In the Space Between: Women's Experiences of Identity Living with Advanced Cancer

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Thesis Portfolio Abstract

The overall aim of this thesis portfolio was to explore women's experiences of self-identity while living with advanced cancer. This aim was addressed through two complementary studies: a qualitative systematic review and meta-ethnography, and an empirical qualitative study.

The systematic review synthesised qualitative research exploring women's experiences of identity while living with advanced cancer. Eleven peer reviewed qualitative studies were included and analysed using a meta-ethnographic approach. Four higher order constructs were generated: *performing normality to protect identity*; *temporal reorganisation in the face of mortality emotional regulation amid shifting priorities;* and *meaning making and reclaiming the narrative.* The synthesis conceptualised identity as an active, relational and morally situated process, shaped by gendered roles, societal expectations and awareness of mortality. Findings highlighted the considerable emotional labour undertaken by women to preserve continuity of self while navigating progressive, incurable illness.

The empirical study utilised Interpretive Phenomenological Analysis to explore the lived experiences of women diagnosed with metastatic breast cancer. Semi-structured interviews were conducted with thirteen women who had been living with a metastatic diagnosis for over six months. Four superordinate themes were identified: *Rupture: the shattering impact of diagnosis; Ripples: Unnerving changes; Fragmentation: living in the shadow of mortality;* and *Who am I now? Reconstruction and reclaiming of identity*. The findings illuminated the impact of metastatic diagnosis on a woman's core sense of self, her relationships and future orientation, alongside identity processes which were found to be actively dynamic moving through adaptation and into reconstruction.

Together, the findings from both papers highlight identity as a dynamic, relational process that is continually negotiated by women under conditions of existential threat. This portfolio underscores the importance of attending to women's identity experiences with psycho-oncological and palliative care interventions and emphasises the need for psychologically informed and person-centred approaches in healthcare which support dignity and agency, in the context of advanced cancer.

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Chapter One

Introduction

Word Count: 1230

Chapter One: Introduction

Context of Portfolio and Terminology

This thesis portfolio explores women's experiences of self-identity while living with advanced cancer. It combines a qualitative systematic review and empirical qualitative study. Advanced cancer is an umbrella term commonly used to describe cancer which is unlikely to be cured, it may also be used to describe a cancer which has spread from its original starting place to other areas of the body (NIH, National Cancer Institute). The term metastatic cancer specifically refers to cancer which has spread from its primary site and metastasised to other areas of the body. Metastatic cancer is also known as stage IV and is considered incurable yet treatable to prolong life.

Advances in cancer treatment have resulted in many individuals living for extended periods with a metastatic diagnosis, transforming this diagnosis into a chronic longer-term condition for some (Hui et al., 2014 & McCaughan et al., 2012). This shift holds psychological significance as it means individuals must navigate a period of life which holds extended prognostic uncertainty and the difficult knowledge that their life expectancy is finite but remains unpredictable. Within this portfolio the term advanced cancer is used as an overarching descriptor and metastatic breast cancer (MBC) is used to refer to a specific diagnosis within the empirical study. MBC also features within the systematic review when relevant to specific studies.

Psychological Impact of Advanced Cancer

A substantial body of literature has documented the psychological impact of advanced cancer, including heightened levels of distress, anxiety, depression and existential fear (Mitchell et al., 2011; Zimmerman et al., 2014; Boston et al., 2011). Additionally, further literature has explored the impact of living with incurable illness which has been associated with uncertainty about the future, fear of death and struggles with meaningful living (Mishel, 1988; Lee et al., 2013; Vehling & Kissane, 2018). However, psychological responses to advanced cancer are heterogeneous, with individuals reporting a wide range of emotional, cognitive and relational experiences (Stanton et al., 2005; Greer et al., 2010).

