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Premature Menopause Symptoms Following Cancer Treatment: A Systematic Review, Synthesis and Qualitative Investigation of Lived Experiences When Choosing Not to Undergo Cancer Treatment

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Doctorate in Clinical Psychology

Institute of Health and Wellbeing  
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## TABLE OF CONTENTS

Table of Contents	2
List of Tables	4
List of Figures	5
Acknowledgements	6
<b>CHAPTER 1</b>	7
1. ABSTRACT	8
2. INTRODUCTION	9
3. MATERIALS & METHODS	11
3.1. Search Strategy	11
3.2. Search Terms	11
3.3. Eligibility Criteria	12
3.4. Study Selection	12
3.5. Data Extraction	13
3.6. Critical Appraisal	13
3.7. Synthesis Method	13
3.8. Reflexivity Statement	14
4. RESULTS	14
4.1. Identification of Studies	15
4.2. Characteristics of Participants and Included Studies	16
4.3. Qualitative Appraisal	24
4.4. Results of Thematic Synthesis	26
5. DISCUSSION	38
5.1. Strengths and Limitations	41
5.2. Implications and Conclusions	42
6. REFERENCES	44
<b>CHAPTER 2</b>	51
PLAIN LANGUAGE SUMMARY	52
1. ABSTRACT	53
2. INTRODUCTION	54
3. MATERIALS & METHODS	56
3.1. Ethics	56
3.2. Design	56
3.3. Reflexivity Statement	57
3.4. Recruitment Procedure	57
3.5. Participant & Clinical Characteristics	58
3.6. Justification of Sample Size	58
3.7. Research Procedure	59
3.8. Thematic Analysis	59
4. RESULTS	59
5. DISCUSSION	71
5.1. Implications for Clinical Practice and Services	75
5.2. Methodological Strengths & Limitations	76
5.3. Future Research	77
5.4. Conclusions	78
6. REFERENCES	79
APPENDICES	86
Appendix 1 – Search Strategy Sample	86

Appendix 2 – Data Extraction Form	87
Appendix 1 [Online] MRP Proposal (Proceed to ethics approval)	88
Appendix 2 [Online] MRP Protocol (IRAS Submission]	89
Appendix 3 [Online] Participant Information Sheet	90
Appendix 4 [Online] Semi-Structured Interview Guide	91
Appendix 5 [Online] Consent Form	92
Appendix 6 – Sample of Transcript (Initial Coding)	93
Appendix 7 – Screenshot of Theme Development	94
Appendix 8 – Excerpts From Reflective Diary	95
Appendix 9 – Ethics Board and NHS Board Approval Letters	96

# List of Tables

## **CHAPTER 1: Systematic Review**

Table 1. Study Sample & Clinical Characteristics Including Core Themes & Sub-Themes.....17

Table 2. Critical Appraisal Skills Programme UK (CASP, 2022) Ratings.....25

## **CHAPTER 2: Major Research Project**

Table 1. Overview of Participant and Clinical Characteristics.....58

Table 2. Core Themes and Sub-Themes.....60

## List of Figures

Figure 1. Adapted PRISMA (2020) Flow Diagram of Search Strategy.....	15
Figure 2. Thematic map of findings, showing the relationship between descriptive themes/sub-themes and analytical themes.....	34

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## Chapter 1

### Women's Experiences of Premature Menopause Following Cancer Treatment: A Systematic Review and Thematic Synthesis

Prepared in accordance with the author requirements for The Frontiers In  
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## 1. ABSTRACT

**Background and Aims:** Premature menopause occurs spontaneously or following medical treatment such as chemotherapy, radiotherapy, hormone therapy or after surgical removal of the ovaries. Symptoms of premature menopause can be distressing and impact quality of life. The review aimed to synthesise and appraise findings of women's experiences of premature menopause symptoms following cancer treatment and to what extent they have felt prepared and supported. **Method:** A thematic synthesis was conducted across eleven articles reporting on nine studies. **Results:** Three overarching analytical themes were identified weaved through a lens of implicit gender bias; 1) women perceived a lack of information and healthcare-related support and felt unprepared for premature menopause symptoms; 2) premature menopause symptoms were perceived as either not being fully addressed, attributed to something else, or minimised; 3) premature menopause was found to be associated with perceptions of accelerated ageing, physical decline, loss of womanhood, sexuality desirability and sexual identity impacting on sexual and psychological health. **Conclusions:** Overall, findings report premature menopause symptoms following cancer treatment as a distressing and often physical and emotionally painful experience impacting quality of life, further compounded by disparities in women's healthcare, inadequate information, support, understanding, and preparation that requires urgent review by health care providers.

Keywords: Qualitative; thematic synthesis; lived experience; premature menopause; cancer treatment

## 2. INTRODUCTION

Menopause is a transition most women experience between ages 45 and 55 (National Institute for Health and Care Excellence, NICE, 2019). Menopause before age 40 is called premature menopause or premature ovarian insufficiency (POI) (NICE, 2019). However, this cut-off has been subjectively applied due to the difficulties in providing accurate age approximations for when natural menopause occurs in women within developing countries (International Menopause Society, 2021). The global prevalence of premature menopause is estimated at 3.7% (Golezar et al., 2019). Premature menopause that occurs following invasive medical procedures has been described in various terms, including: 'chemotherapy-induced menopause' (Poniatowski, Grimm & Cohen, 2001), 'treatment-induced menopause' (Chang, Hu & Chang, 2021) and 'surgical menopause', a procedure where the ovaries have been removed resulting in immediate menopause (Secoşan et al., 2019).

Adjuvant chemotherapy is estimated to cause premature menopause in up to 40% of women under 40, with younger women reporting more severe symptoms (Mar Fan et al., 2010). The risk of premature menopause following radiotherapy is affected by the direction of the radiation field, dose, and age, with the risk following chemotherapy dependent on age and drug dose (Australian Menopause Society, 2020; Wallace et al., 2005; Gracia et al., 2012). Symptoms of premature menopause include hot flashes, vaginal dryness, vaginal bleeding/spotting, vaginal itching, pain during intercourse, cold sweats, night sweats, loss of libido, weight gain, breast tenderness, mood swings, tiredness, low self-esteem, bone thinning and irritability, which can be distressing and impact on quality of life for women (Golezar et al., 2020; Rosenberg & Partridge, 2013).

Women with breast cancer who have undergone cancer treatment may experience temporary or permanent premature menopause, with worsening symptoms of menopause associated with the sudden onset of treatment (Poniatowski, Grimm & Cohen, 2001). For some women, the impact of infertility following cancer treatment or removal of the ovaries as a prophylactic measure to prevent further cancer has been reported to have detrimental effects on psychological wellbeing (Perz, Ussher & Gilbert, 2014). Furthermore, women report feeling ill-prepared for premature menopause following cancer treatment, and further enquiry about menopause symptoms from clinicians would have been welcome

(Knobf, 2002). However, some clinicians have reported feeling ill-prepared to discuss infertility and fertility preservation issues due to cancer treatment (Covelli et al., 2019).

The distressing and life-changing impact of premature menopause symptoms on women's biopsychosocial and sexual functioning is a significant and undertreated clinical issue. Previous qualitative reviews have either focused on women's experience of natural menopause or the overall experience of adult cancer patients. Hoga et al., (2015) conducted a qualitative systematic review exploring women's experiences of natural menopause through a social and cultural lens. Findings revealed how women experience menopause determined by a combination of personal and socio-cultural perspectives. Physical symptoms such as hot flashes and night sweats were reported to have the most detrimental effect on quality of life. However, women's experience of natural menopause can differ from premature menopause following cancer treatment.

After cancer treatment, some women live with distressing menopause symptoms for longer and experience significantly reduced oestrogen levels (Breast Cancer Care, 2014). Hormone Replacement Therapy (HRT) is contraindicated for those with breast and oestrogen-related cancers (NICE, 2022). Additionally, these women are at increased risk of cardiovascular disease and osteoporosis in later life (Shuster et al., 2010). Following cancer treatment or surgery, infertility can be a life-changing event for premenopausal women (Vitale et al., 2017; Griffiths et al., 2020). Bennion and Molassiotis (2013) conducted a systematic review and meta-synthesis of qualitative research exploring symptom experiences following cancer treatment.

Key findings relating to premature menopause were that women felt that menopause symptoms contributed to an extensive list of problems to overcome and came as a shock to some. In addition, both reviews reported a need for improved communication between patients and healthcare professionals (HCPs) for women to feel better prepared for menopause. However, to the author's knowledge, no systematic qualitative reviews have explicitly focused on women's experiences of premature menopause symptoms following cancer treatment. Therefore, this review will update and elaborate on Bennion and Molassiotis' (2013) findings concerning premature menopause following cancer treatment, synthesising the current evidence to inform clinical practice and further research.

The review aims to identify, synthesise, and interpret studies of women's experiences of premature menopause symptoms following cancer treatment, explore their perceptions of related healthcare support, and appraise the quality of studies identified for review. Additionally, results from the qualitative synthesis would aim to inform HCPs, healthcare systems and wider society of the specific needs of this clinical population and the meaning assigned to their experiences. This information may help to tailor interventions, inform policy and clinical practice, and subsequently improve patient outcomes and quality of life during, what may be a challenging adjustment for those women affected.

### **3. MATERIALS & METHODS**

Guidance from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was adhered to (Page et al., 2021). In addition, the review protocol was pre-registered with PROSPERO International Prospective Register of Systematic Reviews [CRD42021224800].

#### **3.1. Search Strategy**

A systematic review of the literature was conducted in December 2021. Electronic databases Medline, PsychINFO, EMBASE and CINAHL were used to locate studies. No predetermined time period was specified for the review. References and citations were searched within included studies. The PICOD framework for systematic qualitative reviews (Soilemezi & Linceviciute 2018), i.e., Population, Phenomenon of Interest, Context, Outcome of interest and Design, was used to develop the review question and search terms (Appendix 1).

#### **3.2. Search Terms**

Key terms were identified following initial scoping of relevant literature and reviewed by specialist librarians for sensitivity and specificity. Databases were searched using the following terms with synonyms and truncated if necessary:

1. (Premature menopause) OR (Early menopause) OR (Surgical menopause) OR (chemo\* induced menopause) OR (Premature ovarian failure)

2. Chemotherapy OR "radiotherapy" OR "Bilateral Salpingo oophorectomy" OR Tamoxifen
3. "Qualitative" OR "semistructured" OR semistructured OR unstructured or informal OR "in-depth" OR indepth OR "face-to-face"

Furthermore, a validated qualitative search filter was used and if necessary, modified according to the database utilised. Search terms were combined with the "OR" Boolean operator into a separate group using the "AND" function to narrow the search and produce a final list of citations. Finally, MESH subject headings were applied where appropriate.

### **3.3. Eligibility Criteria**

Studies were eligible for inclusion if: (i) participants were female, aged 18 years and above and had experienced premature menopause symptoms following cancer treatment or had undergone a bilateral Salpingo-oophorectomy<sup>1</sup> (ii) published in a peer-reviewed journal; (iii) full text available in English; (iv) reported qualitative data. No age limit was set for participants. This allowed the experiences and retrospective accounts of all women who self-identify as experiencing premature menopause symptoms following cancer treatment to be included. Studies were excluded if they: (i) focused on women's experiences of menopause symptoms as a natural biological process; (ii) reported a non-iatrogenic cause for premature menopause symptoms; (iii) used quantitative methods only.

### **3.4. Study Selection**

Following the search, all citations were exported to the RefWorks reference management system, duplicates removed, and titles and abstracts screened against the eligibility criteria. A second reviewer, a research assistant (GG), screened a subset (n =321/914) of titles and abstracts and the full text (n=14/20) of the remaining studies to increase reliability. The initial agreement was 90%. Following further discussion, both reviewers finally reached a 100% consensus regarding all studies that were co-screened/co-rated. (Figure 1).

---

<sup>1</sup> A Bilateral Salpingo Oophorectomy is the removal of both fallopian tubes (Salpingo-) and ovaries (oophorectomy). It is a surgical procedure to treat ovarian cancer.

Unfortunately, one potential paper could not be accessed despite efforts to contact the authors (McCarthy et al., 2007).

### **3.5. Data Extraction**

A data extraction tool was applied to all the included studies within the review (Appendix 2). The subsequent information was extracted from each study: author/s, year, country, number of participants, mean age and range, ethnicity, number of participants with children, sexual orientation, cancer type, type of treatment given, time since cancer diagnosis, data collection method, analysis, core themes and sub-themes. This process included further extraction of the authors' interpretations, supported by participant quotations from each primary study's 'findings' or 'results' section, in preparation for line by line coding and synthesis, including findings reported in abstracts as described in Thomas and Harding's (2008) guidelines.

### **3.6. Critical Appraisal**

The Critical Appraisal Skills Programme Tool (CASP, 2022) is a validated ten-item checklist that appraises the methodology of a study's strengths and limitations and can be used for qualitative research to assess the risk of bias and quality of studies. It was chosen as recommended by the Cochrane Collaboration and is suitable for novice researchers (Long, French & Brooks, 2020). In addition, the CASP tool is designed for health-related research and provides clarity in reporting research practices (CASP, 2022). The second rater (GG) rated a sample of papers (n=3) with initial agreement at 90%, and a complete consensus was reached following further discussion. Since rating quality in qualitative systematic reviews remains contentious due to epistemological differences (Garside, 2014; Dixon-Woods et al., 2006), the rationale for quality appraisal was not to exclude poor-quality studies but to interpret the quality of studies relative to their potential impact on findings (Thomas and Harding, 2008).

### **3.7. Synthesis Method**

Thematic synthesis (Thomas and Harding, 2008) was approached from a critical realist standpoint which assumes that our understanding is connected to our perceptions, attitudes, and opinions; these are then constructed and ingrained within our cultural setting

and language (Barnett, Page, & Thomas, 2009; Braun and Clarke, 2022). Critical realism provided a lens to share and understand women's lived experiences of premature menopause and illuminate their descriptions' social and cultural contexts. Thematic synthesis was chosen in line with the review's aims of integrating information to inform clinical practice. The method was initially developed to help conduct systematic reviews that focus on questions relative to future intervention requirements or effectiveness and are deemed relevant to inform policy and clinical practice (Barnett, Page & Thomas, 2009).

Thematic synthesis is an integrative and interpretative approach (Nicholson et al., 2016) and follows a three-stage process. First, the verbatim findings from the included studies are inductively coded line by line in stage one. Next, in stage two, descriptive themes are created by explaining the concepts from each study in turn, where codes are clustered according to their similarities and variances. Finally, in stage three, the generation of analytical themes helps develop new hypotheses, interpretations, and concepts, stretching beyond the findings of the primary studies, which may help inform health policy and develop an intervention.

