, profession, gender, years post qualification, years in post) will be collected anonymously.

1.20 If not (e.g., in qualitative interviews), what steps will you take to ensure their anonymity in the subsequent steps (e.g., data analysis and dissemination)? Anonymity will be ensured through secure data storage (see 4.4.). Participants will be informed that their names will be changed, but that they may be quoted within thesis extracts and subsequent publications. The researcher will avoid the use of quotations, which may include identifying information.

1.21 How will you ensure participants' details will be kept confidential? Wherever possible, information about participants and the content of interviews will be kept confidential; demographic data and recorded interviews will be only be accessed by the researcher (the research supervisor and examination board may have access to transcripts in which identifying information has been removed or changed). The limits of confidentiality will be emphasised before commencing interviews and confidentiality will only ever be broken in consultation with the research supervisor, if there are safety serious concerns. In the event that it is necessary to break confidentiality due to safety concerns, the researcher will liaise with the relevant authority (e.g. the police, social services etc.) and only share information that is directly pertinent to resolving the safety concern. Otherwise, participant details will be kept confidential through the secure storage of information (4.4)

1.22 How will the data be securely stored? Recorded interviews will be transcribed via Microsoft teams and stored in password protected folders on the UEL OneDrive. Transcripts will also be stored on the UEL OneDrive in a password protected file. Transcripts will be retained by the Research Supervisor electronically on the supervisor's UEL OneDrive, for 5 years following study completion, in keeping with data management procedures and for purposes of publication.

Demographic data (age, gender, profession, years in profession, years in post) will be collected verbally during interviews and responses will be anonymously stored on the UEL OneDrive, in password protected files which will be labelled based dates on which interviews takes place.

In order to facilitate the tracing of a transcript that may need to be destroyed at request of participant, a list of contact details corresponding with interview dates will be kept in a file, separately stored from transcripts which will be uploaded to the OneDrive. Contact details will be deleted once the 3-week period has elapsed for each participant.

Consent forms will be saved in a separate location to other research data in the UEL H Drive

1.23 Who will have access to the data? For the most part, access will be restricted to the researcher however the research supervisor and examination board may also have access to transcripts. The research supervisor and examination board will only be granted access to transcripts in which identifying information has been removed or changed.

1.24 How long will data be retained for? Video recordings will be deleted once transcription is complete and demographic data will be destroyed once the thesis has been examined. Transcripts will be retained for 5 years following study completion by the research supervisor on the UEL OneDrive, in keeping with data management procedures and for purposes of publication.

5. Informing participants

Please confirm that your information letter includes the following details:

1.25 Your research title: ☐

1.26 Your research question: ☐

1.27 The purpose of the research: ☐

1.28 The exact nature of their participation. This includes location, duration, and the tasks etc. invol ☐

1.29 That participation is strictly voluntary: ☐

1.30 What are the potential risks to taking part: ☐

1.31 What are the potential advantages to taking part: ☐

1.32 Their right to withdraw participation (i.e., to withdraw involvement at any point, no questions asked) ☐

1.33 Their right to withdraw data (usually within a three-week window from the time of their participation) ☐

1.34 How long their data will be retained for: ☐

1.35 How their information will be kept confidential: ☐

1.36 How their data will be securely stored: ☐

1.37 What will happen to the results/analysis: ☐

1.38 Your UEL contact details: ☐

1.39 The UEL contact details of your supervisor: ☐

Please also confirm whether:

1.40 Are you engaging in deception? If so, what will participants be told about the nature of the research, and how will you inform them about its real nature. N/A

1.41 Will the data be gathered anonymously? If NO what steps will be taken to ensure confidentiality and protect the identity of participants?

Participants will be assigned a pseudonym within qualitative interviews and all demographic data will be collected anonymously. Demographic data collection may vary depending on how participants are recruited. If participants are recruited from national organisations where identification is less likely, the researcher will ask participants to comment on their geographic location, hospital type (i.e. national, regional, district hospital) years of experience and years in post age and gender. If participants are recruited from a single NHS cancer centre in which identification by colleagues is more likely, demographic information will be limited to age range (e.g. 25-30 etc), clinical specialism and years of experience within particular time frames (e.g. 1-3 years, 4-10 years, 11-15 years etc.)

1.42 Will participants be paid or reimbursed? If so, this must be in the form of redeemable vouchers, not cash. If yes, why is it necessary and how much will it be worth? N/A

6. Risk Assessment

Please note: If you have serious concerns about the safety of a participant, or others, during the course of your research please see your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g. a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

1.43 Are there any potential physical or psychological risks to participants related to taking part? If so, what are these, and how can they be minimised?

As interviews will be conducted remotely via Microsoft Teams, there is minimal physical risk associated with participation in this study. Research indicates that medical professionals can be confronted by difficult emotions when trying to support patients who decline treatment, therefore it is reasonable to expect that some participants may feel distressed during interviews as they discuss these patients. The researcher will encourage participants to take breaks during interviews if necessary and will also remind participants that they are free to withdraw from the study or to stop the interview without penalty. A debrief will be offered after the interview with the possibility for participants to speak about any issues raised. The researcher will signpost participants to the Human Resources and Occupational Health departments, if there are concerns of protracted work-related distress and will also identify supportive organisations within debrief letters.

1.44 Are there any potential physical or psychological risks to you as a researcher? If so, what are these, and how can they be minimised?

The physical risks are minimal, as interviews will be conducted remotely. The researcher will have access to a research supervisor, who will be able to offer guidance and support, should the researcher experience psychological distress throughout the research process.

1.45 Have appropriate support services been identified in the debrief letter? If so, what are these, and why are they relevant?

Human Resources and Occupational Health departments are identified in the debrief letter as these teams are well positioned to provide support around work related distress. The debrief letter also identifies The Samaritans, who offer a listening service, in addition to Macmillan Cancer Services who provide cancer information and support. The Debrief letter also identifies the NHS England Staff Support Line and Project5.org-a wellbeing support service.

1.46 Does the research take place outside the UEL campus? If so, where? Online

If so, a 'general risk assessment form' must be completed. This is included below as appendix D. Note: if the research is on campus, or is online only (e.g., a Qualtrix survey), then a risk assessment form is not needed, and this appendix can be deleted. If a general risk assessment form is required for this research, please tick to confirm that this en completed:

N

1.47 Does the research take place outside the UK? If so, where? No

If so, in addition to the 'general risk assessment form', a 'country-specific risk assessment form' must be also completed (available in the Ethics folder in the Psychology Noticeboard), and included as an appendix. [Please note: a country-specific risk assessment form is not needed if the research is online only (e.g., a Qualtrix survey), regardless of the location of the researcher or the participants.] If a 'country-specific risk assessment form' *is* needed, please tick to confirm that this has been in

NA

However, please also note:

- For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on 'sign in' and then 'register here' using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance.
- For *on campus* students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Head of School (who may escalate it up to the Vice Chancellor).

- For *distance learning* students conducting research abroad in the country where they currently reside, a risk assessment must be also carried out. To minimise risk, it is recommended that such students only conduct data collection on-line. If the project is deemed low risk, then it is not necessary for the risk assessments to be signed by the Head of School. However, if not deemed low risk, it must be signed by the Head of School (or potentially the Vice Chancellor).
- Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

7. Disclosure and Barring Service (DBS) certificates

1.48 Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?

NO

1.49 If so, you will need a current DBS certificate (i.e., not older than six months), and to include this as an appendix. Please tick to confirm that you have included this:

NA

Alternatively, if necessary for reasons of confidentiality, you may email a copy directly to the Chair of the School Research Ethics Committee. Please tick if you have done this instead:

NA

Also alternatively, if you have an Enhanced DBS clearance (one you pay a monthly fee to maintain) then the number of your Enhanced DBS clearance will suffice. Please tick if you have included this instead:

NA

1.50 If participants are under 16, you need 2 separate information letters, consent form, and debrief form (one for the participant, and one for their parent/guardian). Please tick to confirm that you have included these:

NA

1.51 If participants are under 16, their information letters consent form, and debrief form need to be written in age-appropriate language. Please tick to confirm that you have done this

NA

* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) ‘vulnerable’ people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living

in institutions and sheltered accommodation, and people who have been involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children click here.

8. Other permissions

2. Is HRA approval (through IRAS) for research involving the NHS required? Note: HRA/IRAS approval is required for research that involves patients or Service Users of the NHS, their relatives or carers as well as those in receipt of services provided under contract to the NHS.

NO IRAS approval will not be required for this research. However, if it proves feasible to recruit staff via a particular NHS Trust then an application for R&D approval will be submitted to the HRA in addition to seeking R&D approval from the Trust itself.