Beyond symptom or treatment related distress, advanced cancer poses challenges to an individual's sense of self. The changes experienced to the body, functional ability, social roles, and

anticipated life trajectory all destabilise previously held assumptions about identity. Qualitative research has highlighted some of the methods which individuals may engage with to preserve their sense of identity whilst living with incurable illness such as legacy building (Chochinov et al., 2005; Allen et al., 2008). Legacy building refers to methods a person may use to create enduring memories or tangible artefacts such as memory boxes, which palliative care research has suggested supports a continued sense of meaning and identity when approaching the end of life (Allen et al., 2008).

Existing research suggests that experiences of identity with advanced cancer may be particularly pronounced for women, whose identities are thought to be closely intertwined with gendered roles such as caregiving and motherhood (Ginsberg et al., 2023). In addition, the impact of advanced cancer on fertility, sexuality and body image further contribute to identity related challenges faced by women (Kaiser, 2008; Ussher et al., 2013) underscoring the need for research which explores the gendered and relational dimension of identity when living with advanced cancer.

Identity and Advanced Cancer

Identity is a complex psychological construct which encompasses an individual's sense of who they are, how they understand themselves and how they are understood by others (APA Definition, 2019). Historically, identity has been theorised to be a developmental task, largely completed by adulthood (Erikson, 1968), within this framework identity was believed to be relatively stable once achieved, providing continuity across the lifespan. Although influential, this model has been criticised for its failure to acknowledge the context dependent development of identity in adulthood in response to major life events (Whitbourne et al., 2009). Subsequent theories offered perspective which challenged static conceptualisations of identity, instead highlighting its potential for disruption through illness or social changes (Bury, 1982). Bury (1982) proposed a concept of biographical disruption which marked a turning point in how chronic illness was no longer considered just a physical event, but a biographical and identity altering experience.

In addition, narrative approaches further developed these ideas by conceptualising identity as constructed and maintained through how individuals tell the story of their lives (Frank, 1995; Ricoeur, 1992; Crossley, 2000). From this perspective, as individuals are actively making sense of their identity through organising their experiences into a narrative, illness destabilises these efforts forcing revision or reconstruction of their life story, subsequently impacting their identity. Importantly, narrative theories also recognise the moral, relational and cultural dimension of identity, positing that stories of the self are shaped by dominant social narratives and expectations (McLean, 2008).

There is some research in which identity is described to be more dynamic, with participants describing disruption and reconstruction, as they seek to integrate illness into their sense of self whilst maintaining their own valued identity, resisting socially enforced expectations of becoming a 'cancer patient' (Little et al., 2002; Mathieson & Stam, 1995). Considered together, this provides a strong foundation for qualitative enquiry, as further investigation is needed of lived experience, to better understand the concept of identity whilst living with advanced cancer.

Researcher's Position

It is acknowledged that the researcher's experiences and assumptions will have shaped the content of this portfolio due to the qualitative nature of the work undertaken. To be actively reflective of their own experiences and assumptions, the lead researcher; Amelia Smith kept a reflective journal for the duration of the project, commencing at the first research supervision when ideas were developed about research questions. As a 38-year-old female, who is also a mother, there were inevitably pre-existing conscious and unconscious biases held that may have shaped the direction of the work. The lead researcher had not worked directly with this patient group, though had worked in acute health settings as an Assistant Psychologist. The lead researcher had no direct family experience of advanced cancer. Transparency was maintained throughout via extensive documentation of processes and bias was mitigated where possible through mindful reflection, use of research supervision and a reflective journal. The ontological and epistemological stance of this portfolio is one of critical realism and this is further discussed in the Empirical Paper (Chapter Four) and in further detail in Chapter Five: Extended Methodology.