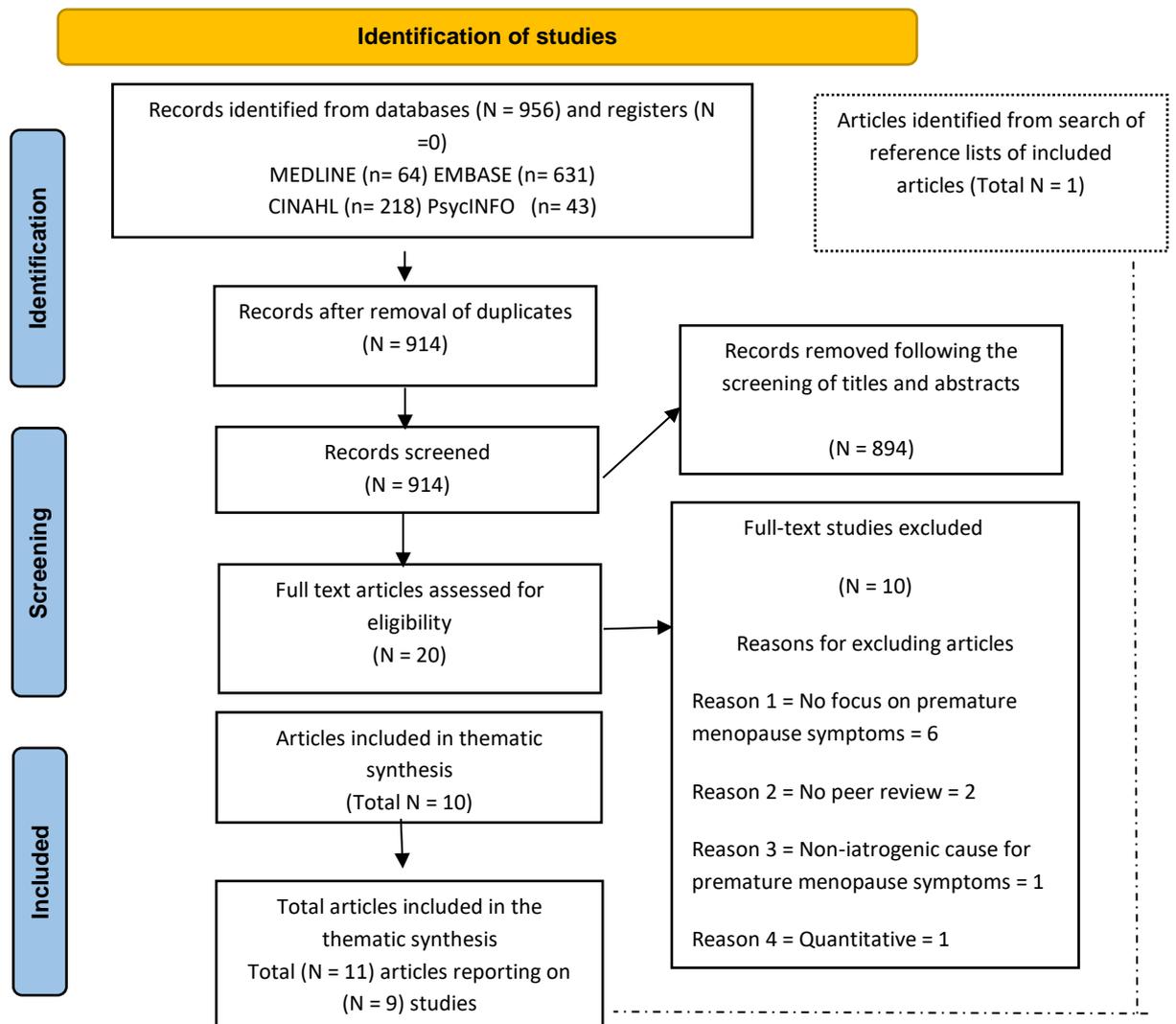
### **3.8. Reflexivity Statement**

The primary reviewer (AC) is a white Trainee Clinical Psychologist from a working-class background in the West of Scotland with previous training in mental health nursing and cognitive behavioural psychotherapy. Initially, navigating, acknowledging, and reconciling their positivist orientation in evidence-based practice was challenging. A reflexive inductive, interpretative approach to the research was adopted. Documenting in a journal and engaging in reflexive discussions during supervision provided space to acknowledge how their values, subjective experiences of menopause and cancer, and social and political alignment have shaped the research from the original question formation to data collection, analysis, and interpretation.

## **4. RESULTS**

#### 4.1. Identification of Studies

Electronic database searches identified 956 citations. Duplicates were removed, leaving 914 titles and abstracts to be screened for inclusion (Figure 1), resulting in 20 full texts being retained. Of the remaining 20 articles, 10 were excluded. A reference list citation search was conducted for the remaining ten articles, and one additional article that met eligibility was discovered. Three articles reported the same study sample (Knobf, 2001; Knobf, 2002; Knobf, 2008). However, they were all included as they report on different characteristics relative to women’s experience of premature menopause following cancer treatment. The three articles were collated into a single source point to minimise sample over representation within the consequent synthesis. The synthesis, therefore, included nine studies from eleven articles.



**Figure 1.** Adapted Prisma (2020) Flow Diagram of Search Strategy

## 4.2. Characteristics of Participants and Included Studies

The nine studies included in the synthesis were published between 2000 and 2017 (Table 1). Four were conducted in the United States, two in Canada, two in Australia and one in the United Kingdom. Data were collected from 1053 female participants aged 25 to 68 (mean = 44.7 years). The majority (66%) of participants' ethnicity was not reported; 28.6% were reported as Caucasian, 2% as Latina, with the remainder identifying as Black British (3.32%), African American (0.04%) and 'other' (0.04%).

Qualitative data were obtained from one-to-one and telephone interviews, focus groups and open-ended survey questions, with 72% of participants diagnosed with breast cancer, 8% with gynaecological cancer, 8.7% with haematological cancer and 11.3% reported as having other cancer types. Treatments reported included chemotherapy, radiotherapy, and/or hormone therapy (Tamoxifen). One study (Parton et al., 2017) did not report which type of cancer treatment was administered. The primary author was contacted but could not provide the information at the time of the request. The time since cancer diagnosis was not reported for four studies, with the remaining five studies reporting time since diagnosis between six months and ten years.

Six studies did not report whether participants had children. Of the three studies reporting this, 81% had children. Only two studies reported sexual orientation, reporting all participants as heterosexual. Analysis methods included thematic analysis, grounded theory, thematic decomposition analysis, content analysis and phenomenological analysis. Studies primarily focused on understanding and describing women's experience of premature menopause or sexual functioning following cancer treatment. Themes and sub-themes reported ranged from working through the menopause experience, menopause symptoms, seeking information and the impact on functioning from a biopsychosocial lens.

Table 1. Study, Sample & Clinical Characteristics Including Core Themes/Sub-Themes

Study	Authors (Year) & Country	Sample & Clinical Characteristics	Data Collection Method & Analysis	Core Themes and Sub-Themes
S1	Anderson et al., (2011)  Australia	n = 16 <b>Mean age (Range):</b> 44 (35-53) <b>Ethnicity:</b> N/R <b>Number with Children:</b> N/R <b>Sexual Orientation:</b> N/R <b>Cancer Type:</b> Breast Treatment: Surgery, Radiology or Chemotherapy <b>Time since cancer diagnosis:</b> N/R	Focus groups  <i>Thematic analysis</i>	<b>Menopausal Symptoms: Types and Experiences</b> <i>Hot Flushes, night sweats &amp; sleeplessness</i> <i>Dry vagina &amp; lack of sex</i> <i>Irritability, depression &amp; memory impairment</i> <i>Weight gain</i> <i>Positive aspects of menopause</i>  <b>Lack of Knowledge and Information</b> <b>Feeling Old</b> <b>Effects on Work-Life and Career</b> <b>Health Practitioner Support and Management and Supportive Strategies</b>
S2	Archibald et al., (2006)  Canada	n = 30 <b>Mean age (Range):</b> 45 (31-57) <b>Ethnicity:</b> "Mostly Caucasian" <b>Number with children:</b> N/R <b>Sexual Orientation:</b> N/R <b>Cancer Type:</b> Breast <b>Treatment:</b> <ul style="list-style-type: none"> <li>• Tamoxifen 20%</li> <li>• Chemotherapy 30%</li> <li>• Tamoxifen &amp; Chemotherapy 47%</li> </ul>	Semi-structured interviews  <i>Thematic Analysis</i>	<b>Changes in Sexual Functioning Following Treatment</b> <i>Negative changes</i> <i>No change</i> <i>Positive changes</i>  <b>Impact of Negative Changes in Sexual Functioning</b> <i>Negative impact</i> <i>Indifference</i>  <b>Moderators of Experienced Negative Impact</b> <i>Obtaining information</i> <i>Adjusting sexual repertoire</i> <i>Patience and understanding</i>

		<b>Time since cancer diagnosis:</b> Between 1 and 4 years		<i>Looking for a brighter side</i>
<b>S3</b>	Avis et al., (2004)  United States	<b>n</b> = 204 <b>Mean age (Range):</b> 43 (25-50) <b>Ethnicity:</b> <ul style="list-style-type: none"> <li>• Caucasian 96%</li> <li>• African-American 2%</li> <li>• Classified themselves as other 2%</li> </ul> <b>Number with children:</b> n = 150 (74%) <b>Sexual Orientation:</b> N/R  <b>Cancer Type:</b> Breast <b>Treatment:</b> chemotherapy, radiotherapy <b>Time since cancer diagnosis:</b> 3 years	Open-ended survey questions  <i>Thematic Analysis</i>	<b>Some women welcomed end of menses</b> <b>Impaired sexual functioning</b> <b>Bothersome menopause symptoms - hot flashes (64%), vaginal dryness (49%), and pain with sexual intercourse (45%)</b> <b>Difficulties adjusting to premature menopause</b> <b>Difficulties adjusting to infertility</b>
<b>S4</b>	Brisbois (2014)  United States	<b>n</b> = 20 <b>Mean age (Range)</b> = 45 (30-60) <b>Ethnicity:</b> Latina <b>Number with children:</b> N/R <b>Sexual Orientation:</b> N/R	Telephone Interviews  <i>Interpretative Description Methodology</i>	<b>Bigger Than Menopause</b> <i>Experiencing menopause</i> <i>Ever-changing landscape</i> <i>Working through the experience</i>  <b>Experiencing Menopause</b> <b>Ever-Changing Landscape</b>

		<p><b>Cancer Type:</b> Breast</p> <p><b>Treatment:</b> Chemotherapy, surgery, radiation therapy</p> <p><b>Time since cancer diagnosis:</b> Average 4.6 years, (SD=2.6, range 0.17-11)</p>		<p><b>Working Through the Experience</b></p> <p><i>Being Held Back</i></p> <p><i>Keeping Things Running</i></p>
S5	<p>Davis, Zinkand &amp; Fitch, (2000)</p> <p>Canada</p>	<p>n = 8</p> <p><b>Mean age (Range):</b> 41 (33-57)</p> <p><b>Ethnicity:</b> N/R</p> <p><b>Number with children:</b> 8 (100%)</p> <p><b>Sexual Orientation:</b> N/R</p> <p><b>Cancer Type:</b></p> <ul style="list-style-type: none"> <li>• Breast 50%</li> <li>• Gynaecological 50%</li> </ul> <p><b>Treatment:</b> Chemotherapy, radiation, bilateral Salpingo-oophorectomy &amp; omentectomy</p> <p><b>Time since cancer diagnosis:</b> N/R</p>	<p>Audio recorded interviews</p> <p><i>Phenomenological analysis</i></p>	<p><b>The Cancer Experience</b></p> <p><b>The Menopause Experience</b></p> <p><b>“Getting through”</b></p> <p><i>Taking and Keeping Control</i></p> <p><i>(Not) Returning to Normal</i></p> <p><i>Maintaining/Changing Sense of Self</i></p> <p><b>The Power of Knowing</b></p> <p><b>The Power of Support</b></p>
S6	<p>Hunter et al., (2009)</p> <p>United Kingdom</p>	<p>n =35</p> <p><b>Mean age = 52, SD= (6,3)</b></p>	<p>Questionnaires</p>	<p><b>Cognitions Associated With Hot Flushes and Night Sweats</b></p>

		<p><b>Ethnicity:</b></p> <ul style="list-style-type: none"> <li>• White British: 91%</li> <li>• Black British: 9%</li> <li>• Number of women with children: N/R</li> </ul> <p><b>Sexual Orientation:</b> N/R</p> <p><b>Cancer Type:</b> Breast</p> <p><b>Treatment</b></p> <ul style="list-style-type: none"> <li>• Chemotherapy 57%</li> <li>• Radiotherapy 86%</li> <li>• Tamoxifen 74%</li> <li>• Adjuvant therapies 17%</li> </ul> <p><b>Time since cancer diagnosis:</b> N/R</p>	<p>Open-ended Survey questions</p> <p>Thematic Content Analysis</p>	<p><i>Embarrassment/ social anxiety</i> <i>Out of control/unable to cope</i> <i>Night sweats, sleep quality and resulting tiredness</i></p> <p><b>Behavioural Strategies To Deal With Hot Flushes and Night Sweats</b></p> <p><i>Carry on and ignore them</i> <i>Taking practical steps to cool down</i> <i>Avoidance</i> <i>Communicate with others</i></p>
<b>S7*</b>	<p>Knobf (2001; 2002; 2008)</p> <p>United States</p>	<p>n = 27</p> <p><b>Mean age:</b> 41, SD = (3, 7)</p> <p><b>Ethnicity:</b> White</p> <p><b>Sexual Orientation:</b> N/R</p> <p><b>Number of women with children:</b> N/R</p> <p><b>Cancer Type:</b> Breast</p>	<p>Interviews</p> <p>Constant comparative method of data analysis for Grounded Theory</p>	<p><b>The Menopausal Symptom Experience (2001)</b></p> <p><i>Menopausal symptoms</i> <i>Weight gain</i> <i>Alterations in mood and memory</i> <i>Sexuality</i> <i>Long-term effects of menopause</i></p> <p><b>The Process of 'Carrying On' – Four Stages (2002):</b></p> <p><i>Being focused</i> <i>Facing uncertainty</i> <i>Becoming menopausal</i></p>

		<p><b>Treatment:</b></p> <ul style="list-style-type: none"> <li>• Chemotherapy: 100%</li> <li>• Tamoxifen: 37%</li> </ul> <p><b>Time since cancer diagnosis:</b> 4.5 years (<math>\pm</math> 0.43) with a range of one to nine years</p>		<p><i>Balancing</i></p> <p><b>The Process Of 'Carrying On' – Three Types Of Responses (2008):</b>  <i>Making the best of it</i>  <i>Struggling</i>  <i>Barely noticing</i></p>
<b>S8</b>	Parton et al., (2017)  Australia	<p><b>Total n</b> = 695 completed online survey</p> <p><b>Subset n</b> = 61 of the total took part in semi-structured interviews</p> <p><b>Mean age:</b> 42 (SD = 14.21)</p> <p><b>Ethnicity:</b> N/R  <b>The number of women with children:</b></p>	Open-ended survey accounts and one-to-one semi-structured interviews for a subset of participants Thematic decomposition	<p><b>'I Don't Feel Like a Whole Woman': The Incomplete Woman</b>  <b>'I Often Feel Frumpy and Depressed: 'The Abject Asexual Woman</b>  <b>'I Feel Old Before My Time.': Out Of Time and Social Isolation</b></p>