If yes, please note:

- You DO NOT need to apply to the School of Psychology for ethical clearance if ethical approval is sought via HRA/IRAS (please see further details here).
- However, the school *strongly discourages* BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
- If you work for an NHS Trust and plan to recruit colleagues from the Trust, permission from an appropriate manager at the Trust must be sought, and HRA approval will probably be needed (and hence is likewise strongly discouraged). If the manager happens to not require HRA approval, their written letter of approval must be included as an appendix.
- IRAS approval is not required for NHS staff even if they are recruited via the NHS (UEL ethical approval is acceptable). However, an application will still need to be submitted to the HRA in order to obtain R&D approval. This is in addition to a separate approval via the R&D department of the NHS Trust involved in the research.
- IRAS approval is not required for research involving NHS employees when data collection will take place off NHS premises, and when NHS employees are not recruited directly through NHS lines of communication. This means that NHS staff can participate in research without HRA approval when a student recruits via their own social or professional networks or through a professional body like the BPS, for example.

2.1 Will the research involve NHS employees who will not be directly recruited through the NHS, and where data from NHS employees will not be collected on NHS premises? Most likely

2.2 If you work for an NHS Trust and plan to recruit colleagues from the Trust, will permission from an appropriate member of staff at the Trust be sought, and will HRA be sought, and a copy of this permission (e.g., an email from the Trust) attached to this application? N/A

2.3 Does the research involve other organisations (e.g. a school, charity, workplace, local authority, care home etc.)? If so, please give their details here.

This study may recruit from professional, medical organisations such as The National Association of Clinical Nurse Specialists, the Association of Cancer Physicians, The Royal College of Radiologists, The Royal College of Physicians and The Royal College of Surgeons and The Faculty of Oncology & Palliative Care within the BPS Division of Clinical Psychology

2.4 Furthermore, written permission is needed from such organisations if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation. If that is the case, please tick here to confirm that you have included this written permission as an appendix: A number of professional organisations have been approached to request support with participant recruitment. While this process is ongoing and full permission has not yet been secured, some organisations have indicated that they can support with recruitment once ethical approval has been obtained (see Appendix A).

In addition, before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as ‘my’ or ‘I’ with ‘our organisation,’ or with the title of the organisation. This organisational consent form must be signed before the research can commence.

Finally, please note that even if the organisation has their own ethics committee and review process, a School of Psychology SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s as may be necessary.

9. Declarations

Declaration by student: I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.

Student's name (typed name acts as a signature): Jennifer Lennon

Student's number: 1945489 Date: 03/02/21

As a supervisor, by submitting this application, I confirm that I have reviewed all parts of this application, and I consider it of sufficient quality for submission to the SREC committee.

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Lorna Farquharson

SUPERVISOR: **Kenneth Gannon**

STUDENT: Jennifer Lennon

Course: Professional Doctorate in Clinical Psychology

Title of proposed study: Patients who decide to forgo Breast Cancer treatment: Perspectives and Experiences of Cancer Professionals

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

2. Approved, but minor amendments required before the research commences

Minor amendments required *(for reviewer)*:

More clarity and consistency is required in relation to the collection of demographic data. In the ethics application it says that demographic data collection may vary depending on how participants are recruited, but it will important to be clear and consistent in the study materials (a decision about the most appropriate way of reporting the demographic data can always be made at a later date). It is not clear why the participant's age would be collected if recruiting from a single NHS site, but not through a national organisation. Given the focus on breast cancer, would gender not also be an important variable to consider?

There also needs to be more clarity and consistency in the data storage plans. In the ethics application form, it says that the transcripts will be retained for 5 years following study completion, there are no details of the length of time that data will be retained in the participant information sheet and in the debrief form it says that transcripts will be stored for 3 years.

In the participant information sheet, it would be more appropriate to say that you are conducting research into "healthcare professionals' experiences of working with breast cancer patients who decline conventional cancer treatments" rather than "medical professional's experiences…". On the last page of the information sheet, it should be "affect your employment" rather than "effect your employment" and the Chair of the School of the Psychology Research Ethics Sub-committee is now Dr Trishna Patel.

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):* Jennifer Lennon
Student number: u1945489@uel.ac.uk

Date: 30/3/2021

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☐ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: Lorna Farquharson

Date: 23.02.2021

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

Appendix D: Participant Information Sheet

University of
East London

PARTICIPANT INVITATION LETTER

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

Who am I?

I am a postgraduate student in the School of Psychology at the University of East London and am studying for a Professional Doctorate in Clinical Psychology.

What is the research?

I am conducting research into health professional's experience of working with breast cancer patients who decline conventional cancer treatments.

My research has been approved by the School of Psychology Research Ethics Committee. This means that the committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Why have you been asked to participate?

You have been invited to participate in my research as someone who fits the kind of people I am looking for to help me explore my research topic. I am looking to involve Clinical Nurse Specialists, Surgeons, Medical Oncologists and Clinical Oncologists who have worked with breast cancer patients that declined conventional cancer treatment. I am interested in speaking with cancer professionals who have worked with women who

1) Declined treatment outright (intended to cure or palliate)
2) Declined conventional treatment in favour of complementary or alternative approaches
3) Declined treatment before later deciding to pursue conventional cancer therapy.

I am also interested in speaking to Psychologists who work in a psycho-oncology context and who support patients who decline conventional therapies for breast cancer and provide consultation to the cancer professionals involved in their care.

I emphasise that I am not looking for ‘experts’ on the topic I am studying. You will not be judged or personally analysed in any way and you will be treated with respect. You are quite free to decide whether or not to participate and should not feel coerced.

What will your participation involve?

If you agree to participate in this research, you will take part in one interview that will last approximately 60 minutes. Interviews will take place remotely through Microsoft Teams, to observe social distancing and to ensure that interviews take place in a way that protects your health and safety.

As interviews will be conducted remotely, they can be arranged at your convenience. During interviews, no one else will be present unless you would like someone else to be there. To ensure confidentiality and protect your privacy, interviews should take place from a secure, comfortable location where you will not be interrupted. Interviews will be video-recorded and transcribed for analysis at a later date. You may also request a digital copy of your interview.

During the interview you will be asked to recount your experiences of working with women who have declined cancer treatment. If you decide to participate, I may ask you questions about what it is like to work with these patients, or what factors influence how you might understand a patient’s decision to decline breast cancer treatment. However, the interview will ultimately be an open conversation where we discuss what you deem important and relevant.

I will not be able to pay you for participating in my research, but your participation would be very valuable in helping to develop knowledge and understanding of my research topic

Your taking part will be safe and confidential

Your privacy and safety will be respected at all times. You will not be identifiable within any written material resulting from recorded interviews, or in any write up of the research. Demographic information such as age and gender may appear in the thesis and works based on it, but this will not be such as to permit the identification of individual participants. Direct quotes may be included within the final report, however any details that could be used to identify an individual participant will be removed.

Anonymised extracts of interviews may also be used in presentations, reports, publications and any other ways in which the findings of the research will be disseminated.

Your participation in this study is entirely voluntary and you are free to withdraw your participation without penalty. You are under no obligation to answer all questions asked of you, and you can stop participation in interviews at any time without penalty.

What will happen to the information that you provide?

Transcripts will only be accessible myself, my research supervisor Dr Kenneth Gannon at the University of East London, and thesis examiners. Video recordings and transcripts will be saved on the University of East London OneDrive in password-protected folders. Any personal, contact details that are shared when arranging interviews will also be stored on the University of East London OneDrive in password protected documents. This information will be deleted once interviews have been transcribed. Research transcripts will be retained by the research supervisor for 5 years on the UEL OneDrive by the research supervisor, for use in subsequent publications.

My contact details are included at the end of this letter, should you need to get in touch after your participation in this study has ended.

Sharing the Results

At the end of the study, I will be happy to send you a summary of the results. If you would like a copy of this please send a request using the contact details below. You are also welcome to use these details to ask any questions that you may have at any point during this study. Once the research is complete, my supervisor and I aim to share research findings in academic journals and conferences and the thesis will be publicly accessible on UEL's institutional repository.

What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw your data even after you have participated data, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

Risks of the Study

There are minimal physical risks or dangers involved in taking part in this study, although I am asking you to share personal information, and it is possible that you may feel uncomfortable or distressed when thinking about patients who have declined treatment.

You do not have to answer any questions, which make you feel uncomfortable or distressed and you do not have to provide reason or explanation for not answering certain questions or for deciding to discontinue the interview. If you would like to take a break at any point during the interview you can also do so.

Although it is not expected that the interview will reveal any information pertaining to harm to yourself or others, if such information is disclosed within interviews, I will be duty bound to report this to relevant professionals.

TAKING PART IN THIS RESEARCH WILL NOT AFFECT YOUR EMPLOYMENT

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Jenny Lennon u1945489@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr Kenneth Gannon, School of Psychology, University of East London, Water Lane, London E15 4LZ, Email: K.N.Gannon@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel. School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: t.patel@uel.ac.uk)

Appendix E: Consent Form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Patients who decide to forgo breast cancer treatment; perspectives and experiences of cancer professionals

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun.