Thesis Rationale and Aim

This portfolio presents a qualitative systematic review in Chapter Two alongside an interpretive phenomenological analysis in Chapter Four. The systematic review identifies core constructs across existing literature while the empirical study offers detailed exploration of lived experience within a clinical subgroup. This thesis portfolio addresses a substantial knowledge gap in the existing literature around identity in life-limiting illness by exploring women's experiences of identity while living with advanced cancer. This then has impacts the support and clinical care that women living with cancer may receive, for example, the current NICE guidelines for psychological care in women with advanced cancer are to offer "Assessment and discussion of the patients' needs

for physical, psychological, social and spiritual support...” (NICE 1.4.1, 2009), yet there is a lack of evidence based, informed understanding around the psychological needs of this subgroup of women, who do not fit in the ‘survivor’ category, yet, with some life expectancy reaching beyond ten years post advanced cancer diagnosis, are not facing imminent end of life and do not find their needs met within the palliative care guidance either. These women are ‘in between’. This thesis portfolio aims to explore the needs of these women specifically focussing on the impact on their identity, which arguably lies at the core of psychological wellbeing, with the goal of generating new knowledge about their experience, which we hope will begin to inform patient care, service and guideline development and staff education.

Chapter Two

Systematic Review

Women's Experiences of Self-Identity Living with Advanced Cancer. A Systematic Review and Meta-Synthesis of Qualitative Evidence.

Prepared for submission to The Journal of Health Psychology

(Author guidelines found in Appendix D)

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Women's Experiences of Self-Identity Living with Advanced Cancer. A Systematic Review and Meta-Synthesis of Qualitative Evidence.

Abstract

Advanced cancer presents profound challenges to a woman's sense of self. It disrupts identities, roles and life trajectories. While qualitative studies have explored aspects of women's lived experience no previous synthesis has integrated these accounts to generate higher order theoretical understanding of women's identity with advanced cancer.

This review aimed to synthesise qualitative research exploring women's experiences of identity while living with advanced cancer to develop an interpretative line of argument that furthers conceptual and clinical understanding. A systematic search was conducted and eleven qualitative studies met inclusion criteria. Meta-ethnography was conducted and reported in line with eMERGe guidelines.

Four interrelated higher order constructs were identified: (1) Performing normality to protect identity; (2) Temporal reorganisation in the face of mortality; (3) Gendered moral labour and emotional regulation; and (4) Meaning making and reclaiming the narrative. Across diverse contexts women engaged in sustained identity work to preserve a sense of self. Identity was actively reconstructed through relational, temporal, emotional and moral processes.

This meta-ethnography extends existing psychosocial theories of identity with incurable illness by illuminating the relational, gendered and morally driven nature of identity. Clinical practice should consider moving psychological support alongside symptom focused care, to recognise and support the invisible identity labour undertaken by women living with advanced cancer.

Introduction

Patient experiences are increasingly at the forefront of oncology practice, with increased attention focused on understanding this (Scherrens et al, 2024; Mitchell et al, 2020). The term advanced cancer typically refers to malignancies that are unlikely to be cured and that have either metastasised (spread to other parts of the body) or are locally extensive, often corresponding to stage four disease (National Cancer Institute, 2024). Although advances in systemic therapies have extended survival and improved symptom control, a diagnosis of advanced cancer remains life limiting and has been associated with increases in physical, psychological and existential distress (Hui et al., 2014 & McCaughan et al., 2012). Patients often face an evolving disease trajectory marked by periods of remission, recurrence and progressive decline which can generate ongoing uncertainty (Kendall et al., 2013). Adapting to prognostic awareness is complicated by the challenges women face in living meaningfully whilst also preparing for death (Clayton et al., 2007).

Bury (1982) conceptualised illness as a form of biographical disruption which serves to challenge an individual's continuity of self and their life narrative. Similarly, Charmaz (1981) describes chronic illness as a threat to selfhood, where individuals are required to reconstruct identity amid progressive loss whilst also navigating social stigma and expectations. These theoretical perspectives are particularly salient for women living with advanced cancer, whose identities may be deeply embedded within gendered social roles. Advanced cancer may disrupt a woman’s roles such as mother, partner and professional through the wide-reaching impact of the illness (Ginsberg et al., 2023). Societal expectations, physical changes and existential concerns related to one’s own mortality may all further impact the self-identity of women experiencing advanced cancer (Obispo et al, 2022; Hopkins et al, 2024).