		<ul style="list-style-type: none"> <li>• Survey respondents: 57%</li> <li>• Interviewees: 26%</li> </ul> <p><b>Sexual Orientation:</b></p> <ul style="list-style-type: none"> <li>• Heterosexual (98%)</li> <li>• Non-heterosexual (1.88%)</li> </ul> <p><b>Cancer Type:</b></p> <ul style="list-style-type: none"> <li>• Breast (56.7%)</li> <li>• Gynaecological (12.9%)</li> <li>• Hematologic (12.7%)</li> <li>• Other (17.1%)</li> </ul> <p><b>Treatment:</b> N/R</p> <p><b>Time since cancer diagnosis:</b> N/R</p>		
S9	Wilmoth (2001)  United States	<p>n = 18</p> <p><b>Mean age:</b> 50, Age range 35-68</p> <p><b>Ethnicity:</b> Caucasian 100%</p> <p><b>Number of women with children:</b> N/R</p> <p><b>Sexual Orientation:</b> Heterosexual</p>	<p>One-to-one interviews</p> <p>Grounded Theory</p>	<p><b>Losses</b></p> <p><i>Missing parts</i></p> <p><i>Loss of bleeding-becoming old</i></p> <p><i>Loss of sexual sensations</i></p> <p><i>Loss of womanhood</i></p> <p><b>Influencing Pieces</b></p> <p><i>Relationships</i></p> <p><i>Information control</i></p>

		<p><b>Cancer type:</b> Breast</p> <p><b>Treatment:</b></p> <ul style="list-style-type: none"> <li>• Adjuvant chemotherapy with radiation therapy (44%)</li> <li>• Adjuvant chemotherapy only (17%)</li> <li>• Adjuvant chemotherapy with hormone therapy (33%)</li> <li>• No adjuvant therapy (1%)</li> <li>• Lumpectomy (39%)</li> <li>• Mastectomy (61%)</li> </ul> <p><b>Time since cancer diagnosis:</b> range 6 months to &gt;10yrs</p>		<p><b>The Core Variable</b> <i>Altered sexual self</i></p> <p><b>Underlying Process</b> <i>Taking in</i> <i>Taking hold</i> <i>Taking on</i></p>
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Abbreviations: N/R = Not Reported \* = Three articles collated as they reported from the same sample

### 4.3. Quality Appraisal

Most studies were rated as high quality (Table 2). Overall, the aims of the included studies were clearly stated, and the appropriate qualitative methods were adopted. Research designs and data collection methods were suitable and addressed the research questions. Avis, et al., 2004; Davis et al., 2000; Hunter, et al., 2009 and Parton et al., 2017 did not report data saturation. Most studies reported ethical approval. However, Avis et al., (2004) did not report details of ethics approval or discussions. There was some description of the process of getting patient names from the New England Research Institutes (NERI), but overall, ethics was not discussed, and ethical approval details were not provided. Knobf (2001; 2002; 2008) cited approval from the Institutional Review Board (IRB) but provided no further details. Overall, study findings were clearly stated and of value to the evidence base of women's subjective experiences of premature menopause symptoms following cancer treatment.

The influence of researcher positionality, reflexivity and researcher-participant relationships is essential when conducting ethical research (Andrew and Holmes, 2020). However, it was unclear from most of the studies if researchers had considered bias/positionality. Knobf (2001; 2002; 2008) reports an ongoing dialogue with faculty and peers (potentially to supplement their views) and cites mentorship from a senior qualitative researcher, which suggests greater collaboration. Anderson et al., (2011) describe the author's experience with the menopause topic but no further elaboration. The majority of studies provided clear explanations and could justify their analysis methods. However, Hunter et al., (2009) and Davis et al., (2000) were given unclear ratings for the rigour of data analysis and for providing an imprecise statement of qualitative findings due to lack of detail. However, findings were discussed relative to the original research question.

**Table 2. Quality Appraisal of Included Studies (CASP, 2022) Ratings**

STUDY	AUTHORS (YEAR)	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
S1	Anderson et al., (2011)	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
S2	Archibald et al., (2006),	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
S3*	Avis et al., (2004),	Y	Y	Y	Y	Y	?	?	Y	Y	Y
S4	Brisbois (2014),	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
S5	Davis, Zinkand & Fitch, (2000	Y	Y	Y	Y	Y	?	Y	?	Y	Y
S6	Hunter et al., (2009)	Y	Y	Y	Y	?	?	Y	?	Y	Y
S7	Knobf (2001*); 2002; 2008]	Y	Y	Y	Y	Y	?	?	Y	Y	Y
S8*	Parton et al., (2017)	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
S9	Wilmoth (2001),	Y	Y	Y	Y	Y	?	Y	Y	Y	Y

**Abbreviations:** Y = Yes (high quality); ? = Unclear quality; N = No (low quality); Q1 = Aims clearly stated; Q2 = Qualitative methods appropriate; Q3 = Appropriate research design; Q4 = Recruitment strategy appropriate; Q5 = Suitability of data collection methods; Q6 = Consideration given to participant and researcher relationship; Q7 = Ethical considerations; Q8 = Rigour of data analysis; Q9 = transparent statement of findings; Q10 = Is research valuable

\*= Articles rated by co-rater

#### 4.4. Results of Thematic Synthesis

Four descriptive themes and ten sub-themes were generated from the thematic synthesis: The Impact of premature menopause, (*hot flashes, impact on sexual functioning, impact on emotions*). The personal meaning of premature menopause (*feeling old, feeling isolated from peers*). Experiences of loss (*loss of sexual self and loss of fertile self*) and experiences of healthcare-related support (*feeling unprepared, lack of relevant information, and the need for support*). A comprehensive description of the themes and subthemes is presented below with participants quotes denoted by quotation marks and authors quotes denoted by italics.

##### 4.4.1. Descriptive themes and sub-themes

##### 4.4.2. *The Impact of Premature Menopause*

Symptoms of premature menopause were primarily physically based, i.e., changes in biological, sexual, emotional, and cognitive functioning. These changes were reported as having a detrimental impact on many aspects of the participants daily lives. As Davis (2000, p.17 ) notes, symptoms such as hot flashes *ranged from being mild and nonintrusive to severe and all-consuming.*

##### 4.4.3. *Hot Flashes*

Participants within the primary studies perceived hot flashes and night sweats as uncomfortable, often disrupting sleep but varied in severity, intensity, and frequency:

*“Early on in the treatment, menopause set in and it started with hot flashes—getting hot flashes in the daytime, very intense. Night-time getting up, maybe four times a night, having to change my night clothing and put on new clothing, having trouble sleeping”.* (Brisbois et al., p.E285)

*“Hot flashes are annoying and even more annoying some days. That is my biggest problem I would say. I still have them. Initially they were more intense; now they seem to be milder. Sometimes I’ll go weeks without having any and then all of a sudden, I’ll have them again. So it might be something cyclical”.* (Knobf, 2008, p.390)

#### 4.4.4. *Impact on Sexual Functioning*

Sexual difficulties attributed to premature menopause were frequently reported by participants across most studies and for women, the adverse effects of cancer treatments and menopause symptoms, i.e., severe pain and vaginal dryness impacted on their readiness to engage in sexual activity and was experienced as a difficult adjustment, resulting in significant distress, potentially impacting on existing relationships:

*“And I said to my husband, ‘we won’t be able to have sex again, this is just too painful’. It’s awful . . . You’ve already had to cope with showing your body [with changes from surgery, etc.] . . . and then you know, it [dry vagina] freezes you up a bit sexually” (woman >40 years). (Anderson, et al., p. 789)*

*“The chemotherapy made me menopausal and the vaginal atrophy and decreased lubrication makes intercourse extremely painful. Going into premature menopause has been the worst. We were pursuing having children prior to the diagnosis, so at some points it seems like why bother having sex or continue to be married. The discomfort, decline and dissatisfaction (lack of drive) are really hard for me to accept and deal with.” (Avis et al., 2004, p. 302)*

Furthermore, adverse symptoms of premature menopause made it difficult for some women to even contemplate being in an intimate relationship at all, which Parton et al., (2017, p. 1117) interpreted as, *sexual changes as being at odds with other aspects of their gendered subjectivities, such as being a younger woman with the menopausal woman being positioned as ‘old’ and menopausal change as ‘horrible’*:

*‘As a young woman it is difficult to consider being in a relationship due to the symptoms of menopause – dryness, loss of libido etc.’ (Parton et al., 2017, p.1117-118)*

#### 4.4.5. *Impact on Emotions*

Psychological distress and uncertainty associated with fluctuations in mood as a consequence of the premature menopause and cancer experience was perceived as multifaceted and confusing for participants when attempting to understand the aetiology of the adverse symptoms experienced:

*“Probably the just feeling angry. Um, but in hindsight too, that – that could have been, I think, probably my hormones were bringing on the anger, but I think, probably, I also had a lot of anger because I hadn’t dealt with things... all of a sudden, it was like we would be having these huge screaming matches with each other and it was like, where did that come from? Um, and I think that it was probably my hormones plus the stress of everything that was happening. So that would be my – the worst – the worst, um, side effect, I think, is that anger.”* (Parton et al., p. 1116).

*“I was very depressed, but I don’t know if that was the menopause or because I was going through breast cancer. Lots of anxiety. . . . Was that my situation or was it the menopause? I don’t know. I thought depression might be part of menopause . . . the depression. . . . it came and went. I would always have a feeling of wanting to cry. . . . I never knew, was it because of depression or menopause or what. . . . I mean, could it be menopause, could it just be a group of things? It’s hard to tell.”* (Knobf, 2008, p. 392)

#### **4.4.6. The Personal Meaning of Premature Menopause**

This theme focused on the perceived personal meaning of premature menopause following cancer treatment as reported across studies relative to participants experiences being *inconsistent with the life stage of their peers* (Parton et al., 2017, p. 1119) in that they reported feeling old and isolated from their peers.

#### **4.4.7. Feeling Old**

Feeling old as a consequence of premature menopause was reported across studies and as (Anderson et al., 2011, p. 791) notes, *none of the younger participants had anticipated menopause for some time and its suddenness and severity clearly had a significant physical and psychological impact*, as evidenced in the following excerpts:

*“Well, again, I guess, what I was thinking there was that, how will I ever find somebody who can handle, you know, a woman whose body is like a 51 year old woman who doesn’t want to have sex, who doesn’t—it gets hard . . . how will I ever*

*find somebody who will want to put up with—I mean there is not too many young men out there that would want that.” (Tanya, aged 31) (Archibald et al., 2006, p. 95)*

*“I feel like a- like a 55-year-old woman in a 36-year-old body. When I should be at the prime of my life. It’s – it’s pretty unfair.” (Parton et al., 2017, p. 1119)*

*“I was thrown into an instant menopause, so I feel like an old lady. (participant 7).” (Wilmoth, 2001, p. 282)*

#### 4.4.8. Feeling Isolated from Peers

Premature menopause was perceived as isolating for younger participants and as (Anderson et al., 2011, p.791) interpreted, *participants felt isolated by their experience of menopause because their peers were not undergoing menopause at the same time and did not understand their experiences post cancer treatment:*

*“it’s really hard talking to your friends when they’re planning kids and you’re worried about whether or not you can open a window.” (Parton et al., 2017, p. 1119)*

*“For the older women, they have had friends and so on who have gone through menopause, so they know what to talk about and they know what the symptoms are . . . But we don’t know anyone our age who is going through it . . . (woman 40 years).” Anderson et al., 2011, p. 791)*

##### 4.4.8.1. Experiences of Loss

Experiences of perceived loss of self-identity resulting from premature menopause for participants, was closely tied up in a sense of loss in relation to their sexual self and fertile self, and interpreted as *a lack of control; a loss of possibility, fertility, womanhood, and cherished dreams*, (Davis et al., 2000,p. 17).

##### 4.4.8.2. Loss of Sexual Self

*“During that time I would say, I just felt less, like—less of a sexual person I guess, or less of a woman, maybe. . . . I am just a person, I am not really feminine, you know what I mean?” (Lesley, aged 36). (Archibald et al., 2006, p. 95)*

*“First you lose your breast. Then you lose your womanhood”. (Wilmoth, 2001, p. 283)*

For some participants the loss of a once youthful appearance when faced with the perceived unattractiveness experienced when transitioning to an unwelcome menopausal body, impacted on women's positive sense of self. Parton et al., (2017, p. 1115) interpreted these perceived experiences as *symbolic of abject bodily excess where the body's boundaries were breached through fluid (sweat), weight and hair growth, in contrast with culturally desirable feminine bodies that privilege sexual attractiveness through bodily containment and control:*

*'Sweating. Sweating, and I ended up with hair under my chin ... black hairs – lots of them. So I became very self-conscious of it' (Jemima (43 years, gynaecological cancer))". (Parton et al., 2017, p. 1115)*

#### 4.4.8.3. *Loss of Fertile Self*

For younger women having undergone cancer treatment and experiencing sudden menopause, fertility loss was experienced as evoking feelings of helplessness and unjustness:

*"Also issues of fertility, because your decision is taken from you, whereas a woman of 60 has probably had children, or has decided not to have children. Whereas for all of us, that's not on the cards (woman 40 years)." (Anderson et al., 2011, p. 791).*

Furthermore, *menopausal change signalled a threat to fertility and a loss of choice to become a mother (Parton et al., 2017, p. 1114):*

*'the chemo had sent me into premature menopause so that then, you know, it means you're not ovulating, so it then takes away the chance of getting pregnant.'* (Parton et al., 2017, p. 1114)

#### **4.4.8.4. Experiences of Healthcare Related Support**

Experiences of healthcare related support was perceived and reported as not meeting the physical, emotional, and sexual needs of women undergoing premature menopause, with women reporting that a combination of feeling unprepared, unsupported, and uninformed by HCPs contributed to their feelings of shock and uncertainty.

#### 4.4.8.5. *Feeling Unprepared*

*“It is hard to sort out what is what. Is it because you are suddenly deprived of estrogen or is it because you have cancer and you are dealing with a life threatening disease? At first you think it is the cancer, then you think, gee, this could be part of the menopause. But people don't tell you that. They are saying: you are going for treatment, you will be okay . . . smile . . . think positive. It is all woven together”.* (Kbnof, 2002, p. 8)

*“It was a shock to reach menopause after my first chemo treatment. Something the doctors did not prepare me for.”* (Avis et al., 2003, p. 301)

#### 4.4.8.6. Lack of Relevant Information

Participants reported minimal information was provided by HCPs about managing premature menopause symptoms resulting in feelings of uncertainty:

*“But when you can't have any topical oestrogen or any artificial oestrogen or anything like that; it's actually really hard to find out what to do”* (woman 40 years). (Anderson et al., 2011, p. 790)

#### 4.4.8.7. Need for Support

Women also had to learn how to manage the physical symptoms of menopause without the benefit of support from medical personnel (Wilmoth, 2001, p.282) and felt like they were dealing with the experience all on their own (Kbnof, 2008, p. 390):

*“I feel that I was completely blind sighted about menopause—it was so far out in the stratosphere. Yes, I did know that I might lose my period, but that wasn't even suggested by my doctor. I had heard of it, so when I started having the sweat pour down from my head, I just figured it was the wig and the heat contained in my body because of the hats I always had to wear. So for me to connect the hot (what I determined to be hot flashes) finally with the treatments and the loss of periods, I felt cheated or whatever that I had to determine all this stuff by myself.”* (Kbnof, 2008, pp. 390-91).