I confirm that I have read the information sheet dated 30/03/2021 (version 1.0) for the above study and that I have been given a copy to keep. ☐

I confirm that I have read the information sheet dated 30/03/2021 (version 1.0) for the above study and that I have been given a copy to keep. ☐

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that my participation in the study is voluntary and that I may withdraw at any time, without providing a reason for doing so. ☐

I understand that my participation in the study is voluntary and that I may withdraw at any time, without providing a reason for doing so. ☐

I understand that if I withdraw from the study, my data will not be used. ☐

I understand that I have 3 weeks from the date of the interview to withdraw my data from the study. ☐

I understand that the interview will be recorded using Microsoft Teams. ☐

I understand that my interview data will be transcribed from the recording and anonymised to protect my identity. ☐

I understand that my personal information and data, including audio recordings research team will have access to this information, to which I give my permission. ☐

It has been explained to me what will happen to the data once the research has been completed ☐

I understand that short, anonymised quotes from my interview may be used in the thesis and that these will not personally identify me. ☐

I understand that the thesis will be publicly accessible in the University of East London’s Institutional Repository (ROAR). ☐

I understand that short, anonymised quotes from my interview may be used in material such as conference presentations, reports, articles in professional and academic journals resulting from the study and that these will not personally identify me. ☐

I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to. ☐

I agree to take part in the above study. ☐

Participant's Name (BLOCK CAPITALS)

…………………………………………………………………………………….

Participant's Signature

……………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

……………………………………………………………………………………..

Researcher's Signature

………………………………………………………………………………………

Date: …………………….…….

Appendix F: Debrief Letter

University of
East London

PARTICIPANT DEBRIEF LETTER

Thank you for participating in my research study on cancer professionals' experiences of supporting patients who decline conventional medical treatment for breast cancer. This letter offers information that may be relevant in light of you having now taken part.

What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided.

- Any personal, contact information that is shared when organising interviews will be stored in a password protected file on the UEL OneDrive.
- Video recordings of interviews will be destroyed once interviews have been transcribed by the researcher and transcripts will be stored in password protected folders on the UEL OneDrive.
- To preserve anonymity, pseudonyms will be used in transcripts, thesis extracts and resulting publications and any identifying information will be removed or changed.
- Anonymised interview transcripts may be viewed by the researcher, research supervisor and thesis examiners. These transcripts will be stored for 5 years on the UEL OneDrive by the research supervisor, for use in subsequent publications.
- You are entitled to withdraw your data from analysis within the next 3 weeks. After this point it may not be possible to facilitate the withdrawal of your data, as the analysis will have begun.

What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been adversely impacted by any of the issues that were discussed in interviews, you are encouraged to make contact with the Human Resource and Occupational Health departments in your place of work. If you have been affected in any of those ways you may find the following resources/services helpful in relation to obtaining information and support:

Macmillan Cancer Support: 0808 808 0000

Macmillan are an organisation that require information and support around cancer. Macmillan have support centres around the country, which can be located at macmillan.org.uk/inyourarea.

Samaritans: 116 123

Samaritans is a registered charity aimed at providing emotional support

Staff support line: **0800 069 6222**

A confidential NHS staff support line, with free to access from 7:00am – 11:00pm, seven days a week. This support line is here for when you've had a tough day, are feeling worried or overwhelmed. Whatever your worries, trained advisers can help with signposting and confidential listening.

Alternatively, you can text FRONTLINE to 85258 for support 24/7 via text

Project5.org Wellbeing Support Service

Free 1-2-1, confidential support sessions available for our NHS staff. Project5.org is an online booking system which gives NHS staff access to free one-to-one support online from a team of accredited clinical psychologists and mental health experts.

Appendix G: Recruitment Poster

University of
East London

HELP US UNDERSTAND THE NEEDS OF HCPS WHO WORK WITH PATIENTS WHO DECLINE CONVENTIONAL BREAST CANCER TREATMENTS

WHO?	Breast Care Nurses, Clinical Nurse Specialists, Oncologists and Surgeons who are involved in the care of breast cancer patients
WHERE?	A location of your choosing! Interviews will be conducted via Microsoft Teams
WHAT'S INVOLVED?	An interview exploring your experiences of working with breast cancer patients who have declined conventional cancer therapies.
HOW LONG?	Only one hour!
WHY GET INVOLVED?	To support doctoral research that seeks to identify the support needs of professionals and patients, in the context of treatment refusal.
INTERESTED?	Contact Jenny Lennon @ u1945489@uel.ac.uk

This research is being undertaken as part of a Professional Doctorate in Clinical Psychology at the University of East London

Appendix H: Provisional Interview Schedule

As the interviews will be semi-structured and questions will follow participants' responses, the following questions reflect ideas for areas to be covered within interviews.

Introductions and engagement

Thank the participant for agreeing to take part and re-iterate consent, confidentiality and the right to withdraw or take breaks at any point. Explain that the interview should take approximately one hour. Check this is okay and that that the participant is somewhere private where they can speak openly. Once consent process is complete, begin video recording.

Demographic Questions

1. Could you please confirm your occupation?
2. How long have you been working as a XXXXXX?
3. Where do you work (i.e. national, district hospital)
4. How long have you been in your current post?

Areas for questions

You agreed to take part in this study as you have experienced working with breast cancer patients who have declined conventional cancer treatment

1. Can you tell me about a time when you have worked with a patient who declined treatment.
2. What was it like for you?
3. What did you think of their decision? How did you understand it?
4. Why do you think these patients decide to forgo conventional cancer treatments?
5. How do you feel when a patient makes this kind of decision?
6. What does it mean for you?
7. How is working with these patients different to working with patients who accept medical advice?
8. How do you usually respond to these patients? Is that different to the way you would normally respond to a patient?
9. Why do you think you respond in that way?
10. How does the team make sense of a patient's decision to forgo cancer treatment?
11. Which team members find these decisions more or less challenging?
12. How does working with patients who decline treatment impact on you?
13. What emotions do you experience when supporting a patient who decides against having conventional cancer treatment?
14. What do you consider best practice, when working with women who decline conventional cancer therapies?

Debriefing Questions

1. How are you feeling about the conversation that we just had?
2. Did we discuss anything during the interview that was difficult for you, or that is still bothering you?
3. Is there anything that we didn’t get to talk about?

Appendix I: Recruitment Application to United Kingdom Oncology Nursing Society

UKONS
Oncology Nursing Society

The aim of the UKONS Research Members Interest Group (MIG) is to promote excellence in cancer nursing research. To make sure that our involvement in your research project will be relevant and beneficial, please complete this form about your research and how you would like UKONS to be involved in your project.

A. RESEARCHER DETAILS

1. Title and Name: Jennifer Lennon Trainee Clinical Psychologist University of East London

2. Organisational affiliation/Main study site: University of East London (UEL)

3. Post(s) held: Trainee Clinical Psychologist

4. E-mail address: u1945489@uel.ac.uk

5. Telephone: 07999049750

6. Date of Request (date when form submitted): 12/04/2021

B. ABOUT YOUR RESEARCH PROJECT

1. Short title of your research project (maximum 12 words):

Patients who forgo Breast Cancer treatment: Perspectives and Experiences of Cancer Professionals.

2. Overall aim of your project (maximum 25 words):

To explore how cancer professionals understand the decision to forgo standardised breast cancer treatment and experience patients who decline treatment, on a personal and professional level.

3. Briefly indicate the project's key milestones or stages:

3	Submit UEL Ethics Application	Jan 2021
4	Receive and implement feedback of UEL Ethics Committee Approach	Feb 2021
5	Register research	Feb 2021
6	Begin recruitment	Apr 2021
7	Conduct Interviews	Apr 2021-Oct 2021
5	Complete data collection, transcription and analysis	Apr 2021-Oct 2021
6	Draft introduction/literature review	Nov 2021
7	Draft methodology	Dec 2021
8	Draft results	Feb 2022
9	Draft discussion	March 2022
10	Submit draft to Supervisor	April 2022

11	Make necessary amendments	April-May 2022
12	Submit thesis	May 2022
13	Viva preparation	June 2022
14	Make amendments post viva	July 2022
15	Discuss publication with supervisor and prepare manuscripts for publication	July-Sept 2022

4. Is the project being conducted as a student project? If yes, please complete questions 5 and 6. If no, please go to question 7.