Understanding these experiences of identity, may inform psychological oncology interventions, communications strategies, staff training and understanding of patient experiences to

support frameworks which uphold dignity and agency within palliative care (Le Boutillier et al., 2019). Existing research describes self-identity as a dynamic and relational construct (Brown et al., 2001 & McClement et al., 2013). For women, the onset of an incurable disease may result in profound psychosocial consequences, yet these processes and the experiences of the women whom they impact remain unexplored in a focused and integrative way (Donnovan et al., 2001 & Mathieson and Stam., 1995). Although prior reviews have elucidated models of living with and beyond cancer (Le Boutillier et al., 2019) no previous reviews have focused explicitly on identity among women with advanced cancer. A qualitative synthesis is thus timely and necessary to illuminate how these subjective experiences inform patient-centred psycho-oncological care and guide future research priorities (Popay et al., 2006).

Given the interpretive and conceptually heterogeneous nature of qualitative evidence in this area a qualitative evidence synthesis that moves beyond aggregation or descriptive summaries to generate new interpretive insights is required. Meta-ethnography is an explicitly interpretive method designed to preserve the contextual richness of the primary qualitative studies while enabling development of new conceptual understandings through the comparison and translation of key concepts and themes.

Meta-ethnography has been successfully employed in previous synthesis examining illness experience (Basile et al., 2024; Toye et al., 2015; Young et al., 2024) and used to explore patient experiences of cancer recurrence (Sinding & Aronseon, 2003).

Review Objective

The aim of this review was to examine the psychological impact of an advanced cancer diagnosis on women's self-identity, synthesising findings from qualitative research. Advanced cancer, defined in this review as stage IV or metastatic cancer, refers to cancer that has spread from the primary site to secondary locations and is typically considered incurable.

Methodology

Design

This review employed a systematic qualitative synthesis using meta-ethnography as described by Noblit and Hare (1988). The review was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA 2020), ENTREQ, and eMERGe reporting guidelines to ensure transparency and methodological rigour. The review was registered with PROSPERO on 3rd January 2025, ID CRD42025633634 (Appendix A).

Search Strategy

A systematic search was conducted using EBSCOhost, including the following databases: CINAHL Plus, APA PsycINFO, MEDLINE and SocINDEX. The final search was conducted on 11th December 2025. Search terms combined controlled vocabulary and free-text keywords relating to; Women (e.g., women, female); Advanced Cancer (e.g., advanced, metastatic, stage IV, terminal); Identity (e.g., identity, self-identity, sense of self); Qualitative research (e.g., qualitative, interviews, focus groups).

```
(experience* OR "lived experience*" OR perception* OR attitude* OR views) AND (wom#n
OR female OR "adult wom#n" OR females) AND ("neoplasms" [MeSH Terms] OR "advanced
cancer*" OR "terminal W3 cancer" OR "stage four cancer" OR "metastatic W3 cancer") AND
(identity OR "self identity" OR "self-identity" OR "self concept" OR "self-concept") AND
(qualitative OR "qualitative study" OR "qualitative research")
```

Figure 1: Example of search string

The search strategy was informed by preliminary scoping of qualitative and psychosocial literature, which indicated that identity-related concepts are variably labelled across disciplines including health psychology, nursing sociology and palliative care. Consequently, search terms were intentionally broad to capture diverse conceptualisations of identity and lived experience (Figure 1).

To assess whether the inclusion of qualitative filters restricted retrieval, the qualitative methodology filter was temporarily removed during the search process. This yielded few additional studies none of which met inclusion criteria, providing reassurance that relevant studies were not excluded. Reference lists of included papers were hand-searched to identify additional eligible studies.

Eligibility Criteria

Inclusion Criteria

Studies were eligible for inclusion if they: Focused on adult women (≥18 years) diagnosed with advanced, stage IV, or metastatic cancer; explored women's experiences of identity, including concepts such as self-identity, sense of self, or self-concept; utilized a qualitative methodology, including (but not limited to) phenomenology, grounded theory, thematic analysis, interviews, or focus groups; were published in English in a peer-reviewed journal.