*“No, [doctors] did not mention [sexual functioning]. No, I had to mention it to them . . . and sometimes in the books you read, they don’t mention it at all.”* (Archibald et al., 2006, p. 97)

#### **4.5. Analytical Themes**

Descriptive themes and sub-themes informed the development of three overarching analytical themes from the thematic synthesis: *We Need To Talk About Premature Menopause, Feeling old, Incomplete, and Washed Up* and *Avoidable Pain Endured*. Analytical themes were interconnected by a central concept of implicit gender bias. For a thematic map of the findings (Figure 2).

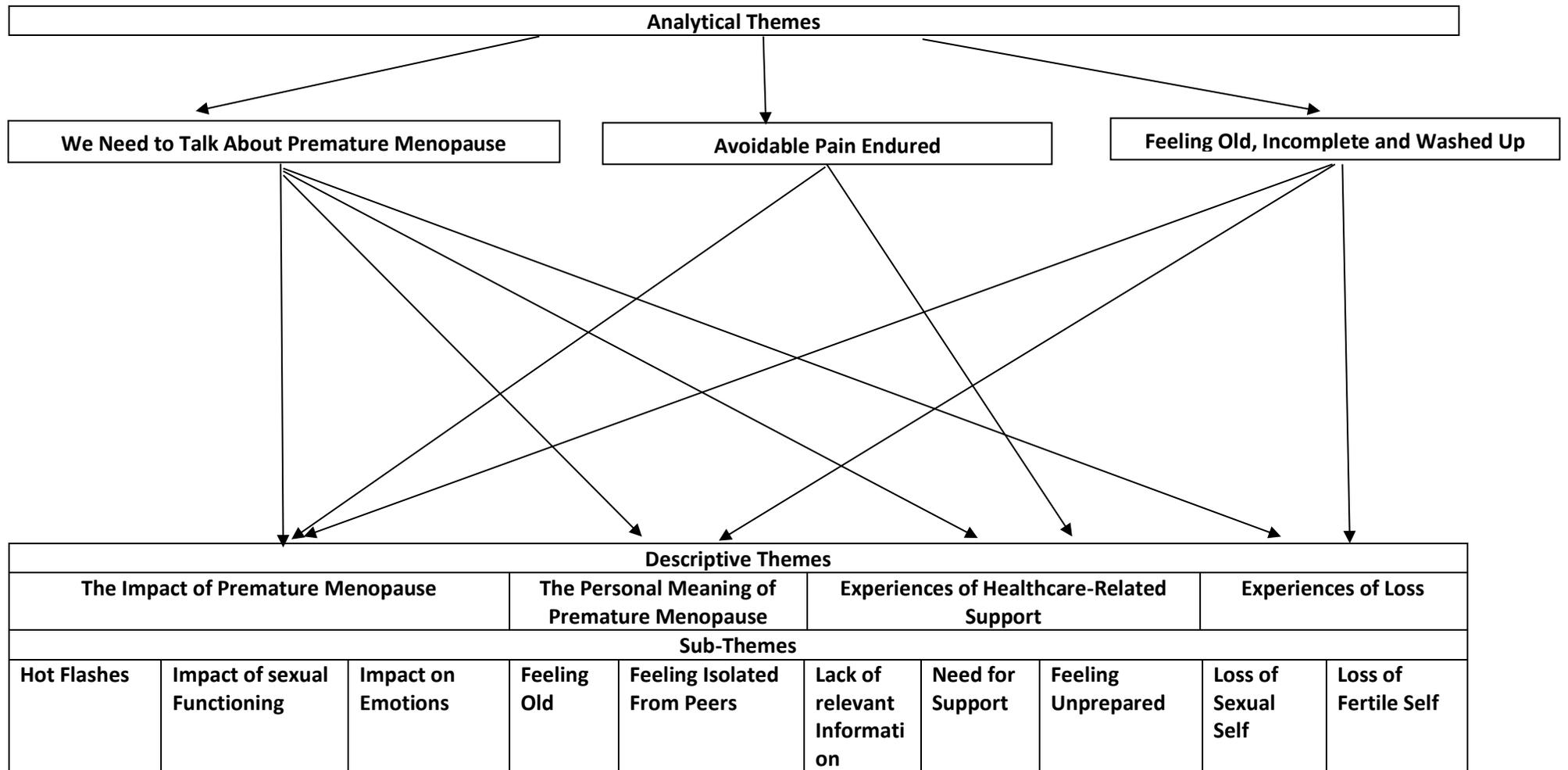
#### **4.6. We Need To Talk About Premature Menopause**

A perceived lack of relevant information, preparation, and support regarding premature menopause was reported. Some participants described having limited or no awareness of impending premature menopause symptoms following cancer treatment. In addition, oncologists were perceived as seldom initiating discussions or fully understanding women’s experience of premature menopause. As one participant reflected, their discussion with HCPs was conducted long after they completed cancer treatment, precipitating feelings of anger that they had suffered distress that may have been avoided:

*“After coming off the chemo, I expected to feel better and I never did and the hot flashes—it’s been 3 years. They (health care providers) finally said, ‘what you are going through, what you are feeling, you’re not sick, it’s from menopause. “I was ready to strangle any doctor that was near me. . . Why didn’t you tell me! At first I thought, maybe it’s me, mentally. . . . I never dealt with the cancer, maybe I am overcompensating. . . . I even went to a psychologist. What am I doing? Am I nuts?’. I always feel sick and I know I am healthy every time I go to the doctor, but it took me all this time to realize that it was actually the menopause symptoms that I was dealing with.”* (Knobf, 2008, p.391).

A lack of relevant information was not always reported as a concern by participants, but this may be due to some studies not focusing primarily on the overall premature menopause experience. Hunter et al., (2006) conducted a mixed-method study exploring

participants' cognitive and behavioural reactions to specific menopause symptoms, e.g. hot flushes, from a cognitive behavioural perspective and participants recruited in the Parton et al., (2017) study were initially part of a wider study on fertility following cancer treatment.



**Figure 2.** Thematic map of findings, showing the relationship between descriptive themes/sub-themes and analytical themes (adapted from Long et al., 2019)

Participants in the Brisbois et al., (2014) study described receiving minimal cancer information, which may have impacted on how they integrated the menopause and cancer experience. Participants described how they felt unprepared for the physical side effects of premature menopause, as highlighted by the following participant, who perceived their anxiety and uncertainty might have been avoided:

*“Well, the physical side of it, the vaginal dryness, of course, and that there might be a possibility that I would not be interested in sex . . . yeah—and the sexual arousal, I don’t know if it is related to [hormonal changes] or not, but if it is, the same thing. I would have liked to have known ahead of time, to know what to expect. Like, is this normal? Is it just something I am feeling?. I would have been prepared for it. Like I wouldn’t have been as worried about it, or as concerned about it.”* (Lesley, aged 36) (Archibald et al., 2006, p.98).

Knobf (2008) described how women who reportedly struggled with premature menopause experienced increased symptom severity and feelings of uncertainty. Feeling supported by HCPs and relevant others was described as necessary for participants and perceived as not adequately meeting the needs of some participants, e.g. as described in Brisbois et al., (2014), language barriers and lack of acculturation impacted participants’ ability to access information and healthcare support regarding cancer and premature menopause as a consequence of cultural disparities. For some participants experiencing support, understanding and patience from their partners regarding sexual intimacy was viewed with greater importance than obtaining support for other menopause symptoms (Davis et al., 2000).

Overall, most participants described difficulties adjusting to premature menopause symptoms, i.e. they did not feel prepared, and many felt that they were not adequately informed, resulting in feelings of shock at the sudden onset of menopause symptoms, anger, and uncertainty, impacting their emotional and sexual functioning.

#### **4.7. Avoidable Pain Endured**

In all studies, participants described pain resulting from menopause (vaginal dryness). The impact on sexual functioning and identity was described as a significant problem. Additionally, some participants described feeling that their physical symptoms were not

being addressed, attributed to something else, or minimised due to a perceived lack of understanding from HCPs regarding their concerns:

*“I was told I would go into menopause, and nothing else was mentioned. I could deal with that. I went for a check-up, and a female intern was in the doctor’s office and I expected to get a positive response and good feedback. So I took the plunge and told her I was having hot flashes, my skin was dry, my eyes were dry, and that I didn’t have any vaginal lubrication. She looked uncomfortable and said it was due to the chemotherapy and you need drops for your eyes and didn’t say anything about how to deal with the vaginal dryness or any of those kinds of things” (Wilmoth, 2001, p.282)*

It appeared that implicit gender bias towards females within healthcare may explain, to some extent, participants' experiences, where the severity of women’s pain may have been underestimated and therefore endured unnecessarily, alongside the psychological impact, rather than alleviated, had participants perceived more supportive responses from HCPs. This interpretation was generated from three articles (Knobf, 2001; 2008 and Wilmoth, 2001) where participants described pain or discomfort that was perceived to be not always fully understood, taken seriously, or approached with sensitivity within a healthcare system where generational, cohort beliefs and implicit biases may exist, therefore negatively impacting the potential for the pain to be avoided or to some extent managed effectively, as the following excerpt highlights:

*“These guys (physicians) think it’s ridiculous that women are complaining about this stuff (vaginal dryness). My girlfriend went to her doctor and he said use anything that will ‘slip and slide’ . . . .You are dealing with dinosaurs out there.” (Knobf, 2008, p.391).*

#### **4.8. Feeling Old, Incomplete and Washed Up**

Participants across studies described how premature menopause had unwelcomingly aligned them with longstanding socially constructed negative views of ageing and menopause as a period of decline, with loss of youth, fertility, perceived sexual attractiveness and potential, as highlighted in the following excerpts:

*“Old. I felt really, mmm, like a bit of a – maybe a bit of a has been, a bit of a – yeah, I don’t know, a bit washed up, and I think tied in with the whole menopausal – you know, the fatigue and the – the changes in your skin and all these things I didn’t know about. Um, it just – I felt old (laughter) yeah, sad, and old.”* (Parton et al., 2017, p.1118).

Loss associated with the overall premature menopause experience was described. Evoking feelings of anxiety and a perceived loss of control, related to having the opportunity to conceive and gain control of vasomotor symptoms<sup>2</sup> impacting potential sexual intimacy and the possibility of future motherhood:

*“I guess because of my age (twenties) and I was not married, my biggest fear was the fact that I wouldn’t be able to have children. I don’t even think the cancer part hit me.”* (Davis et al., 2000, p.18)

*“I avoid dating as I’m afraid of having hot flushes at the time, I don’t feel very sexy then. . . . I also worry that my sex life would be affected by night sweats”* (D149) (Hunter et al., 2009, p.338).

Younger participants described feeling older than their peers who struggled to understand what participants were going through, leaving participants feeling isolated. Participants described the impact of infertility due to premature menopause in terms of loss and feeling ‘incomplete’ as a woman.

However, some participants described feeling free from pregnancy (Parton et al., 2017) or reported no concerns, about whether to conceive, as this was discussed before undergoing cancer treatment (Kbnof, 2001; 2002; 2008).

Most participants described menopause as a transition associated with old age, loss and, at times, as an isolating experience for younger participants. Conversely, the change seemed smoother for older participants who were already perimenopausal: *“At 51, I was more confident of myself and aware of what I am and who I am.”* (Davis et al., 2000, p.17). However, it is important to emphasise that most narratives are drawn from western

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<sup>2</sup> Hot flashes or night sweats are also known as vasomotor symptoms

perspectives, which may hold more negative internalised beliefs about ageing compared with other cultures.

## 5. Discussion

This review aimed to synthesise published research on women's experiences of premature menopause symptoms following cancer treatment and explore the perceptions of related healthcare support. The thematic synthesis resulted in the generation of three overarching analytical themes: *'We Need to Talk About Premature Menopause'*, *'Avoidable Pain Endured'* and *'Old, Incomplete and Washed Up'*. Findings revealed aspects of menopause were perceived by some participants to have been ignored or dismissed by HCPs. Furthermore, participants highlighted the importance of timely and adequate information and being more prepared by HCPs to help adjust to the impact of infertility, loss of sexual identity, perceived loss of control and physical changes to their body as a consequence of premature menopause.

A perceived lack of communication, preparation and sharing of relevant information between participants and HCPs was reported. Many participants felt that HCPs routinely did not initiate discussions about premature menopause. They described feeling isolated and needing to seek out information themselves or start conversations, often described as uninformative or anxiety-provoking. Some studies provided a different narrative across all participants; with some participants reporting they did not require further information or support. For example, adjusting and recovering from the cancer experience was considered a priority for some (Davis et al., 2000; Kbnof, 2008), and menopause information was welcomed following treatment (Davis et al., 2000). However, some participants declined further information or support regarding sexual changes (Archibald et al., 2006).

Most participants perceived information and support regarding premature menopause as lacking. Gender-related health inequalities and access to healthcare are significant worldwide problems affecting women at all stages of their lives: *"We must acknowledge that for generations women have lived with a healthcare system that is designed by men, for men"* (Department of Health and Social Care, 2022, p.1), where women have been significantly overlooked in terms of support for debilitating menopause symptoms driven by gender bias (Skillicorn-Aston, 2022). A proportion of Latina participants within the Brisbois

et al., (2014) study was described to have experienced little or no information on cancer, its side effects relative to premature menopause, and an absence of healthcare was also reported. Cultural bias and discrimination exist within healthcare towards Latino/Hispanic individuals compared to white individuals within the United States, where disparities in access to healthcare are dominant (Chapman et al., 2019). This disparity is evident within the included studies in that most participants were white and had access to healthcare. In addition, there is a high risk of cardiovascular disease for women who have experienced premature menopause, especially younger women. There is a mistaken belief within society and healthcare that cardiovascular disease affects only men, an example of gender bias that requires urgent redress (Bernhardt and Lawson, 2019).

It can be postulated that HCPs may be initially hesitant in initiating discussions about managing menopause side effects because of their primary focus on monitoring cancer treatment and recovery in line with their area of expertise. Additionally, there may be an expectation that women are already informed about premature menopause or that overloading them with too much information may be overwhelming and challenging to absorb, given the overall cancer experience. It has also been suggested that male oncologists may not initiate discussions about sexual side effects due to a lack of training or knowledge (Scanlan et al., 2012). In summary, participants perceived that HCPs ineffectively communicated information regarding premature menopause, resulting in women feeling unprepared. Additionally, women did not feel as if they were supported during this challenging transition, which may be partially explained by ongoing implicit gender bias within healthcare systems.