☐√ Yes ☐ No

5. Please tick a box below to indicate the final student award for which this project is being conducted:

☐ MSc

☐ MRes

☐ PhD

☐ DPhil

☐ √ Prof Doc

☐ Other (please state):

6. If it is a student project, has your academic supervisor approved the proposed request?

☐ √ Yes ☐ No

If No, please explain why not:

7. Does the project have Patient and Public Involvement (PPI)?

☐ √ Yes ☐ No

If Yes, please provide details of PPI:

The researcher intends to consult with women who have declined breast cancer treatment for support in developing the interview schedule (i.e. gaining patient perspectives around important questions/lines of inquiry). By including the perspectives of patients who have declined treatment, this project can include/elevate patient voices while exploring professionals' experiences

If No, please explain why not:

7. Has this project already received ethical approval?

☐ √ Yes ☐ Not yet ☐ Not applicable

8. Expected completion date of your project: May 2022

9. Expected number of study participants (sample size)

☐ √ <100 ☐ 100 – 500 ☐ > 500 ☐ Not applicable

Between 12-15

10. What plans do you have for disseminating the findings of your research project, including with UKONS members?

Once the thesis has been examined and passed it will be drafted for publication in relevant journals/at relevant conferences. The researcher would be prepared to work with UKONS in deciding the most effective way to disseminate findings to UKONS members. The researcher will also send a copy of the completed thesis to interested participants.

C. UKONS INVOLVEMENT WITH YOUR RESEARCH PROJECT

1. Deadline for response from UKONS Research MIG Committee: As soon as possible-the hope would be to commence recruitment around May 2021.

2. Request made to UKONS Research MIG Committee. Please state your request (including wording for a message publicising your research project that you wish to be shared with UKONS members, if you are making such a request):
I am requesting UKONS support in recruiting nurses who have worked with patients who have declined breast cancer treatment. I am hoping that UKONS can support by including details of the study within newsletters, email bulletins or on the UKONS website. I have included wording for a publicising message/advertisement below.

Treatment Refusal in Women with Breast Cancer: Perspectives and Experiences of Professionals

Help us to understand the needs of cancer professionals who work with patients who decline treatment for breast cancer

Recent decades have seen increased interest in non-pharmacologic approaches to cancer management, however there is evidence suggesting that the popularity of these approaches has been accompanied by a concerning trend of treatment refusal in women with breast cancer, in which patients decline evidence-based treatment in favour of 'alternative interventions'.

I am a student on the University of East London Professional Doctorate in Clinical Psychology and am conducting research on cancer professionals' experiences of treatment refusal for my doctoral thesis. I hope to learn about the experiences of cancer professionals when working with women who decline treatment, which may be curative or life sustaining. I want to hear about what you think lies behind these choices, how you discuss such decisions with patients and how such experiences effect you both professionally and personally.

If you are interested in participating or would like to find out more about this research, please contact Jenny Lennon at u1945489@uel.ac.uk

Preferred date for circulation:	May 2021
End date for recruitment/inclusion on website:	January 2022
Short summary with weblink for Newsletter: As above	

Advert with weblink and if applicable copyrighted image/organisation logo (for the website)
240-character twitter advert with link **Surgeons, Oncologists and Oncology Nurses! I am researching HCPs experiences of working with patients who decline breast cancer treatment. If you are interested in taking part or hearing more about this research please get in touch on u1945489@uel.ac.uk** **https://twitter.com/JennyLennon18/status/1382695448750796802**

Other Requests:

3. Please tick the box below to confirm that you will provide an annual report (maximum 2 sides of A4) of your research project to UKONS Research MIG Committee until the project's completion:

☐ √ I confirm I will provide an annual report of my research project to UKONS Research MIG Committee until the project's completion

4. Please tick the box below to confirm that you will acknowledge the UK Oncology Nursing Society in reports and publications by its full title and credit UKONS for any involvement of its members in your research project.

☐ √ I confirm I will acknowledge the UK Oncology Nursing Society in reports and publications by its full title and credit UKONS for any involvement of its members in your research project

5. Are you a member of UKONS? If YES, please answer question 6. If NO, please go to question 7.

☐ YES ☐ √ NO

6. What is your UKONS membership number?

N/A

7. How did you find out about the UKONS Research MIG?

☐ UKONS Breaking News
☐ √ UKONS website
☐ UKONS conference or event
☐ UKONS Ambassador
☐ Referred by a colleague or supervisor
☐ Other (please state):

Requests are welcomed at any time. If you have any queries about completing this form, please contact one of the Co-Chairs or Secretary of the UKONS Research MIG Committee.

Please submit your completed application form by e-mail to:
Dr Joanne Bird, Co-Lead UKONS Research MIG Committee
joanne.bird@sheffield.ac.uk

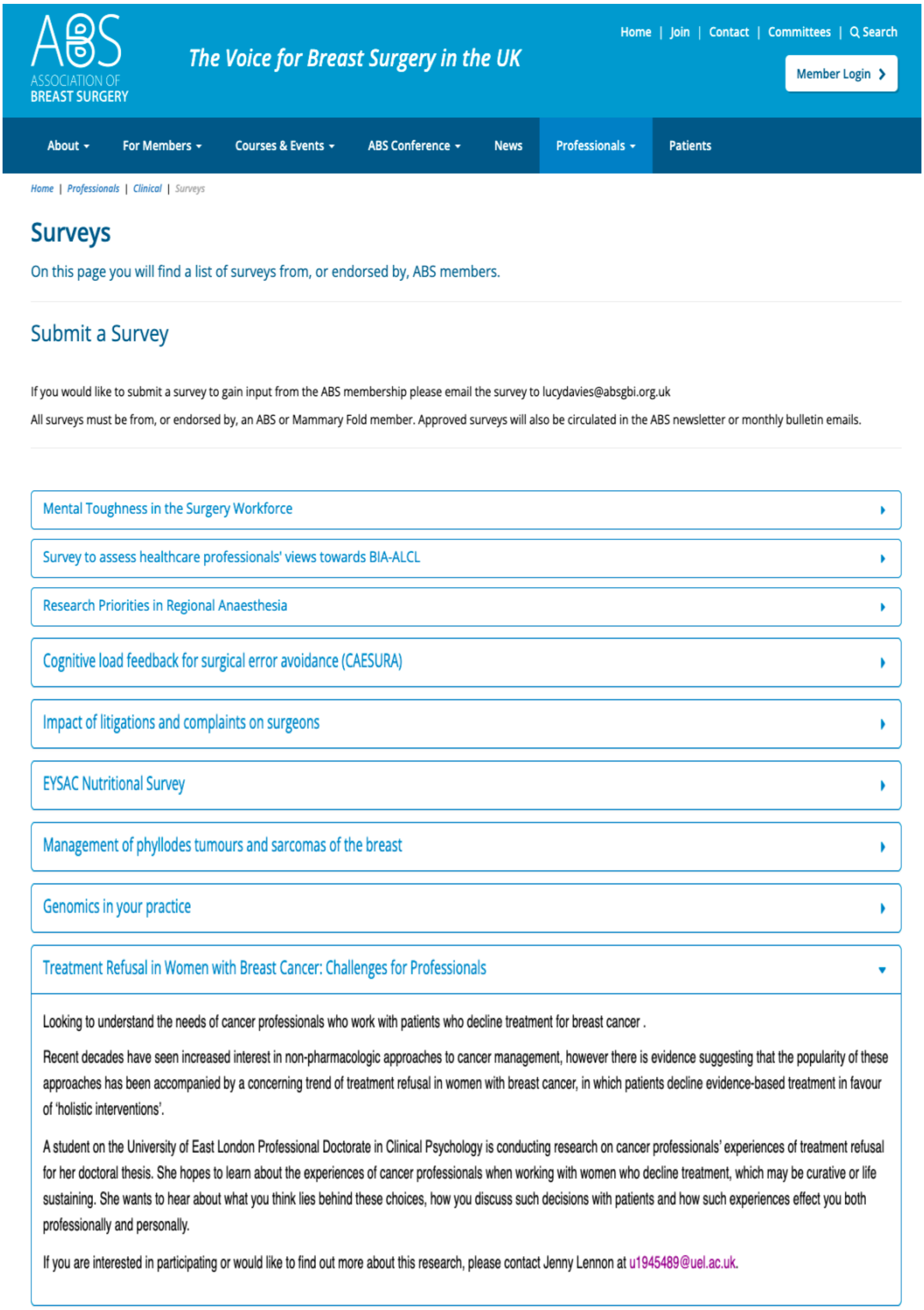
Anne Croudass, Secretary UKONS Research MIG Committee
Anne.Croudass@cancer.org.uk

Thank you for providing this key information about your research project

How we use your information

With respect to any and all information including, but not limited to, protocols, data forms, agreements with third parties, research, product plans, study results acquired by UKONS. UKONS agrees that it will keep such information confidential and will not use said information other than for the purposes of this agreement.

Appendix J: Recruitment Advertisement of Association of Breast Surgery Website



Surveys

On this page you will find a list of surveys from, or endorsed by, ABS members.