Exclusion Criteria

Studies were excluded if: participants were not women or did not identify as women; participants did not have a diagnosis of advanced cancer; participants were under the age of 18; the study did not use a qualitative research design or did not provide extractable qualitative data.

Study Selection

All records identified through database searching were imported into Microsoft Excel and duplicates removed. Title and abstract screening were conducted by the lead reviewer (AS) for all retrieved studies. To ensure screening reliability, an independent second reviewer (SS) screened a random 25% sample of titles and abstracts using the same predefined eligibility criteria. Agreement between reviewers was assessed during this stage and no discrepancies requiring resolution were identified. Following title and abstract screening, full-text screening was conducted by both reviewers for 100% of eligible articles. Any disagreements at the full text stage were resolved through discussion until consensus was reached. The number of records identified, screened and assessed for eligibility, and included in the final synthesis are reported in a PRISMA 2020 flow diagram (Figure 2).

Data Extraction

A standardised data extraction form was developed and pilot tested. Data extracted is detailed in Table 1 and was combined and stored in data extraction sheets. The conceptual framework guiding the data extraction process was informed primarily by sociological and psychological theories of chronic illness and identity transformation, particularly Bury's (1982) concept of biographical disruption and Charmaz's (1981) theory of loss of self, which both provide foundational insight into how a serious illness and facing one's own mortality may alter sense of identity. Extracted data included Author(s); year; country; study aim and design; participant characteristics; type and stage of cancer; analytical approach and identity-related findings.

Quality Appraisal

The Critical Appraisal Skills Programme Qualitative Studies checklist (CASP, 2018) was used to assess the quality of included studies (Appendix B). Quality assessment was carried out

independently by the lead author (AS) and second reviewer (SS) on 100% of studies included in the review. The CASP Qualitative Studies checklist offers a framework for assessment commonly used for critical appraisal in qualitative systematic reviews (Long et al., 2020). Studies were classified by their overall score as either low quality (0-3, medium quality (3.5-7.5) or high quality (8-10). Differences in ratings between AS and SS were discussed and resolved to reach an agreement on overall ratings. All 11 studies were rated as high quality and included in the synthesis.

Analysis

The analysis steps the phases shown are overlapping and iterative but are best described as the 7 steps shown and defined by Noblit & Hare (1988) (Figure 2). These steps are (1) Getting Started; where the synthesis was guided by the review question: How do women experience and negotiate identity while living with advanced cancer? This question was intentionally exploratory and interpretive, reflecting the aim of generating conceptual understanding rather than aggregating outcomes. (2) Deciding what is relevant; studies were selected for inclusion based on eligibility criteria and relevance was determined by the presence of rich qualitative date relating to identity, self-concept or sense of self in the context of advanced cancer. (3) Immersive reading of studies and identification of key concepts; included studies were read repeatedly. First order constructs (participant quotations) and second order constructs (original authors interpretations) were identified and extracted. Attention was paid to metaphors, recurring concepts and analytic language used to describe identity processes. (4) Determining how studies are related; In phase four, studies were compared to identify conceptual relationships across findings. Key concepts relating to identity (e.g., normality, temporality and emotional regulation) were mapped across studies using constant comparison. Concepts were examined for similarity (reciprocal relationships), difference or tension (refutational relationships). (5) Translating the studies into one another; translation involved comparing how similar concepts were expressed and interpreted across studies. A conceptually rich index study (Study 5) was selected to anchor initial translations due to its strong theoretical framing of identity as a dynamic process. This allowed for reciprocal and refutational translations without biasing