Participants described distressing pain during sexual intercourse due to vaginal dryness. They described these uncomfortable symptoms as having a significant impact on their sexual identity, sexual functioning, psychological health, body image, and sexual relationships. Participants who had experienced premature menopause at younger age struggled to envisage themselves as sexually desirable to potential partners of similar age, often feeling out of sync with same-age peers. Most participants described a perceived lack of information, preparation and support for concerns related to vaginal dryness and other distressing menopause symptoms, meaning that some may continue to experience physical pain and discomfort for an extended period due to younger women experiencing premature

menopause symptoms for longer (NICE, 2022). However, for some participants, no further information was required. Implicit gender bias exists within women's healthcare (Samulowitz, et al., 2018). Concerns about the negative impact of estimating women's pain experience have been argued to be related to existing gender stereotypes, with women experiencing disparity within healthcare compared to males. Unfortunately, pain is often undertreated, and women's verbal and non-verbal reports are overlooked (Zhang et al., 2021). Overall, pain as a consequence of vaginal dryness was a commonly reported symptom of the menopause experience and often perceived by women as distressing and ignored, minimised, or dismissed by HCPs and is postulated to be woven through a thread of implicit gender bias as observed within a traditional patriarchal system of healthcare.

Participants described subjective experiences related to accelerated ageing aligned with loss of womanhood, control, sexual attractiveness, and youth across most studies. For younger women, this sense of loss was experienced as a challenging adjustment feeling that this unexpected life stage had arrived with unwelcome permanency. Physical changes to their bodies and how they processed these changes alongside their experiences of cancer compared to same-age peers were also described as a difficult adjustment. These feelings can be understood when examining socially constructed negative views of ageing and menopause. As far back as the 19<sup>th</sup> century, menopause was pathologised and considered a period of mental and physical deterioration in a woman's life. Societal views of women's bodies and appearance reveal age and gender biases, where fertility and attractiveness are admired, and a woman's ageing body is regarded as having lower social worth. Conversely, traditional Japanese culture view ageing (*konenki*, meaning renewal) as a natural life transition, where no definitive word for menopause exists (Hagège, 2020). The ongoing medicalisation of menopause currently reinforces these negative views regarding reproductive ageing, i.e. assuming that HRT is the gold standard treatment and that by confronting gender-based ageism and stigma while providing balanced information, women may feel better able to manage the challenges of the transition (Hickey et al., 2022). This is especially pertinent for women experiencing premature menopause following cancer treatment where HRT is contraindicated and may require alternative management of distressing menopause symptoms.

## 5.1. Strengths and Limitations

To the author's knowledge, this is the first systematic review to synthesise specifically women's experiences of premature menopause symptoms following cancer treatment. However, limitations must be noted that may have impacted the reliability and validity of the review findings, namely that a single reviewer had conducted the data extraction and analysis. Sandelowski & Barroso (2002) report the challenges qualitative researchers face when attempting to locate what constitutes findings within the primary studies when synthesising qualitative research. Challenges reported include, "misrepresentation of data findings" (Sandelowski & Barroso, 2002, p. 216), where researchers may provide detailed descriptions and overlong quotes without attempting to interpret the data. Furthermore, they argue the misuse of quotes and failure to acknowledge how a theme was developed or when studies provide minimal description to support interpretations, may all have implications for accurately reporting findings to the researcher's intended audience. Having two reviewers conduct data extraction and code each article or sub-set of articles independently and also including 'experts by experience' (i.e. utilising focus groups or surveys with policy makers, patients, and HCPs) may have helped to increase reliability and validity (Lasserson, Thomas & Higgins 2022). The reviewer wished to include published studies but acknowledges that there may be potential findings within the grey literature that this review does not address. Including, i.e. unpublished theses, dissertations, or reports may help minimise publication bias, provide a balanced account of the available evidence, and increase inclusivity (Paez, 2017). As evidenced within this review, a significant lack of qualitative literature is reflected in the small sample of studies synthesised. Author reflexivity and positionality in all studies were unclear, an important factor when interpreting findings. An explanation for this omission might be that authors are limited in word count when submitting manuscripts for publication. However, missing detail was also evident in some articles, which may have affected quality appraisal due to inadequate reporting (Long, French & Brooks 2020).

Furthermore, three of the eleven articles included in the review were from the same sample (Kbnof; 2001; 2002; & 2008), which may have overrepresented related themes and interpretations. The primary reviewer attempted to attend to this risk by collating the findings as one reference source. Three articles did not report ethnicity. One article

represented the experiences of Latina women, and the majority of participants in the remaining five studies were white. Additionally, seven articles did not report sexual orientation. Therefore, it is unclear if these women have been represented, which may limit transferability. Lack of reporting and underrepresentation of minority groups is a recognised issue in research more broadly (Turner et al., 2022). Exploring experiences in these diverse populations may help to further understand women's experiences of premature menopause following cancer treatment. Finally, studies were conducted in different countries, i.e. the United States, where racial disparities due to poverty and implicit bias within healthcare exist for Black/African American women compared to white women (Holmes et al., 2020). This review explored the challenging experiences of mainly white women, which raises further questions as to how women from minority backgrounds who are already marginalised experience menopause symptoms following cancer treatment. It may explain why these women are underrepresented within research studies on this subject. For example, if those from ethnic minorities are struggling to access basic healthcare (Thakur et al., 2020), it is easy to understand why the needs of this population may have been overlooked.

## **5.2. Implications and Conclusions**

Symptoms of premature menopause may cause further distress, pain, anxiety, and stress for women following cancer treatment compared to women moving through natural menopause. The impact on psychological health due to infertility cannot be ignored. These findings aim to inform service providers and oncology services of the unique challenges women with premature menopause experience following cancer treatment, heightened where implicit gender bias exists. Women may benefit from discussions regarding preserving their fertility with specialists, albeit this may be hugely expensive if funding is unavailable (Inhorn et al., 2018). A Multidisciplinary Team (MDT) approach within oncology services that incorporates premature menopause into individual care plans for those that seek support would help to ensure that care is individualised to need. Furthermore, access to peer support groups, accessible routes for information and signposting for specialist support and guidance should be considered. HCPs may benefit from awareness training in implicit gender bias (Zeidan et al., 2019) and specific training in menopause which may open dialogue within healthcare to benefit women at all life transitions.

Most studies described a perceived lack of communication, information, and preparation for premature menopause symptoms. These findings support and enhance the findings of Bennion and Molassiotis (2013) and Hoga et al., (2015) in that findings explicitly explore premature menopause following cancer treatment while illuminating implicit gender bias within women's healthcare. For most participants, premature menopause was perceived as distressing and associated with loss regarding the physical changes to their bodies, sense of womanhood and sexual functioning. Across studies, women reported pain due to vaginal dryness, which some participants felt was overlooked by their healthcare providers. This review highlights how the experiences of premature menopause for women following cancer treatment may be shaped through a lens of implicit gender bias, whereby ongoing disparities in how healthcare is accessed and delivered to women may cause avoidable distress and undue suffering.

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## Chapter 2

Choosing Not To Undergo Further Cancer Treatment: A Qualitative Study  
of the Lived Experiences of Those with Advanced Cancer and The Factors  
That May Have Influenced Their Decision To Decline Adjuvant Or  
Preventative Treatments

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## Plain Language Summary

### Declining Cancer Treatment: A Study of Lived Experiences During Treatment Decision-Making

#### **Background**

The decision to decline cancer treatment is a sensitive, under-studied topic which can pose challenges for clinicians. Research suggests that treatment decisions can be influenced by personal values, beliefs, and preferences.

**Aims and Questions:** To understand the lived experiences of individuals who have declined further cancer treatment, explore their experience of the treatment decision process and what influenced their decisions.

**Methods:** Six participants with an advanced cancer diagnosis who had declined further cancer treatment participated in semi-structured interviews. Interviews were analysed using Reflexive Thematic Analysis to identify patterns of meaning across the participants' experiences.

#### **Main Findings**

Three main themes were identified. 'Reaching a Shared Understanding', Choice Versus 'One Size Fits All' and "What Mattered Most: 'A Meaningful Life'. Most participants perceived and described poor communication by Health Care Professionals (HCPs) during treatment decision making, with no choice of alternative treatments or pathways offered by oncologists. Most participants also described feeling pressured by HCPs, friends, and family to reconsider their decision to decline treatment. Being in control of their treatment decisions and how they live the remainder of their lives aligned with their values was especially important for participants.

#### **Conclusions**

Participants described how their values, preferences and beliefs influenced their decision to decline further treatment. Discussions regarding alternative treatments would have been welcome. Findings showed potential communication barriers. Services should consider reviewing Communication Skills Training (CST) for HCPs. Declining cancer treatment can feel isolating. Patients may benefit from peer support.

## 1. ABSTRACT

**Objectives:** Declining cancer treatment is a sensitive topic infrequently reported in research. Research suggests that patients make treatment decisions according to their personal values, beliefs, and preferences. The primary aim of the research was to understand individuals' lived experiences and sense-making of decisions to decline recommended cancer treatment, or aspects of treatment. A secondary aim was to explore how decisions reached were influenced by personal values. **Design:** Semi-structured interviews were conducted with patients with an advanced cancer diagnosis ( $n=6$ ; female, 39 – 85 years) who had declined further adjuvant or preventative treatments. Qualitative data were analysed using reflexive thematic analysis **Results:** Three core themes and seven sub-themes described participants' experiences, illustrating perceived barriers to communication and mismatched expectations with Health Care Professionals (HCPs) during treatment decision-making. Participants reported no choice regarding alternative treatments and pathways other than standard treatments. Finally, participants described a wish to live the remainder of their lives engaged in what mattered most to them, free of potential treatment side effects, as influencing their decision to decline treatment. **Conclusions:** Perceived communication barriers and implicit bias within healthcare may impede reaching a shared understanding during treatment decision-making. Treatment decision-making aligned with patients' values, preferences, and beliefs is essential when planning oncology care. Findings support the need for oncology services to consider communication skills and implicit bias training for HCPs. Development of a patient decision aid should also be considered. Declining cancer treatment can be isolating. The development of peer support groups is recommended.

*Key words: Cancer, Declining Treatment, Values, Decision-making, Implicit Bias*

## 2. INTRODUCTION

Cancer is a leading cause of death worldwide (World Health Organisation, 2022). Recommended cancer treatments include surgery, chemotherapy, radiotherapy (Cavalcanti & Soares, 2021) and immunotherapy (Kulwal & Sawarkar, 2021). The main treatments for breast and ovarian cancer include surgery, radiotherapy, chemotherapy, targeted therapy, and hormone therapy. Women may have one or a combination of these treatments. The type of treatments will depend upon the stage of the cancer, the person's general health and whether they have experienced menopause (Macmillian Cancer Support, 2022). Treatments are sometimes offered with curative intent, though in circumstances where this is not thought to be possible, treatments can be offered to reduce symptoms or prolong life (World Health Organisation, 2008).

The Breast Cancer Trialists Collaborative Group (1998) reported that for those who had taken hormone treatments, such as Tamoxifen, breast cancer recurrence reduced by 47% and mortality by 26% over ten years. Non-adherence to cancer treatments, particularly preventative treatments such as Tamoxifen have been associated with poor health outcomes in women with breast cancer. Women who perceived that the benefits of non-adherence outweighed the side effects were more inclined to stop treatment (Moon et al., 2017). Adherence is "the extent to which patients are able to follow the recommendations for prescribed treatments" (Hugtenburg et al., 2013, p. 675). In a recent systematic review exploring contributory factors to medication adherence, psychological and cognitive factors were consistently reported across studies to impact adherence. Factors reported explicitly for cancer patients were related to patient beliefs, perceptions, and concerns regarding medication side effects. Additionally, experiences when engaging with Health Care Professionals (HCPs) and healthcare factors such as communication, provision of comfort, counselling, being provided with relevant information and support were also reported as contributing to adherence, as was obtaining adequate social support (Peh, et al., 2021). Furthermore, depression has been reported to be correlated with reduced adherence to adjuvant treatment in women receiving breast cancer treatment (Fann et al., 2008).

Adverse effects of some cancer treatments can include sexual dysfunction, infertility, hair loss, cognitive impairment, painful or dry mouth, increased infection risk, changes to kidney, liver, heart or lung function, urinary and faecal incontinence, fatigue, and nausea (Cancer Research UK, 2022). Consequently, patients with cancer can face difficult treatment decisions balancing QOL with the extension of life (Laryionava et al., 2014).

Personal values, beliefs and preferences are integral to treatment decision-making (National Institute for Health and Care Excellence, NICE, 2021) and may influence decisions to decline recommended or potential treatment (Frenkel, 2013; Huijjer & Van Leeuwen, 2000; van Kleffans & van Leeuwen, 2005). Refusing recommended cancer treatments or aspects of treatment can pose a challenging dilemma for clinicians, who may experience the emotional impact of the patient's decision (Dohrtre et al., 2015; Carlson, 2014). In addition, differentiating between the patient's illness stage, whether curative or not curative, is a significant factor for oncologists when evaluating treatment refusal decisions by patients (van Kleffans & van Leeuwen, 2005).

Cancer patients and oncologists report mixed responses when describing what they deem important when making treatment decisions, with oncologists and patients highlighting the importance of the efficacy of treatments and managing physical side effects. However, when making treatment decisions, patients also consider additional factors such as the wish to attend family events, remaining in employment, and the logistics of travelling for treatment, (Rocque et al., 2019). Patient preference on who should guide decisions in cancer treatment is also mixed. Some view the oncologist as the 'expert' (Rocque et al., 2019). In contrast, others report feeling pressured by the oncologist and family to have treatment (McCaffery et al., 2019), with treatment decision-making guidance being more welcome around diagnosis but less so over time (Ziebland et al., 2014).

In summary, cancer treatments may cause adverse side effects for patients with emotional, psychological, and systemic factors impacting on adherence to preventative cancer treatments such as Tamoxifen. Furthermore, personal values and

preferences are essential factors in patients' and clinicians' treatment decision-making (NICE, 2021). However, there are mixed findings on how well patients feel supported and informed about the shared decision-making process (Rocque et al., 2019).

Choosing to decline cancer treatments or aspects of treatment is a sensitive topic rarely reported within research studies. This paucity within the literature may be attributed to several factors, including patients disengaging from oncology services after deciding not to proceed with treatment. In addition, patients may be too unwell to participate in research. Some who decline treatment may not wish to be involved in oncology research, especially if based in hospital settings, which may elicit unpleasant memories and feelings (van Kleffans & van Leeuwen, 2005).

The present study aims to gain a deeper understanding of the lived experiences of patients who choose not to undergo cancer treatment. Specifically, it seeks to explore their experiences of the treatment decision-making process and how and to what extent their values have influenced treatment decisions. In addition, study findings seek to inform how therapeutic models such as ACT may increase our understanding of treatment refusal and how to support treatment decision-making.

### **3. MATERIALS AND METHODS**

#### **3.1. Ethics**

Ethics approval was sought and obtained from the West of Scotland Research Ethics Committee (21/WS/0129) and NHS Greater Glasgow and Clyde (GG&C) Research and Innovation Department (GN21ON302; Appendix 5).