Submit a Survey

If you would like to submit a survey to gain input from the ABS membership please email the survey to lucydavies@absgbi.org.uk

All surveys must be from, or endorsed by, an ABS or Mammary Fold member. Approved surveys will also be circulated in the ABS newsletter or monthly bulletin emails.

- Mental Toughness in the Surgery Workforce
- Survey to assess healthcare professionals' views towards BIA-ALCL
- Research Priorities in Regional Anaesthesia
- Cognitive load feedback for surgical error avoidance (CAESURA)
- Impact of litigations and complaints on surgeons
- EYSAC Nutritional Survey
- Management of phyllodes tumours and sarcomas of the breast
- Genomics in your practice
- Treatment Refusal in Women with Breast Cancer: Challenges for Professionals

Looking to understand the needs of cancer professionals who work with patients who decline treatment for breast cancer .

Recent decades have seen increased interest in non-pharmacologic approaches to cancer management, however there is evidence suggesting that the popularity of these approaches has been accompanied by a concerning trend of treatment refusal in women with breast cancer, in which patients decline evidence-based treatment in favour of 'holistic interventions'.

A student on the University of East London Professional Doctorate in Clinical Psychology is conducting research on cancer professionals' experiences of treatment refusal for her doctoral thesis. She hopes to learn about the experiences of cancer professionals when working with women who decline treatment, which may be curative or life sustaining. She wants to hear about what you think lies behind these choices, how you discuss such decisions with patients and how such experiences effect you both professionally and personally.

If you are interested in participating or would like to find out more about this research, please contact Jenny Lennon at u1945489@uel.ac.uk.

Appendix K: Transcription Extract with Initial Codes

Angela: and she's, I don't, I don't think she's still even getting it that if she'd had it then, that's what we were trying to do. We were trying to prevent this from happening, so its just, you know that's our starting position now, so.

Interviewer: And when, when, or if these types of patients broach the idea of complementary therapies, or pursuing, you know, alternative therapies (Angela: yeah) what, what do you tell them?

Angela: So a variety of things really, it depends what they want to do. So if people want to have complementary therapies instead of conventional treatment, I would try to dissuade them not to do that, and that they should have conventional treatment. I'm very happy that they go and discuss it with whoever they want to discuss it with. Uhm if they want to have complementary therapies supporting their chemotherapy, depending what it is, then we would support that, because if they feel that that's helping them, that's fine. So if it's a certain drug that might interact with some of our drugs, we wouldn't want them to do that. But if it was other things or drugs, you know vitamins or something like that that wouldn't interact, then we're very happy they do that as well.

Angela: And and I think you know, people like to feel that they're helping themselves, and that's absolutely fine. So, so it's a spectrum, but we wouldn't it [unclear] you know, we wouldn't say or couldn't say don't do it, but we would, you know, we'd, we'd push the conventional standard

Unnecessary disease progression

You work with what's in front of you

Encourage patients to accept conventional treatment

Open to complementary approaches provided they don't jeopardise standard treatment

Patients needing to have agency in the process treatment where we have the the research, um evidence but if they want to do something else, then that's that's that's fine.

Professionals' role is to provide evidence supported treatments

Appendix L: Extract From Coding Tables

Code	Participant Quote
Unfathomable decision to the professional mind	Sophia: not a natural, er, outcome from a consultation for a patient. So, um, you know, if, if we could prevent this, er, it will have been so much better. Um, there is something which doesn't seem very normal about that Andrea: well, I need to make sure I [inaudible 00:23:50], that I don't say things that are, you know, too, um, too tough on them, you know, so I can't tell them that you're being stupid even if I think they are
Failing these patients	Lucy: So, I think from that point of view, I don't feel like I'm achieving maybe as much as I I would be able to for a patient. Athena: I suppose I really struggle with feeling that is there more that we could have done or how sad it is. Lucy: but more frustrating that we're not meeting their needs. So, I think that's, that's the…the difference that I think we probably could be doing more. And could have better understanding, and…you know? But, but the one model doesn't fit all.
It's the patients decision to make, not the professional's	Angela: That's still the choice, isn't it really so? Yeah, I think you know it. I don't believe that forcing people to take the treatment that you're offering, for these women is the right way because I've never done it. Catherine: I mean, it's personal choice, isn't it? I mean, it's not what I would do. But, yeah, part of me thinks it's madness, and the other part of me thinks, 'Well, it's her right to try, isn't

	it? And, you know, however it starts and however it finished, you've got to be, um, happy in your own mind as you're doing it…But, again, we're back to she has to do what she's comfortable with. Edward: And actually, these are the patients' choices to make. They're not mine..

Appendix M: Initial Codebook showing grouping of connected codes (exported from NVivo)

Name
BOUNDARIES OF RESPONSIBILITY
Can't deliberate on alternative treatments for patients
Duty is to the patient not to the system
Emotional work delegated to nurses
Have to ensure that patients fully understand what they're deciding
Not all professionals feel a responsibility to explore patients’ contexts, beliefs and decisions
Patients should be supported to do what is right for them
Professional's job is to provide the information and facts, not to force patients to have treatments
Professionals job is to treat the disease and provide the best evidence-based treatments for the patient
CLOSING THE GAP
Build trust by being there and helping
Challenging Beliefs
Compromise and openness to patients’ preferences
Exploring beliefs and understanding where the patient is coming from
Facts and logic are the tools used to convince patients
Giving an honest and frank opinion
Giving the patient the time they need-multiple consultations
Sensitive and tailored communication
Stepping outside of the professional role to understand the patient
DISCOMFORT ELICITED BY INCREASED RISK OF DEATH
Different positions on life and death
Disappointing because treatment can make such a difference
More sad when patients try and it doesn't work
Panicked that patients will die without treatment
Survival is the assumed objective
Upsetting when patients decline because professionals know the person may die

Name
Work harder to convince palliative patients
Young women missing the opportunity to be cancer free
EXPERTISE GROUNDED IN EVIDENCE
Conventional treatments offer a better chance of survival than complementary approaches
Health professionals would welcome alternatives to systemic treatments
Inaccuracies within patient beliefs
Patients are free to believe what they want but professionals know best
Patients don't know what professionals know
We know what will happen
Surgeons identifying as experts and expecting that patients wish to avail of their expertise
FORMULATION OF TREATMENT REFUSAL
A lot of information for the patient to take in
A pressure on patients to do all they can to fight cancer
Believing that faith will cure the cancer
Breast cancer and treatments can steal definitive aspects of patients' selfhood
Cancer and treatments incompatible with lifestyles and identities
Cancer forcing people to renegotiate health beliefs
Cancer is stigmatised in certain cultures
Circumstances may prevent patients from accepting treatment
Denial-disbelief
Difficult for patients to step down from entrenched positions
Disillusionment and rejection of medical authority
Fear of treatments and side effects
Holding onto control
Patients just aren't ready
Some patients don't fear death
The internet and social media providing women with alternative frameworks for understanding cancer and treatments
IT'S ABOUT GETTING THE RIGHT FIT
Different professionals have different stances on how to respond to patients
Every professional has their own relationship with treatment refusal
How the evidence is communicated is a matter of personal preference
Impact of consultant's gender

Name
It's about getting the right fit
Some clinicians get more involved
Some patients appreciate paternalism
Uncertainty as a moderator of professionals' responses
IT'S JUST A SHAME
Breast cancer is a very treatable cancer
Encouraging patients to consider their future
Hard to understand treatment refusal when contrasted with patients who would do anything but die
It seems a shame
More understandable when patients decline non-curative treatments
Often they're young and the cancer is curable
Outcomes have improved
Patients agree when it's too late
Struggling to understand patients reasoning
Trying to make patients see reason
Trying to make patients understand without frightening them
JUST IN CASE
A flexible system that minimises wait times and allows patients to return
Accepting another consultation indicates room for maneuver
Always open to further discussion if there's a chance they'll change their mind
Always try to bring people back
Ethical obligation to keep the door open
Keeping patients on the books just in case
Keeping the door open if there's hope
Making the patient feel welcome to return
The team works hard to hold onto these patients
LEARNING WHEN TO DRAW THE LINE
a good outcome is the patient doing what's right for them
Accepting the patient's right to choose comes with time and experience
Can't keep having the same conversation
Clinical resources better saved for patients who accept treatment
Developing an openness to patients’ beliefs and perspectives
Learning that doing everything is not always the right thing