a single population or metaphor. To ensure the synthesis was not an artefact of the index study, initial translation checks were repeated using Study 1 and Study 11 as alternative anchors. The core translation sets remained stable supporting the credibility of the translation process. (6) Synthesising translations; translated concepts were synthesised to generate third-order constructs that extended beyond the findings of any individual study (Appendix C). This involved interpretive integration of translated concepts into higher order explanations of how women negotiate identity while living with advanced cancer. Four interrelated third order constructs were developed through this process. Relationships between constructs were examined to develop a coherent line of argument that explained that for women living with the experience of advanced cancer, identity is actively sustained and reconstructed over time. (7) Expressing the synthesis; the synthesis is presented in the results section below as a narrative line of argument supported by illustrative examples from studies. Findings are reported using third order constructs while retaining participant quotations and original metaphors to preserve contextual richness. A conceptual model visually represents the identity work of women living with advanced cancer (Figure 4).

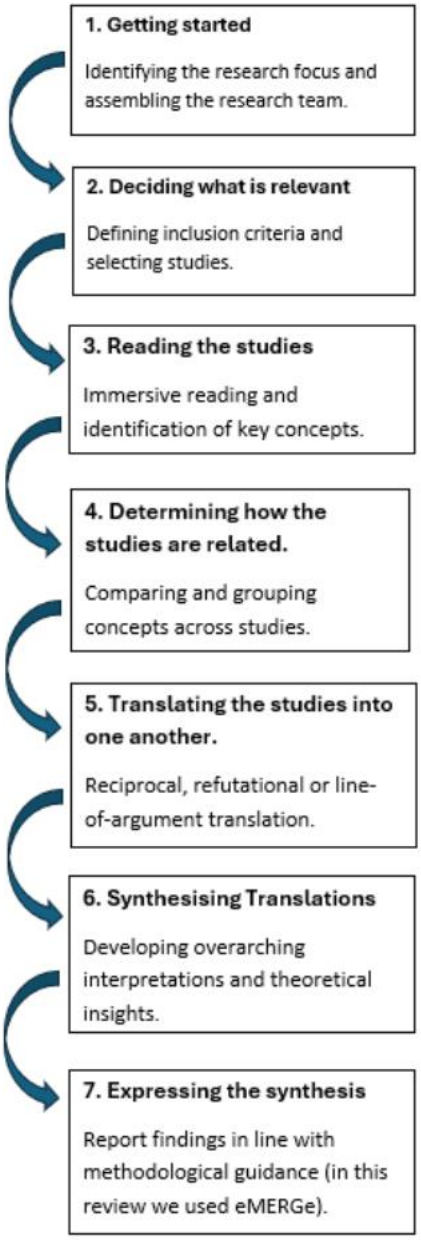


Figure 2

The Seven Steps of Meta-Ethnography adapted from Noblit & Hare (1988).

Results

Electronic database searches identified 57 records, and a further 14 records were identified through hand searching. After removal of 6 duplicate records, 65 titles and abstracts were screened for eligibility. Of these, 53 records were excluded for not meeting inclusion criteria. Twelve full text articles were retrieved and assessed for eligibility, with one study being excluded at this stage as it did not include participants with advanced cancer. A total of eleven studies were included in the final synthesis (Figure 2). These studies represented a total of 201 women living with advanced cancer and were conducted across a range of cultural, clinical and socioeconomic context. The included studies varied in cancer type, participant age, study setting and qualitative methodology, offering diverse perspectives on women's experiences of identity in the context of advanced cancer (Table 1).