#### **3.2. Design**

A qualitative design using Reflexive Thematic Analysis (RTA) (Braun and Clarke, 2022) was adopted and approached from a critical realist standpoint. This assumes that our understanding is connected to our perceptions, attitudes, and opinions; these are then constructed and ingrained within our cultural setting and language (Braun & Clarke, 2022). Critical realism provides a lens through which to share and understand the lived experiences of cancer patients who decline cancer treatment. It can illuminate descriptions' social and cultural contexts. This can be explained in the

context of cancer and its distinctive meaning. While we can acknowledge the existence of the realities of cancer, how we comprehend these realities (e.g., meaning and experience of cancer) is informed by our subjective assumptions and biases, facilitated by culturally and socially determined language (Maxwell, 2011).

### **3.3. Reflexivity Statement**

The researcher adopted a reflexive inductive, interpretative approach to the research. Adopting an inductive approach relates to coding and developing themes within and driven by the content of the data, in contrast to being moulded by an established descriptive or theoretical framework that cannot be separated from the researcher's beliefs and worldview. An interpretative approach to the data involves discovering and "unpacking" meanings and looking at the significance of those meanings (Braun and Clarke, 2022, p. 289). The researcher is a white Trainee Clinical Psychologist from a working class background in the West of Scotland. Initially, it was difficult to navigate, acknowledge and reconcile their positivist orientation in evidence-based practice and other professional training experiences in their previous nursing and cognitive behavioural psychotherapist roles. However, maintaining a journal and engaging in reflective discussions during supervision enhanced reflexivity by allowing the primary researcher to acknowledge how their values, personal experience of cancer, previous subjective experiences of nursing cancer patients, advocating for the rights, values and wellbeing of patients and the researcher's social and political alignment have shaped the research from the original question formation to data collection, analysis, and interpretation.

### **3.4. Recruitment Procedure**

A purposive sample of six current outpatients at the Beatson West of Scotland Cancer Centre, including patients who were open to review and had attended an outpatient clinic within the last year, were recruited for the study. Patients aged over 18 with a cancer diagnosis were eligible. Individuals were excluded if they could not understand or speak English, provide informed consent, or if the degree of disease progression would deem participation inappropriate. Oncology staff identified and invited eligible patients during clinics or via letter and sought assent for the researcher to contact

those who expressed interest. Potential participants were provided with a Participant Information Sheet (PIS), which included contact details of relevant cancer support organisations (Online Appendix – Participant Information Sheet, p.84).

### 3.5. Participant and Clinical Characteristics

*Table 1. Overview of Participant and Clinical Characteristics*

Pseudonym	Age	Ethnicity	Cancer Type	Cancer Treatment Declined	Cancer Stage
Helen	63	White	Ovarian	Adjuvant Chemotherapy	Advanced
Fiona	64	White	Ovarian	Adjuvant Chemotherapy	Advanced
Rosie	39	White	Breast	Adjuvant Chemotherapy	Advanced
Grace	64	White	Breast	Tamoxifen	Advanced
Susan	63	White	Breast	Tamoxifen	Advanced
Marion	85	White	Ovarian	Adjuvant Chemotherapy	Advanced

The final sample consisted of six white females with an average age of 63 years (range 39 - 85 years) based in the West of Scotland. All participants were at an advanced stage of breast (n=3) or ovarian (n=3) cancer and had declined either adjuvant chemotherapy (administered after primary treatment, e.g. surgery; n=4) or hormone therapy (Tamoxifen; n=2).

### 3.6. Justification of Sample Size

Issues around whether sample size should be determined before data collection and analysis to achieve data saturation and whether data saturation is necessary to provide evidence of rigour in qualitative research (Morse, 1995) continue to be a point

of interest and debate among qualitative researchers (Hennink & Kaiser; 2021; Braun & Clarke, 2021).

In line with Braun & Clarke's (2021) guidance for reflexive TA researchers, the researcher set a provisional sample size of six to ten participants to generate a richly nuanced narrative regarding patterns of meaning within the data. The final sample size decision was shaped by the richness of the data to address the research questions during data collection.

### **3.7. Research Procedure**

Interviews were conducted according to patient preference either in person at the Beatson West of Scotland Cancer Centre (n = 5) using a digital voice recorder or digitally via Microsoft Teams (n = 1). Written informed consent was obtained (Online Appendix - Consent Form, p.86). The researcher conducted one-off individual interviews using an interview guide (Online Appendix – Semi-Structured Interview Guide, p.85), which was informed by the current literature to elicit participants' subjective experiences, decisions, values, and perceived healthcare support when declining cancer treatment (Kallio et al., 2016). The duration of the interviews was between 37 and 62 minutes. Interviews were transcribed and coded (Appendix 6).

### **3.8. Thematic Analysis**

RTA was chosen because it provides flexibility within a systematic framework to explore patient experiences, such as how they perceive their world following their decision to decline cancer treatment. RTA helps identify and analyse patterns of meaning within the data explaining participants' experiences, opinions, observations, and descriptions. In addition, it acknowledges the role of the researcher, e.g., their values, biases, assumptions, and political and social alignments, at the centre of the process (Braun and Clarke, 2022) and how their experiences influence how they shape and engage with the data. There are six stages in RTA (Braun & Clarke, 2022), with each stage building on the previous stage while moving fluidly between stages (University of Auckland, 2022).

## **4. RESULTS**

This reflexive thematic analysis resulted in three core themes with seven sub-themes (Table 2). To illustrate the analysis process and findings, excerpts of the transcripts are included when exploring themes.

Table 2. Core Themes and Sub-Themes

Core Theme	Sub-Theme	Participants
<b>Reaching a Shared Understanding</b>	“Understanding Where you are Coming From”	Helen, Fiona, Susan & Rosie
	“I Said No”	Helen, Fiona, Rosie & Grace
	“Feeling Pressured”	Helen, Fiona, Rosie & Grace
<b>Choice versus “One Size Fits All”</b>	“I Am Not A Standard Person”	Helen, Fiona, Rosie Susan, & Grace
	“You Don’t Get A Choice”	Helen, Fiona, Susan & Grace
<b>“What Mattered Most”: A Meaningful Life</b>	“Quality of Life: Important, Simple Things”	Helen, Fiona, Susan Rosie Marion & Grace
	Taking Control: “It’s My Life, And It’s My Death”	Helen, Fiona, Susan, Rosie, Marion & Grace

#### 4.1. Reaching a Shared Understanding

This theme highlighted perceived communication barriers and mismatched expectations impeding the development of a shared understanding between participants and oncologists. It also highlighted how participants felt pressured to consider accepting treatment by the oncology team and, for some participants, also from friends and family. It consisted of three sub-themes, “*Understanding Where You Are Coming From*”, “*I Said No*”, and “*Feeling Pressured*”.

##### 4.1.1. “*Understanding Where You Are Coming From*”

Four participants reported that communication by oncologists regarding the consequences of their decision could have been treated with more sensitivity and less

alarm, as Helen highlights following a meeting with an oncologist who had been explaining the potential impact on her physical health following her decision to decline treatment:

*“It’s about talking to people; it’s about people understanding where you are coming from, not frightening you like the oncologist did.” (Helen)*

This lack of sensitivity was also felt by Fiona when reflecting on her subjective experiences during one meeting with her oncologist:

*“I just think the way people [oncologists] talk to you, it deflates you, completely deflates you. ‘You know well it’s probably coming back anyway because it spreads really quickly’. You don’t need to say that to people; get some bloody training on your social skills, please. Do you know what I mean? You don’t need to say that to people”. (Fiona).*

These experiences were echoed by Susan when describing how she felt that more time was needed to make such important decisions:

*“Instead of scaring them-you know, I mean, we have got breast cancer, we are not going to drop dead right away, you know, so just, take it-take them through it a lot slower”. (Susan)*

Conversely, when discussing treatment decisions, Marion perceived communication between her and her oncologist as a positive experience:

*“She [oncologist] was lovely. I asked her if I could have the weekend to think about it, and she said yes, and she called me, and I thought it through, and I talked to friends”. (Marion)*

One participant who identified as being self-informed described feeling patronised when attempting to communicate their knowledge and preferences about cancer treatment with their oncologist:

*“I like to think that I am not stupid in a lot of ways and that I can have an intelligent conversation with an oncologist and have a good understanding of*

*what I am talking about. So, for him, I felt like he spoke to me like I was a bit of an idiot, and I didn't like that". (Rosie)*

#### **4.1.2. "I Said No"**

Four participants described feeling that oncologists and, on occasion, family and relevant others often appeared surprised or uncomfortable when participants asserted themselves regarding their decision to decline treatment, as further reflected by Rosie:

*"I said no, actually I have decided that I am not going to have that [chemotherapy]. It sort of threw her [oncologist] into a bit of a tizzy; she was a bit like 'oh', and she was scrambling on papers and things, and I felt that no one has ever questioned this decision-making before". (Rosie)*

All participants reported feeling they had made the correct decision to decline treatment and reported no regrets. However, for one participant, this was after a period of further self-reflection and initial self-criticism, having informed friends and family of their decision. They wished their decision to be respected, as reflected in the following excerpt:

*"I feel like I am being selfish when friends and family say, 'Well, maybe you should.' I feel, well, again, I feel like saying, 'Maybe I am being selfish. It's me; it's my body, and I want to be selfish. I don't want to go through chemo, and it's just one of, that's my thought, you know, and I don't regret it. I think I said that before, I don't regret not having treatment" (Marion)*

For Helen, her decision to decline treatment involved further emotional turmoil when considering her needs and those of her loved ones:

*"I have said to myself, you know, 'why are you not taking this chance for your daughter? When you know, she is the most important thing to you. Why are you not prepared to take this chance now?' I believe it is the right decision for us both. That's the only thing I can say, you know". (Helen)*

For Marion and Helen, working through how their decision may impact others was an essential and emotional consideration, but it was ultimately a decision based on their lived experience of cancer and how they wish to live the remainder of their lives.

All participants contemplated their treatment decisions, citing potential side effects as an influencing factor in declining treatment. In addition, participants reflected on their experiences of the power dynamic when engaging with the oncology team. For example, as one participant reflected following a meeting with their oncologist where they were told that they were being booked in for chemotherapy:

*“[Oncologist said] ‘I want to book you in for it’ [treatment]. I say, ‘Well, I am not coming. I am going to tell you that’s how I feel.’ So she [oncologist] says, ‘I will book you in anyway; well, I was booking you in anyway, and you can change your mind’”. (Fiona)*

The power dynamic was also evident for Rosie and Grace during meetings with their oncologists; their accounts positioned themselves as rebels taking back power and control when asserting their treatment decisions:

*“it almost felt like your mum, ‘this isn’t what we are telling you to do’ kind of thing. ‘You should do what we want you to do’, and it just made me feel like a little bit of a naughty schoolgirl. I am not doing what they want me to do, basically. But I felt really empowered that I had made that choice”. (Rosie)*

*“I have always been and in some, most respects, I am very compliant; you know, I do exactly what I am told to do, I certainly do at work, and I am not someone to rock the boat ever; you know, I am always trying to placate people. So in a way, I am quite surprised at this rebel instinct in myself”. (Grace)*

#### **4.1.3. “Feeling Pressured”**

Perceived pressure to rethink their treatment decision was a recurrent theme, as illustrated by Rosie:

*"I think it was just a mixture of like the relief of having gone through with saying what I felt and not backing down, feeling pressured by the medical professions but also feeling their disapproval almost". (Rosie)*

This feeling of having to endure continuing pressure to commence a proposed treatment was experienced as so "stressful" that one participant wondered if future encounters with their oncology team might lead them to "succumb" to the treatment they'd previously refused:

*"Well, I suppose I have refused so many times, so it's very stressful every time, and I can't say that I won't succumb eventually, but I wouldn't say that I am being bullied, certainly not, but it is very persuasive". (Grace)*

Conversely, another participant's account of their oncology team was no sense of frustration or pressure to change their mind, which the participant valued:

*"My god, it was wonderful; she [oncologist] didn't say, 'oh, you should' or not. She was wonderful; they were wonderful, all of them. Nobody said, 'you should try". (Marion)*

Participants described feeling a sense of frustration or disapproval from oncologists following their decision to decline cancer treatment. The decision to decline treatment was deemed so atypical, that some oncologists had requested that patients attend psychology to further their understanding of the patient's decision:

*"I just felt her frustration. I know she was trying to help me. I felt that from her, I felt she was trying to help me. But that's when she suggested that I speak to a psychologist just in case there was something deep-rooted that was stopping me from having the treatment". (Helen)*

*"They wanted to check that I was thinking clearly" (Rosie).*

In summary, most participants reflected on their oncology team's perceived lack of understanding and frustration following their decision to decline cancer treatment. The importance of feeling their decision was respected rather than challenged was

further borne out by the one participant whose account of their healthcare team differed, in which they described the perceived lack of pressure as “wonderful”.

#### **4.2. Choice Versus “One Size Fits All”**

This theme highlighted participants' experiences of having limited choice aligned to their preferences during treatment decision-making. It consists of two sub-themes: “*I Am Not A Standard Person*” and “*You Don't Get A Choice*”. Participants described feeling that treatments were not individualised, as highlighted by Grace when discussing her recommended treatment with her oncology team:

*“They [Oncologists] say, ‘well, this is the dose we think you are going to do best on’. You know it’s a sort of standard one size fits all”.* (Grace)

Most participants described a seeming expectation of compliance that treatment will be accepted, as Fiona reflects when engaging with the oncology team after declining chemotherapy:

*“I found it quite difficult because it’s as if they don’t expect you to do that [decline treatment]. It’s like you are all in this box, and the minute you step out of the box, you’re stepping out of line, you’re making it difficult for people, you know, em, because that’s not how they work”.* (Fiona)

##### **4.2.1. “I Am Not A Standard Person”**

Most participants said they would have welcomed further discussion regarding options other than chemotherapy or hormone therapy. Participants described their frustration and disappointment that their individual circumstances or past health and lifestyle did not seem to have been considered during treatment planning, feeling as if their life before their cancer diagnosis did not factor into their current circumstances, as emotively illustrated by Fiona:

*“There is nothing. No alternative. Nobody has asked me anything, anything at all, about my lifestyle. Nobody asked me what I worked as. Nobody has asked me about my diet, which I think is massively important”.* (Fiona).

Rosie reiterated frustration that her individual needs were overlooked. She described herself as an *“advocate for my own health”*. She questioned why her oncologist changed her treatment without discussing her individual needs, leaving her feeling like *“an inconvenience”* when attempting to ask further questions. Her need to be respected as an individual and not perceived as *“a file name or number”* was evidenced in the following excerpt:

*“He [Oncologist] was like ‘well, that’s just the standard treatment’, and I was like, I am not a standard person, am I. I am my own person, and I don’t want the standard treatment. I want a treatment plan that is going to suit me individually, but that’s not something that they do”*. (Rosie)

This perceived rigid lack of individuation and perspective taking by oncologists may be explained in the context of implicit bias towards prescribing standard treatments above others with less of an evidence base.