Name
May persevere if the patient is declining due to circumstance
No point trying to convince a patient who has made up their mind
Observing more experienced clinicians
Once you've done all you can, you can do no more
Patients who decline move the goal posts
Renegotiating responsibility towards patients to preserve emotional wellbeing
Will invest more effort into patients who are on the fence
LENGTHS YOU GO TO
Doing everything possible to support patients to have treatment
Enlisting others who can better understand the patient needs
Hard to give up on a patient
Helping with the bigger picture
Keeping the door open but the patient has to want it
Keeping the door open takes time
Recruiting all one's energy and compassion
Repairing after breakdown
Starting from scratch when the patient returns with advanced disease
Tolerating opposition and aggression
LEVELS OF LEGITIMACY
Anti-scientific beliefs that should be respected on the grounds of equality and inclusivity-enshrined in law and policy
Moral or religious objections to treatment are more acceptable
Can only make arguments that emanate from one's own belief system (science)
Certain belief systems more legitimate than others
Making a case for conventional treatments through trials and research
Physical needs take precedence over emotional or spiritual
Professionals have research to legitimize their recommendations
Professionals make their case using logic and facts
Respect for decisions made based on faith
Such things as 'good' and 'bad' evidence
The evidence and recommendations are not up for interpretation but how its relayed to patients is a matter of style and preference
PATIENT CHOICE VERSUS PROFESSIONAL SKILL AND INFLUENCE
Ability to handle the consultations improves with experience
Communication can make a difference

Name
Emphasizing that the patient is free to choose and won't be pressured
Facts or persuasion may not be a match for emotionally laden beliefs
Limited belief in ability to influence-it's the patient’s choice
Nurses’ close relationships with patients make it harder to accept their decisions
Patients expecting judgement, paternalism and persuasion
Patients may be able to change their minds if they feel respected and safe with their HCPs
Patients may decline treatment if they don't feel pressured or uncomfortable with HCPs
Patients may sense clinician's frustration
Professionals reticent to explore what they can't understand
PATIENTS OR CUSTOMERS
Conventional treatments archaic and health professionals narrow minded
Desire for treatments that do more than manage disease
Finite range of options
Generic medicine too standardised and doesn't take a holistic health promoting approach
Getting a second opinion
Patients feel that health professionals are not sufficiently open to or aware of alternatives
Patients have access to all sorts of information about cancer which influences decision making
Patients not satisfied with the options available on the NHS
Patients spending money on ineffective treatments
Patients still want the professionals support and expertise even if declining treatment
Patients want to be seen as people
Proactive, informed patients
Taking a harder line as the second consultant
PATIENTS STEER THE COURSE
Longevity less important than QoL
Patients become more open to treatment when they start experiencing symptoms
Patients don't listen
Patients don't share plans to have alternative treatments
Patients spending money on ineffective treatments
Patients voting with their feet
Revolving door patients

Name
Some patients don't disclose alternative treatments
SUPPORTS AND RESOURCES
Absence of policy or protocols for handling these patients
Doctors seen as capable of managing without support in normal circumstances
Learning and reflecting with colleagues
Nurse role critical for the patient
Patients can be offered psychological support
support from colleagues is therapeutic
TEAM FUNCTIONING
Breast care nurses are there to support the patients, not the consultants
Consultants often take nurses advice because they know the patients better
Drs may not value nurses 'softer skills'
Nurses attempting to involve consultants in conversations about patients concerns
Patients are supported by doctors and nurses in initial consultations
Pressure from within the team
Reflection and learning between different disciplines
Shared team response to patients who decline
THAT'S THE JOB
Death and sadness are inevitable parts of the job
Focusing on the patients who can be helped
Not enough time to do right by everyone
patients who decline often return with complications
Pressure of the NHS target for surgeons
Professionalism requires that patients' beliefs are respected
Have to accept the patient's decision
The medical system does not allow for the patient's individuality
Time constraints doesn't allow consultants get into patient's beliefs and preferences
Uncomfortable conversations are part of being a cancer nurse
We can't get emotional about it
THE MEDICAL INSTITUTION
A choice not to treat is a choice to die
Assumption that patients' treatment concerns are misguided
Can accept alternative beliefs but not bad science
Can't alter evidence-based practice to accommodate irrationality

Name
Expectation that patients should do all the can while there is a chance of cure
Expecting patients will do as professionals say
Invoking medical authority in consultations
Patients at the mercy of healthcare professionals
Patients not fully recognizing professional’s position, skill and expertise.
Things have progressed but paternalism persists
Training and skill required to assess and understand evidence
Unfathomable decision to the average mind
Wrong thinking is that which is not logical, and evidence driven
THE PATIENT IS FREE TO DECIDE
Can respect decisions even if they don't agree with it
Consent being a criterion for the evaluation of practice
Emphasising choice and autonomy
If the patient has capacity, they can decide whatever they want no matter how unwise
It's the patient's decision to make not the professionals'
Open to use of complementary therapies
Patients are entitled to their beliefs
Professionals don't take offence if patients decline
The patient is free to stop treatment
THE SPECIFIC CONTRIBUTION OF NURSES
A holistic orientation more embedded within nursing as a profession
Breast care nurses are a support to patients and doctors
Nurses have rapport with patients and know their stories and positions
Nurses may help bridge the gap between patients and professionals
Nursing team responsible for following up with patients
THWARTED WORK
Curing disease and prolonging life is the goal
Difficult to accept that choice, want to help them
Failing these patients
It's smoother when patients just accept
Patient rejecting all that professionals believe in and embody
Patients are content with their choices, but professionals are left conflicted
Patients most time consuming for consultants
Pressure on doctors to do all they can for patients

Name
Tx refusal prevents professionals from realizing vocational aspects of work
US AND THEM
Culture clash
Different concepts of health and disease
different positions on life and death
Disparity between the goals, values and reference systems of patients and professionals
Extremely difficult to understand these patients and empathise with them
Patients are closed off to professionals
Patients responding to power differentials in relationships with professionals
Patients' implicit judgments of professionals and their agenda
Polarisation creating a disconnect between professionals and patients
Position as a scientist-practitioner makes it difficult to relate to patients reasoning
Professionals cannot engage all patients by the virtue of their position within the system
WE CARE ABOUT OUR PATIENTS
Frustrated that can't do more
Human connection
It's not about who's right or wrong
Nurses get to know the person and want to support them through their illness
Patients aren't blamed for disease progression
Persistence comes from a place of love
Personal regret at not meeting these patients needs
Personally invested in patient’s outcomes
Professionals concerned with the safety of alternative treatments
Professionals worry about patients being exploited
Putting thought and care into relationships with these patients
Sadness at seeing the cancer progress
WE'RE HUMAN TOO
Aggressive patients are hardest to deal with
Anxiety, uncertainty, and insecurity
Frustration making it hard to remain completely professional
Going into 'problem solving mode'
MDT meetings as a means of professional-self monitoring and quality assurance
More emotionally challenging when there's a personal resonance

Name
Overwhelming and Disappointing
Professionals have points of sensitivity
Relief when patients eventually accept
Risks of professionals being too entrenched
These cases often stay with consultants
Trying to promote awareness of personal beliefs and biases

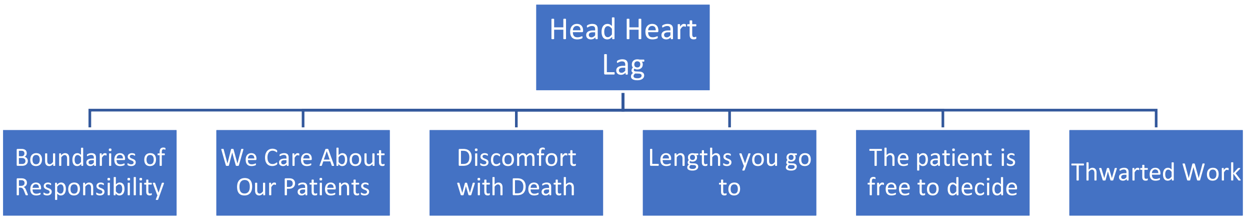
Appendix N: Extract From Reflective Diary

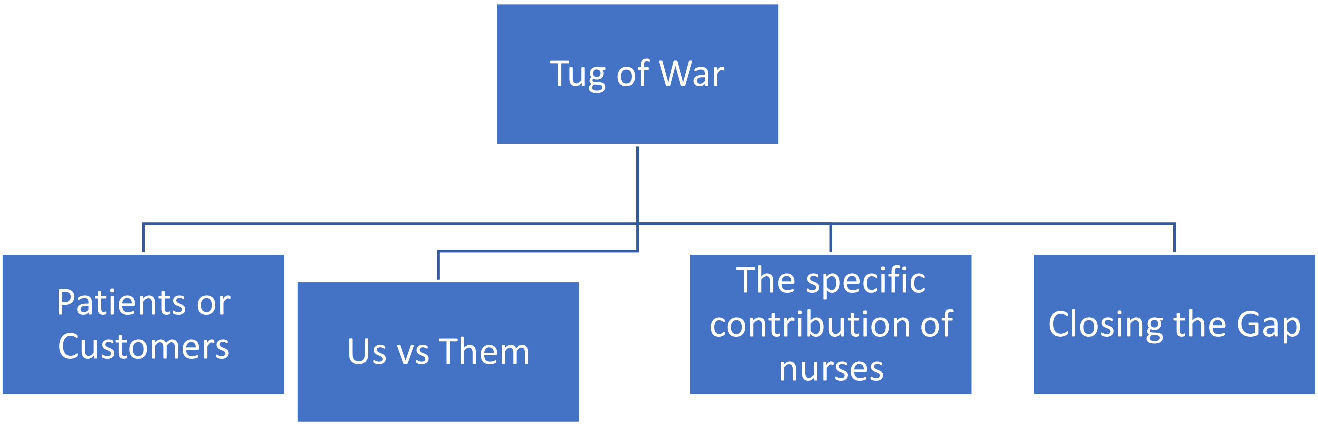
Reflections Interview 1

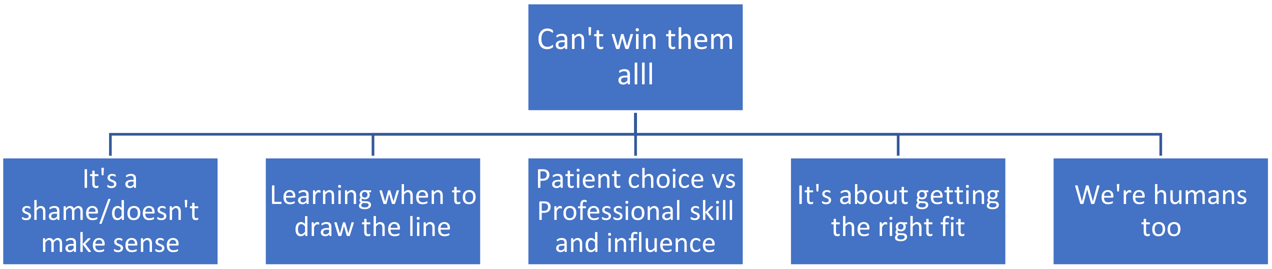
I feel like this participant represents the end result and what I would like to see happening in terms of how health professionals respond to women who decline breast cancer. It was encouraging to hear that they try to promote a respectful culture where a decision not to undergo treatment is not stigmatised within the team’s language. It was encouraging to hear that patients have been appreciative of a more open, curious approach-(means that it’s the right thing, could be effective and might result in patients feeling more inclined to undergo treatment). This felt like an easy interview in the sense that he was telling me everything that I wanted to hear and that we were aligned in our positions on patient centred care. It was interesting to speak with (clinical supervisor’s name) after and it made me wonder whether I’d taken things at face value too much in this interview. Interesting to hear that the team operates as a support system for the individual practitioner in a practical sense i.e. colleagues agreeing to see patients that individuals are struggling with, feeling like they’ve failed. I felt like this participant was very psychologically minded and was able to appreciate the ways in which a diagnosis of cancer is an assault on individual identify-particularly for individuals who are committed to wellness. Interesting discussion around the acceptability of a decision to decline based on religion vs quasi or pseudo-science. An interesting line to explore with future participants could be the doctors duty with respect to preserving life vs. autonomy. Very much felt myself just agreeing with everything he was saying-it was almost too good to be true and noticed myself wanting to go after the difficult, challenging experiences. I noticed myself wondering if he truly was comfortable with the idea that patients have the right to make unwise decisions-is that a personal belief as opposed to a tactic or strategy to convince patients or to hold space for patients reconsidering further down the line

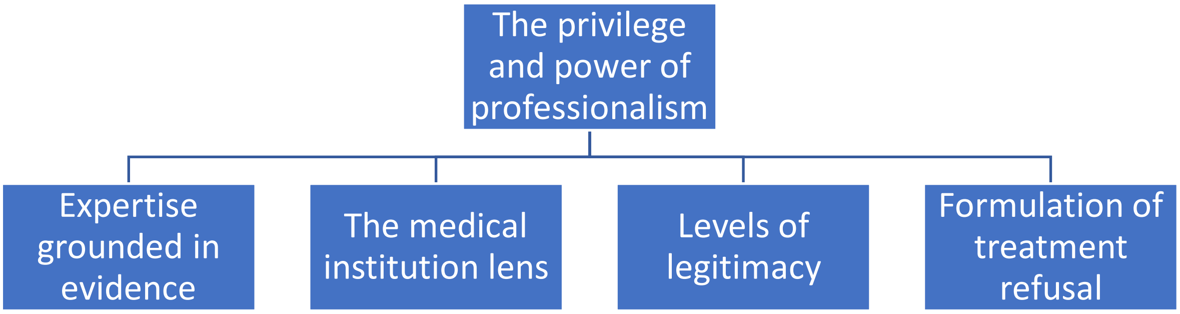
Appendix O: Examples of Progressing Thematic Maps

Initial Thematic Map






Can't win them alll
It's a shame/doesn't make sense
Learning when to draw the line
Patient choice vs Professional skill and influence
It's about getting the right fit
We're humans too


The privilege and power of professionalism
Expertise grounded in evidence
The medical institution lens
Levels of legitimacy
Formulation of treatment refusal

Intermediary Thematic Map

Theme One

Head-Heart Lag

Sub-theme 1: Boundaries of Responsibility

- Can't deliberate on alternative treatments for patients
- Duty is to the patient not to the system
- Emotional work delegated to nurses
- Have to ensure that patients fully understand what they're deciding
- Not all professionals feel a responsibility to explore patients contexts, beliefs and decisions
- Patients should be supported to do what is right for them
- Professional's job is to provide the information and facts, not to force patients to have treatments
- Professionals job is to treat the disease and provide the best evidence based treatments for the patient

Sub-theme 2: Thwarted Work

- Choosing not to treat is choosing to die
- Curing disease and prolonging life is the goal and treatment can make such a difference
- Difficult to accept that choice as want to help patients
- Failing these patients
- Frustration making it hard to remain completely professional
- Hard to give up on a patient
- MDT meetings as a means of professional-self monitoring and quality assurance
- Patient rejecting all that professionals believe in and embody
- Patients are content with their choices but professionals are left conflicted
- Personally invested in patients outcomes
- Professionals worry about patients being exploited
- Putting thought and care into relationships with these patients
- Risks of professionals being too entrenched
- Young women missing the opportunity to be cancer free

Sub Theme 3: The Patient is Free to Decide

- Can respect decisions even if they don't agree with them
- Consent being a criterion for the evaluation of practice
- Emphasising choice and autonomy
- If the patient has capacity they can decide whatever they want no matter how unwise
- It's not about who's right or wrong
- It's the patient's decision to make not the professionals'
- Open to use of complementary therapies
- Patients are entitled to their beliefs
- Professionals don't take offence if patients decline
- The patient is free to stop treatment

Sub-Theme 4: The Lengths you Go To

- Accepting another consultation indicates room for manoeuvre
- Always try to bring people back
- Doing everything possible to support patients to have treatment
- Enlisting others who can better understand the patient and their needs
- Helping with the bigger picture
- Making the patient feel welcome to return
- Recruiting all one's energy and compassion
- Repairing after breakdown
- Starting from scratch when the patient returns with advanced disease
- The team works hard to hold onto these patients
- Tolerating opposition and aggression

Theme Two

Tug of War

Sub-theme 1: Patients or Customers

- Conventional treatments archaic and health professionals narrow minded
- Generic medicine too standardised and doesn't take a holistic health promoting approach
- Getting a second opinion
- Longevity less important than QoL
- Patients don't listen
- Patients have access to all sorts of information about cancer which influences decision making
- Patients not satisfied with the options available on the NHS
- Patients spending money on ineffective treatments
- Patients still want the professionals support and expertise even if declining treatment
- Patients voting with their feet
- Proactive, informed patients
- Taking a harder line as the second consultant

Sub-theme 2: Closing the Gap

- Polarisation creating a disconnect between professionals and patients
- Extremely difficult to understand these patients and empathise with them
- Different concepts of health and disease
- Disparity between the goals, values and reference systems of patients and professionals
- Build trust by being there and helping
- Challenging Beliefs
- Compromise and openness to patients preferences
- Encouraging patients to consider their future
- Exploring beliefs and understanding where the patient is coming from
- Facts and logic as tools for convincing patients
- Giving an honest and frank opinion
- Giving the patient the time they need
- Sensitive and tailored communication
- Stepping outside of the professional role to understand the patient

Sub-Theme 3: Nurses Bridging the Distance

- A holistic orientation more embedded within nursing as a profession
- Breast care nurses are a support to patients and doctors
- Consultants often take nurses advice because they know the patients better
- Disparate team responses to treatment refusal
- Disparity between the goals, values and reference systems of patients and professionals
- Every professional has their own relationship with treatment refusal
- Nurses attempting to involve consultants in conversations about patients concerns
- Nurses may help bridge the gap between patients and professionals
- Patients are closed off to professionals
- Patients more at ease with nurses (less authoritative professionals)
- Professionals cannot engage all patients by the virtue of their position within the system