#### **4.2.2. “You Don’t Get A Choice”**

Having choice over treatments and suggested alternative pathways was important for participants who sought respectful acknowledgement that this is ultimately an individual decision, as illustrated by Helen:

*“I feel for me; this is just for me personally; I feel it would be nicer if doctors maybe approached it with the ‘well, there is treatment, but of course, it’s your decision; there is the other path to go down’*. (Helen)

Some participants felt that suggested messages from oncologists were that *‘well this is your diagnosis, and this is what you’re getting’* (Fiona), with little or no discussion of treatment preference. Susan illustrates her experience of this perceived power imbalance during decision-making:

*“No, you don’t get a choice. They [doctors] know better. They are the ones with the letters after their name, you know. When actual, of fact, maybe they should just sit back and learn that people do know their bodies. They [doctors] have*

*the education, but people know which capacity, that whatever's thrown at their body, the body can take". (Susan)*

Lack of choice was also described in the context of treatment quality: *"I just feel that the NHS is going to give me the absolute cheapest brand, you know"* (Grace), and in relation to wider research: *"all the research money is going into chemotherapy instead of looking at alternatives to it. Softer alternatives"*. (Fiona)

#### **4.3. "What Mattered Most": A Meaningful Life**

This theme highlights how participants considered their decisions to be shaped by living in accord with their values and preferences, seeking empowerment to live the remainder of their life in the pursuit of what they find pleasurable and meaningful. It consists of two sub-themes, *"Quality of Life: Important, Simple Things"* and *"Taking Control: It's My Life, And It's My Death"*.

##### **4.3.1. "Quality of Life: Important, Simple Things"**

All participants were at an advanced stage of illness with varying severity in physical health following their decision to decline recommended treatment. However, engaging in meaningful activities based on their values, beliefs, and preferences - whether previously enjoyed or when trying something new appeared to provide a sense of 'normality' and some welcomed distance from their cancer experience. Marion reflected that being able to stay connected to friends and family while remaining independent at home for as long as possible influenced their decision to decline treatment:

*"I would be homesick for home, homesick for friends in (...) and that was contributing, that was a big factor in the whole thing. I kind of weighed it all out, [accepting chemotherapy] so you can't call (...), they can't call you, and you're in (...). Here [Home] I can do a cup of tea and do what I want".*

The prospect of enduring another cycle of chemotherapy was so distressing for one participant that they had considered ending their life:

*“If I don’t want to live because I am taking a drug to keep me alive, then that’s counterintuitive, and there is absolutely no way I should be taking that drug”.*

(Rosie)

Therefore, returning to everyday life following this crisis had a renewed meaning and purpose, not only for their physical and psychological health but also for helping them create meaningful memories with their daughter, as poignantly illustrated:

*“Last night it was Rainbows - my little girl at Rainbows - and I walked the dogs while I was waiting for her, and then I put her to bed, and I even just sat and watched a couple of episodes of Friends, which I wouldn’t normally do but just doing the things that I enjoy”.* (Rosie)

Overall, the intentional act of distancing themselves to some extent from their cancer experience, often experienced as distressing, was indeed significant, with unpleasant memories of themselves as cancer patients having integrated into their sense of self. In addition, embracing their former roles, i.e., as active parents and individuals with unique life experiences before cancer ‘took control’ of their lives, was essential in restoring their self-identity and engagement in daily life.

All participants described the importance of maintaining a good QOL and what it meant for them. For Helen, QOL meant spending the time leading up to her death in hospice care surrounded by “life and joy”:

*“So for me, that’s the way I want my end to be. How long? It’s the quality, quality of life, quality for me for sure.”* (Helen)

Rosie described her dilemma when making treatment decisions, balancing quality of life with the extension of life. For her, this meant spending any remaining time with her young child, not reliant on others, returning to work, attending the theatre, and attending support groups while avoiding debilitating side effects of chemotherapy:

*“I discovered that the chemotherapy drug that they wanted me to have was only going to reduce my risk of recurrence by 2 to 3 per cent and which I felt was not a big enough difference to warrant six months of my life relying on*

*other people, and having awful side effects, and that actually I would prefer to get back to normal life” (Rosie)*

The importance of creating peaceful and happy memories leading up to death was vital for Fiona in comparison to enduring cycles of chemotherapy and the potential adverse side effects impacting her ability to enjoy what she loves, i.e., walking on the beach, visiting restaurants, and sharing a glass of wine with loved ones:

*“In my death bed, I will see me walking along that beach. I won’t see me in that room around the corner with a drip in my arm. Do you know what I mean? So that quality of life is really important. Really important, simple things, being able to eat.” (Fiona)*

Marion, who lived in a remote and rural area, contrasts how the impact of travelling from fond and familiar surroundings to the total unknown of hospitalisation for treatment would have significantly impacted her QOL and reduced opportunities to experience happiness while maintaining her independence for as long as possible:

*“What mattered most was I would have to leave [home] for a month or five weeks. I have a lovely little garden, and the flowers are out, and the neighbours are wonderful, and I thought, why put myself through that. You know, I don’t know what it was going to be like”. (Marion)*

Similarly, QOL for Grace was about finding pleasure in what she can currently manage independently during a period of respite:

*“I suppose when the weather is lovely, that’s nice. I mean just the little, simple things, I suppose, you know, reading and doing my meditation, that sort of thing”. (Grace)*

For Susan quality of life meant spending time with her dogs and experiencing a sense of reassurance that her finances and her husband’s welfare following her death were taken care of:

*“The things that matter to me most obviously are (...) the two dogs, (...). I want my husband to be in a position where if he needs any medical treatment the money is there for him, so that’s what’s important” (Susan).*

#### **4.3.2. “Taking Control: It’s My Life, And It’s My Death”**

All participants powerfully conveyed a sense of losing control following their cancer diagnosis. For some, this was also evident following previous cancer treatments, as Fiona reflects following initial meetings with her oncology team after surgery, where the subjective experience of being told that she will now receive chemotherapy was viewed as controlling, invasive and unwelcome:

*“There was also the mixture of, em, totally control was taken from your life, do you know what I mean. It was like, ‘This is what is going to happen. Now that you have had the operation, we [oncologists] are going to put you through six sessions of chemotherapy’. I was like, well, no, no, I don’t think so because you know this is my body.”* (Fiona)

This need to regain control over one’s body was also significant for Susan, given their previous negative experiences of healthcare where a considerable amount of emotional adjustment had taken place:

*“No way is somebody going to put something inside me that I can’t control. If you’re on pills, you either come off them or stay on them, but with [cancer drug], you are injected in each buttock with this stuff, and it’s in you for two weeks”.* (Susan)

Susan perceived this treatment as intolerable and uncontrollable, lingering in the body even after administration compared to other types of treatment that may be more tolerable, i.e., oral treatments with greater control of administration and discontinuation.

The impact of losing control of the ability to carry out everyday activities and attend work was experienced as very distressing for Rosie. It was perceived as a constant reminder that cancer had taken over their lives:

*“You know, for me, the loss of control of every aspect of my life has been torturous, has been absolutely terrible. Em, you know, even to the point where you know I can’t go to work, I can’t go to the supermarket.”* (Rosie)

In declining treatment, participants described a sense of regaining control of their lives and the time remaining:

*"I want to live this life; I want to go out the way I want it, you know." (Marion)*

*"I feel in control. I feel completely, in control, you know, so, however long I've got, this is the right decision for me." (Helen)*

Regaining some control over the tangible aspects of their lives when confronted with inevitable disease progression was deemed as central in helping some participants control and plan the end of life, as Fiona movingly described:

*"I felt that I had taken control of my own life and my own destiny, own death, you know it's my death, you know, it's my life, and it's my death" (Fiona).*

## **5. DISCUSSION**

The present study aimed to understand the lived experiences of patients diagnosed with cancer who have declined cancer treatment, to explore the treatment decision-making process and the influence of values. The analysis generated three core themes and seven sub-themes which illuminated aspects of communication, choice, and personally meaningful values.

Findings demonstrated how perceived lack of communication, mismatched expectations and pressure could become barriers to reaching a shared understanding between oncologists and patients over treatment decisions. In addition, results suggest a perceived lack of sensitivity in how oncologists shared potentially distressing information. These findings are consistent with Westerndorp et al., (2022), who explored the patient's perspective of what may be construed as potentially harmful communication for patients with advanced cancer. Their findings suggest potentially harmful communication behaviours by oncologists, i.e., failing to consider the emotional impact experienced by patients when providing information, being too directive during decision-making, lacking empathy demonstrated by not listening, focusing only on medical matters, and neglecting to ask patients their views on what may be potential solutions.

The present study also explored a differing narrative by the eldest participant who lived in a rural community and valued maintaining a positive independent life while planning how they wished to use their time leading up to their death. In addition, they described satisfaction during interactions with their oncology team when discussing treatment decisions and preferences relative to declining chemotherapy. They felt they were given ample time to think and decide, their decision was respected, and there was no persuasion to change their mind. These factors may explain the divergence in their account. A recent qualitative study exploring the perceptions of quality of life by people with advanced cancer who choose to remain at home (Peoples et al., 2020) indicated that patients continue to engage in meaningful activities despite the need to adjust quickly to changing circumstances.

Additional barriers to reaching a shared understanding included perceptions that oncologists reacted to declining cancer treatment with disapproval, frustration, and patriarchal attitudes. This, in turn, led to feelings of frustration for participants, potentially impacting the patient-caregiver relationship. This finding can be understood in the context of literature which indicates that patients who decline conventional cancer treatments may have a strong internal locus of control (Rotter, 1990), in that they are active patients, often self-informed and have given considerable attention to cancer meanings and treatment (Verhoef et al., 2008). It can be postulated that patients who take an active role in their healthcare by seeking information, e.g., conducting independent research, may perceive oncologists as dismissive and disinterested if their attempts to share their knowledge, experiences and preferences appear to be unrecognised. Furthermore, it has been argued that oncologists may focus on a medical perspective and view the patient's decision as irrational if they have declined curative treatments that may extend life (Van Kleefans and Van Leeuwen, 2005), as supported in this study when participants described the referral to psychology being prompted by oncologists querying their reason for declining treatment.

End-of-life discussions are argued to be incredibly stressful and challenging for oncologists (Granek, et al., 2013), who also report experiencing an emotional impact when patients decline cancer treatment (Carlson, 2014). Furthermore, the pressure of

meeting treatment targets and ensuring that patients are seen promptly may compound the oncologist's ability to protect the additional time required to provide a space for a further in-depth patient discussion. In addition, in 50% of countries worldwide, the coronavirus pandemic has affected cancer care services, stretching the resources of an already exhausted workforce (WHO, 2022).

Findings further suggest that participants perceived an absence of options other than standard treatments, i.e., chemotherapy. This lack of choice left participants feeling that their care was not person-centred and tailored to their values and preferences. These findings are supported by Krzyszczyk et al., (2018), who argue that as cancer is complex and heterogeneous, it responds differently in each individual and that the current conventional approach to cancer treatments is too simplified, may be ineffective, and cause unnecessary patient side effects.

The Health Belief Model (HBM, Rosenstock et al., 1988) is a cognitive model for understanding health behaviours that may impede the individual's health-related decision-making. For example, it is utilised to understand predictors of intention for patients refusing surgery for pancreatic cancer (Castillo-Angeles et al., 2017). However, the HBM may not adequately capture all aspects of treatment decision-making, such as personal values and preferences.

Models and approaches, such as Acceptance and Commitment Therapy (ACT) a therapeutic model derived from Relational Frame Theory (Hayes et al., 2006; Zhang et al., 2018), that may be relevant to our understanding of treatment refusal and the importance of personal values in treatment decision-making. For example, Smith et al., (2022) suggest that an ACT approach may help support breast cancer patients with medication decision-making that aims to increase psychological flexibility and improve medication adherence for preventative treatments i.e. Tamoxifen and quality of life.

ACT aims to help patients accept what may be beyond their control and promote committed action toward what matters most to the individual in the present moment through increasing psychological flexibility (Harris, 2009; Hayes et al., 2010). ACT has a growing evidence base within healthcare, including oncology (Fashler et al., 2018) and has been suggested to help those with cancer engage with personal values (Hulbert-

Williams & Storey, 2014) and reduce psychological distress (Zhao et al., 2021). Feros et al., (2013) support this view and reported significant improvements in self-reported distress, mood, and quality of life in patients with cancer following an ACT intervention.

Participants in this present study, due to limited discussions with oncologists regarding their individual preferences, perceived that their oncologists never had a true sense of who they were, i.e., individuals with their own lived experience, personal circumstances, plans for the future, beliefs, and values, resulting in frustration and discordance with their oncology team. These findings are supported by Kuijpers et al., (2022) who suggest participants' experiences of aspects of treatment decision making, i.e., perception of availability of treatment choice, being aware of treatment options and effects and evaluating options aligned with personal values during discussions with HCPs, were reported as inadequate. Additionally, failing to ask patients about their preferences during cancer treatment decisions may lead to the care delivered being misaligned with the patient's needs (Herrmann et al., 2018). LeBlanc et al., (2018) suggest that oncologists may view patients as more engaged in decision-making than patients perceive.

Findings demonstrate that, for participants in this study, living the remainder of their lives aligned with their values, beliefs, and preferences, free from potentially distressing treatment side effects, influenced their decision to decline cancer treatment. For some participants, balancing QOL with the extension of life was a dilemma (Laryionava et al., 2014). However, their decisions were based on what they deemed was best for them and, for some, their families. Engaging in meaningful activities surrounded by people and things that matter most to them while regaining control of their lives, bodies, and sense of self following their individual cancer experience, were essential aspects of establishing distance, creating new and enriching memories, maintaining a good quality of life and, for some participants, having control of their death.

For those with advanced cancer, retaining a sense of control has been linked to psychological adjustment (Hirai, et al., 2002), improvements in mental wellbeing

(Kershaw, et al., 2015) and treatment decision-making aligned to personal values (Sandman et al., 2012). For one participant who continued to experience intrusive distressing recollections of the side effects of a previous cycle of chemotherapy, regaining control was especially important. Cancer diagnosis and treatment can be experienced as traumatic and attributed to feelings of vulnerability, unpredictability, and loss of control (Cordova et al., 2017). This need to maintain control following a traumatic experience can be understood further when referring to the Trauma-Informed Practice (TIP) literature (Harris and Falot, 2001). TIP aims to understand the impact of trauma on the individual's life and consists of five guiding principles, *safety; trustworthiness; choice; collaboration* and *empowerment*. Study findings support the need for consideration of these principles for most participants namely through lack of choice, empowerment and to some extent collaboration during treatment decision making.

### **5.1. Implications for Clinical Practice and Services**

Ineffective communication between HCPs and cancer patients is argued to increase patient anxiety, engender distrust in HCPs, negatively impact the patient's sense of control and lead to non-adherence to recommended treatment (Waller et al., 2014). Previous research suggests that experience may not improve communication skills (Cantwell, 1997). Delays in implementing Communication Skills Training (CST) within medical training have also been reported (Lipkin, 2010). Therefore, improving communication during treatment decision-making is a worthwhile endeavour that may be facilitated by ensuring that CST for those working in oncology settings is delivered and updated where needed. Findings from a recent systematic review (Berg, et al., 2021) support this recommendation. HCPs reported increased confidence in communication and perceived knowledge across studies following online CST. Online CST is likely a more accessible training option given the current uptake of online learning and remote working following the coronavirus pandemic.