Theme Three: You Can’t Win Them All

Sub-theme 1: That’s the Job

- Death and sadness are inevitable parts of the job
- Focusing on the patients who can be helped
- Not enough time to do right by everyone
- Patients agree when it's too late
- Patients aren't blamed for disease progression
- Patients become more open to treatment when they start experiencing symptoms
- Pressure of the NHS target for surgeons
- Professionalism requires that patients beliefs are to be respected
- The medical system does not allow for the patients individuality
- Time constraints doesn't allow consultants get into patients beliefs and preferences
- Uncomfortable conversations are part of being a cancer nurse
- We can't get emotional about it

Sub-theme 2: Patient Choice vs Professional Skill and Influence

- Ability to handle the consultations improves with experience
- Communication can make a difference
- Emphasising that the patient is free to choose and won't be pressured
- Facts or persuasion may not be a match for emotionally laden beliefs
- Limited belief in ability to influence-it's the patients choice
- Nurses close relationships with patients make it harder to accept their decisions
- Patients expecting judgement, paternalism and persuasion
- Patients may be able to change their minds if they feel respected and safe with their HCPs
- Patients may decline treatment if they don't feel pressured or uncomfortable with HCPs
- Patients may sense clinician's frustration
- Professionals reticent to explore what they can't understand

Sub-Theme 3: Learning When to Draw the Line

- Accepting the patient's right to choose comes with time and experience
- Clinical resources better saved for patients who accept treatment
- Developing an openness to patients beliefs and perspectives
- Learning that doing everything is not always the right thing
- May persevere if the patient is declining due to circumstance
- No point trying to convince a patient who has made up their mind
- Observing more experienced clinicians
- Once you've done all you can, you can do no more
- Patients who decline move the goal posts
- Renegotiating responsibility towards patients to preserve emotional wellbeing
- Will invest more effort into patients who are on the fence

Theme Four: The Power and Privilege of the Medical Institution

Sub-theme 1: Formulation of Treatment Refusal

- Believing that faith will cure the cancer
- Breast cancer and treatments steal definitive aspects of patients' selfhood
- Cancer and treatments incompatible with lifestyles and identities
- Cancer is stigmatised in certain cultures
- Circumstances may prevent patients from accepting treatment
- Difficult for patients to step down from entrenched positions
- Disillusionment and rejection of medical authority
- Fear of treatments and side effects
- Holding onto control
- Patients just aren't ready
- Some patients don't fear death
- The internet and social media providing women with alternative frameworks for understanding cancer and treatments

Sub Theme 2: Levels of Legitimacy

- Anti-scientific beliefs that should be respected on the grounds of equality and inclusivity-enshrined in law and policy
- Can accept alternative beliefs but not bad science
- Can only argue from one's own belief system
- Inaccuracies within patients beliefs
- Assumption that patients treatment concerns are misguided
- Certain belief systems more legitimate than others
- Professionals have research to legitimise their recommendations
- Respect for decisions made on the basis of faith
- Such things as 'good' and 'bad' evidence

Sub Theme 3: Translucent Lens of the Medical Institution

- Patients are free to believe what they want but professionals know best
- Can't alter evidence based practice to accommodate irrationality
- Expectation that patients should do all they can while there is a chance of cure
- Expecting patients will do as professionals say
- Invoking medical authority in consultations
- Patients at the mercy of healthcare professionals
- Things have progressed but paternalism persists
- Training and skill required to assess and understand evidence
- Unfathomable decision to the average mind
- Wrong thinking is that which is not logical or evidence driven
- Physical needs take precedence over emotional or spiritual

Final Thematic Map

Theme One

Head-Heart Lag

HCPS recognise their professional obligation to respect the patient’s choice, however this obligation obstructs vocational, altruistic aspects of the role which emanate from the commitment to curing disease and prolonging life. The decision to decline thwarts the life prolongation mission and forces HCPs to engage with patient mortality. This elicits uncomfortable, conflicted feelings that are safeguarded against by intellectually revisiting the ethical frameworks that underpin professional conduct and the boundaries of one’s professional responsibilities and duties. While this helps to guide practice, professionals struggle to completely disengage from their fundamental hope of patients surviving cancer and practices and infrastructures are designed to support patients to reconsider.

Sub-theme 1: Boundaries of Responsibility

- Can't deliberate on alternative treatments for patients
- Duty is to the patient not to the system
- Emotional work delegated to nurses
- Have to ensure that patients fully understand what they're deciding
- Not all professionals feel a responsibility to explore patients contexts, beliefs and decisions
- Patients should be supported to do what is right for them
- Professional's job is to provide the information and facts, not to force patients to have treatments
- Professionals job is to treat the disease and provide the best evidence based treatments for the patient

Sub-theme 2: Thwarted Work

- Choosing not to treat is choosing to die
- Curing disease and prolonging life is the goal and treatment can make such a difference
- Difficult to accept that choice as want to help patients
- Failing these patients
- Hard to give up on a patient
- MDT meetings as a means of professional-self monitoring and quality assurance
- Patient rejecting all that professionals believe in and embody
- Patients are content with their choices but professionals are left conflicted
- Personally invested in patients outcomes
- Putting thought and care into relationships with these patients
- Risks of professionals being too entrenched
- Young women missing the opportunity to be cancer free

Sub Theme 3: The Patient is Free to Decide but…..

- Can respect decisions even if they don't agree with them
- Emphasising choice and autonomy
- If the patient has capacity they can decide whatever they want no matter how unwise
- It's not about who's right or wrong
- It's the patient's decision to make not the professionals'
- Open to use of complementary therapies
- Professionals worry about patients being exploited
- Patients are entitled to their beliefs
- Always try to bring people back
- Doing everything possible to support patients to have treatment
- Enlisting others who can better understand the patient and their needs
- Making the patient feel welcome to return
- Recruiting all one's energy and compassion
- Starting from scratch when the patient returns with advanced disease
- The team works hard to hold onto these patients
- Tolerating opposition and aggression

Theme Two

Tug of War

Dynamic positioning and re-positioning within patient-professional relationships as patients enact their preferences and professionals manoeuvre in an effort to lessen the disconnect with patients whose goals, values and frameworks for understanding cancer fall outside the conventions of contemporary healthcare. Professionals attempt to bridge the distance by stepping into the patient's world or pulling patients into their ways of thinking and acting in response to cancer. Nurses are critical players within this endeavour as their close relationships and personal investment in patient outcomes can facilitate dialogue and care provision that recognises the person as an individual and not a patient. This integration of patient's preferences may reflect a medium through which professional's objectives can be translated into a message that patients can receive and take up.

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- Conventional treatments archaic and health professionals narrow minded
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- Longevity less important than QoL
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- Challenging Beliefs
- Compromise and openness to patients preferences
- Encouraging patients to consider their future
- Exploring beliefs and understanding where the patient is coming from
- Facts and logic as tools for convincing patients
- Giving an honest and frank opinion
- Giving the patient the time they need
- Sensitive and tailored communication
- Stepping outside of the professional role to understand the patient
- Trying to make patients understand without frightening them

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Theme Three: You Can’t Win Them All

The process of professionals reconciling their limitations and learning to step away from the professional raison d'être and accept that sadness and disappointment are unavoidable within oncology. Experience and seniority help professionals realize that part of the work is making peace with factors that are beyond personal control, such as constrained resources and patient decisions, but this can feel risky and precarious when human life is at stake. The ability to accept patients’ decisions develops with time and experience, as professionals grapple with their responsibilities to patients and the wider system and the extent to which they can influence patient decision making. Professionals re-evaluate hopes and objectives for the work with this patient group, striving to connect with patients and to cultivate the conditions in which the patient can safely make the decision that feels right for them, rather than persuading them to have treatment.

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- Focusing on the patients who can be helped
- Not enough time to do right by everyone
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- Will invest more effort into patients who are on the fence

Theme Four: The Power and Privilege of Unbiased Expertise

Professionals have insight into the complex factors which underpin the patient's choice to decline breast cancer treatment, but the ability to truly regard these decisions as valid or reasonable is limited by the epistemic privileging of beliefs and practices that emanate from the medical institution. The ideological basis of these conventions is obscured due to associations with science which is considered an objective, neutral system of inquiry. The neutrality of evidence-based practice legitimises professionals and permits them to evaluate the rationality of patient choices without referencing the power they hold as gatekeepers or purveyors of the scientific evidence, or engaging with the expectations this engenders for patient-professional exchanges. While the objectivity of evidence based practice precludes personal identification with science and medicine as dominant institutions, professionals also exhibit a sense of ownership over scientific pursuits and frustration for patients and treatments who use science incorrectly to justify their claims.

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