HCPs do not consistently facilitate patient engagement in decision-making and adapt care to patient preferences (Couët, et al., 2013). Present findings suggest that unexplored personal preferences and values need to be considered or revisited with

patients during all stages of treatment decision-making. Incorporating Patient Decision Aids (PtDAs) may help address unmet needs within oncology services. PtDAs are evidence-based supplementary tools, e.g., written materials and interactive online programmes that support patient-clinician shared decision-making while incorporating the patient's values and preferences. PtDAs were found to improve patients' decision-making (McAlpine et al., 2018). Finally, findings highlight the ongoing need to implement a trauma-informed approach to cancer care (Lawson and Lawson, 2018).

Participants who decline cancer treatment report feeling isolated in their decision. Developing a pilot peer support group within oncology services or online for those who decline treatment may facilitate this unmet need.

## **5.2. Methodological Strengths and Limitations**

A strength of this study is its recruitment of and insight into a hard-to-reach clinical population through obtaining qualitative data that was rich and nuanced. However, findings may have been influenced by the overall homogeneity of the sample concerning gender, cancer types, ethnicity, and disease progression. Transferability of findings to other populations may be helpful to explore in future research. However, the age range was notably heterogenous. It must also be noted that theme development was undertaken by one researcher, the primary author. Braun and Clarke (2022) argue that in reflexive thematic analysis, theme development is organic, interpretive, and subjective. However, reviewing themes with an experienced researcher in the RTA approach for consensus to check whether the primary author's assertions affected the themes derived, may have helped to increase validity and reliability of the overall findings. Additionally, the researcher may have inadvertently posed questions related to personal values which may have introduced bias. However, it must be noted that questions within the semi-structured interview guide were used flexibly throughout the interviews, aligned with participants responses. In future studies, piloting the interview guide may help to minimise errors and increase validity.

The current study initially intended to recruit patients with gynaecological and urological cancers. However, initial recruitment did not obtain sufficient numbers so the investigation was opened to include breast cancer. There was also a need to

ensure feasibility based on a small scale time-limited project recruiting from one site. The cancer types were selected as they were comparatively under-researched and where treatment side effects were anecdotally reported to impact on decisions to decline.

Interestingly, no men with urological cancers were put forward for potential participation during the recruitment window and reasons for this remain unclear. It is important to acknowledge the impact of only representing women's experiences which indeed may be distinct from men's experiences when declining treatment. Additionally, recruiting participants via cancer charities or organisations could have been explored further. Furthermore, anticipated recruitment rates were lower than previously estimated and may have been affected by pressures on services due to the coronavirus pandemic.

### **5.3. Future Research**

Qualitative investigation exploring men's experiences of declining cancer treatment may provide additional insights into what has influenced their decision and would enhance the evidence base in this under-researched area. For those with brain cancer, the issue of capacity due to disease-and treatment-related cognitive impairment to provide informed consent and make treatment decisions may be compromised and poses an ethical dilemma for researchers and clinicians alike, warranting careful consideration. Future research exploring the clinicians', patients', or and carers' experiences of the shared decision-making process for those with advanced care planning and who have declined treatment would provide insights into what influences further our understanding and support of treatment decisions in this clinical population. Finally, further exploration of clinician perspectives of treatment decision-making in with those who have declined treatment may increase our understanding of their experiences and the current challenges within oncology settings.

#### **5.4. Conclusions**

Patients who decline recommended cancer treatment are an under-researched minority group. Study findings highlighted participants' experiences and perceptions of influencing factors in their decision to decline treatment. All participants described a desire to live the remainder of their lives in accord with their values, beliefs, and preferences, free from potentially distressing and debilitating treatment side effects. Perceived barriers between participants and their oncology team, i.e. lack of communication, mismatched expectations, perceived pressure, or persuasion to accept treatment and feelings of disapproval and frustration, were described as impeding the development of a shared understanding during the decision-making process. The dominance of standard cancer treatments such as chemotherapy, with limited opportunity to discuss other options, could undermine the sense that individual preferences and circumstances are adequately considered. The study highlights the need for review, update and facilitation of communication skills and trauma-informed training for those working in oncology services.

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## Appendices

Appendix 1. Sample of Search Strategy *Search Strategy Database(s): Ovid MEDLINE(R) ALL*

#	Searches	Results
1	exp Menopause, Premature/ or exp Menopause/	61316
2	early menopause.mp.	1132
3	surgical menopause.mp.	913
4	chemo* induced menopause.mp.	35
5	premature ovarian failure.mp. or exp Primary Ovarian Insufficiency/	4462
6	1 or 2 or 3 or 4 or 5	65904
7	cancer treatment.mp.	62626
8	chemotherapy.mp.	501993
9	exp Radiotherapy/	202062
10	Bilateral Salpingo oophorectomy.mp. or exp Ovariectomy/	29706
11	exp Tamoxifen/	22288
12	7 or 8 or 9 or 10 or 11	753123
13	((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj2 (interview* or discussion* or questionnaire*)) or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant")).tw,kw. or interviews as topic/ or focus groups/ or narration/ or qualitative research/	468336
14	6 and 12 and 13	64

Appendix 2 – Data Extraction Form

Title of Study	
Author, Year, Country	
Study Aims	
<p>Sample and Clinical Characteristics</p> <ul style="list-style-type: none"> <li>➤ Age range/mean age</li> <li>➤ Ethnicity</li> <li>➤ Number with Children</li> <li>➤ Time since cancer diagnosis</li>   <li>➤ Type of Cancer Treatment Procedure</li>   <li>➤ Type of menopause Symptoms</li> </ul>	
Data Collection, Methods & Analysis	
Results/Findings/Themes, Sub-Themes & Author Interpretations	

Appendix 1 [Online] MRP Proposal (Proceed to Ethics Approval)

<https://osf.io/zntcw>

Appendix 2 [online] MRP Protocol (IRAS Submission)

<https://osf.io/emh2y>

Appendix 3 [Online] Participant Information Sheet

<https://osf.io/dcwsa>

Appendix 4 [Online] Semi-Structured Interview Guide

<https://osf.io/9vw54>

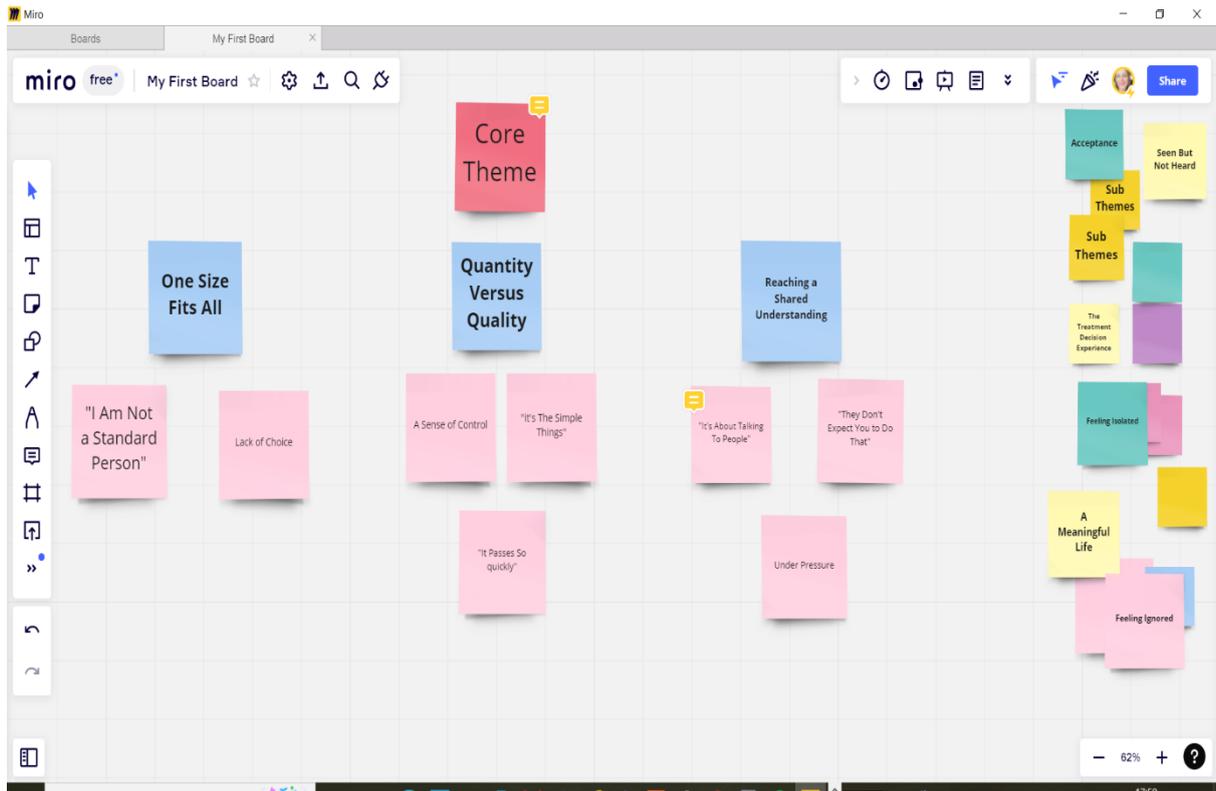
Appendix 5. [Online] Consent Form

<https://osf.io/u3sjv>

Appendix 6. Sample of Transcript (Initial coding)

223		brief chat, and she said, “your	Assumption that cancer treatment is
224		chemotherapy will start tomorrow”, and I	accepted
225		said no, no, and my daughter was with	
226		me, and I got quite upset I said no. That's	Upset and declined treatment
227		one of the reasons I didn't want to come	
228		in here. Well then we had a long chat	Oncologist finally acknowledged
229		after that, and she realised that I felt quite	strength of feeling regarding
230		strongly about it. So, she came back later	treatment decision
231		that night and spoke to me in depth again	
232		like I just said to you. I just felt her	Oncologist appeared frustrated by
233		frustration. I know she was trying to help	decision to decline cancer treatment
234		me. I felt that from her, I felt she was	Oncologist trying to help and
235		trying to help me. But that's when she	understand decision
236		suggested that I speak to a psychologist	Oncologist suggested speaking with a
237		just in case there was something deep	psychologist about my decision
238		rooted that was stopping me from having	
239		the treatment, from having the	
240		treatment, you know.	
241	<b>AC</b>	Thinking back Helen, is there anything you	
242		would have preferred to have been	
243		different about that experience?	
244		Probably at the, like I just said to you	
245	<b>Helen</b>	when I was speaking to the oncologist	
246		initially. I felt not enough, em, emphasis,	More emphasis needed on alternative
247		if you like, was put on ‘there is another	treatments
248		path’, you know. I definitely felt that and I	Feeling afraid
249		felt that fear within me. If someone had	
250		said to me ‘you know I think treatment	
251		would be good for you, but I understand	
252		that you're an individual person, and if	Individual preferences should be
253		you do go down the other road of having	considered
254		no treatment, please don't worry,	
255		because as your symptoms arise we	More reassurance needed that
256		would take care of them’. Rather than	symptoms can be managed effectively
257		saying, ‘your bowel could become	
258		blocked, and if it does not come out one	Need to communicate information
259		end it will come out the other end’.	sensitively
260	<b>AC</b>	Which was obviously very alarming to	
261		hear?	
262	<b>Helen</b>	Terrifying actually	Explanation given by Oncologist was
263	<b>AC</b>	Yes, of course	terrifying
264		So that could be changed, that approach	New approach needed
265		just looking at people individually then,	
266		and understanding that, because nobody	Individual preferences should be
		really in my opinion, what I think it's an	considered

## Appendix 7. Screenshot of Reflexive Thematic Analysis Theme Development



## Appendix 8 Excerpts from Reflective Diary

### Data Collection

#### P2

I felt initially that I was being viewed as “one of them” – another healthcare professional, part of the system that had let her down. She was very angry and I initially felt a bit overwhelmed. It was important to establish a level of trust fairly quickly – some kind words and not rushing in too soon helped. I was stuck at times – referring back to the interview guide in the early stages of the interview (needing reassurance, possibly!). I worried about giving her the time to talk before moving on. It was difficult not to be moved by her experience and will be useful to discuss in supervision.

#### P6

I could feel my eyes filling up at one point in the interview when listening to the participant’s experiences. Important to remain professional and keep the researcher hat on, but also absolutely necessary to demonstrate empathy. It would have been good to have conducted the interview face to face. She reminded me of the older patients I have nursed in the past. Interesting contrasting experiences regarding the delivery of oncology care. My previous training and supervision helped to work through thoughts and feelings following the interview. I noticed that I may have repeated a question, (perhaps making sure that I had covered everything as much as possible).

### Coding Process

I have transcribed the first transcript and started the initial coding. I have never coded before and have spent hours trying to get it right. I suspect that I am wasting valuable time. I do tend to go over things a bit too much (perfectionism? Avoidance? Anxiety?). I may have been too interpretative in the initial coding which may be down to having become so immersed in the data, bringing my own experiences of nursing cancer patients, personal experiences of cancer, and reading the literature (will need to keep a constant check on this to minimise bias as much as possible). Viewing videos by Braun & Clarke and Dr Jarik Kruikow, discussing in supervision and spending time reading their latest book chapter on coding helped me find my way back to the data.

### Recruitment

Recruitment has been much slower than previously estimated. I expected that there may be challenges ahead due to the hard-to-reach clinical population. I have been in regular email contact with the gynaecological and uro-oncology teams at the Beatson. I am also aware that oncology services are very busy, even more so since the start of the pandemic. All of us involved in the project are feeling concerned given the time-limited nature of the project. I have felt a sense of responsibility given the hold-up with ethics. I completely underestimated the massive task of getting through the NHS ethics application. Discussed with supervisor and trying to be more self-compassionate and more proactive going forward.

West of Scotland REC 5

Attendance at Committee meeting on 20 October 2021

Committee Members:

Name	Profession	Present	Notes
Dr Natasha Bilcliff	Consultant Forensic Psychiatrist	No	
<del>Mr</del> Linda Boyle	Retired Company Secretary	Yes	
Dr Stephen Corson	Statistician	Yes	
Dr James Curran	GP	Yes	
Dr James Dale	Consultant Rheumatologist (Vice-Chair)	Yes	Chaired meeting
Dr <del>Kirsteen</del> Goodman	Trial Manager/Research Fellow	Yes	
Dr Palghat Gopalakrishnan	Consultant Neonatologist	No	
<del>Mr</del> Naomi Hickey	Research Nurse (Chair)	Yes	
Dr Audrey Morrison	Research Practitioner	Yes	
<del>Mr</del> Karen Mowbray	Health Records Manager (Alternate Vice-Chair)	Yes	
<del>Mr</del> Charles Sargent	Retired	Yes	
<del>Mr</del> Tracy Taylor	Retired Veterinary Nurse	Yes	

Also in attendance:

Name	Position (or reason for attending)
<del>Mr</del> Sharon Macgregor	REC Manager
Miss Ashley McLaren	REC Manager