Figure 3

PRISMA Flowchart Including Review's Inclusion and Exclusion Criteria

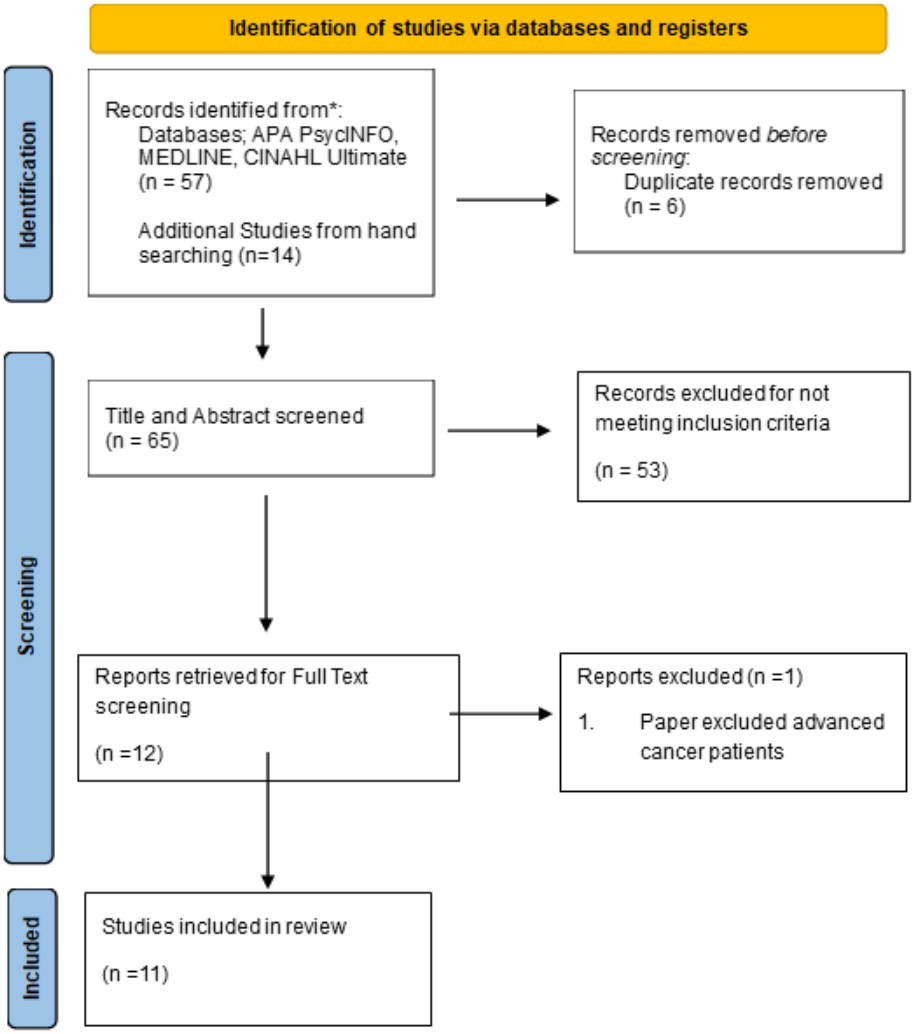


Table 1

Key characteristics and findings related to identity from included studies.

Author & Year	Country	Participants	Cancer Type	Setting	Recruitment	Study Design	Analysis	Areas in findings linked to identity
Lundquist (2019)	USA	12 women ages 31-39 (mean = 36)	Advanced breast (stages III – IV)	Mixed – Community and hospital. Remote interviews.	Purposive sampling via flyers at oncology centres, private Facebook groups for women with breast cancer)	Hermeneutic phenomenology. (1-3 interviews completed over 6 months with participants.)	Hermeneutic interpretive analysis.	False exterior identity (mask). Wanting to be known as the person I am, wanting recognition of both authentic identity and illness identity. Motherhood as a core identity "I'm still Mum". Preservation of normalcy "living is more than surviving". Coping as identity – getting thorough it. Relational identity.
Kahraman-Erkus (2024)	Turkey	8 women ages 27-28.	Varied metastatic cancers (throat, colon, breast, glioblastoma, soft tissue, adenoid cystic, stomach).	Academic Oncology Hospital	Purposive and convenience from University Oncology Hospital.	IPA	IPA	Disruption of core identity – compulsory changes in self-concept. Normalcy becoming the new 'ideal self'. Loss of 'young womanhood". "Minimalist" expectations from others. Guilt and relational identity strain. Forced positivity and burden to family.

Maree (2015)	Zambia	10 women ages 29-66 (mean age 48.2)	Advanced Breast	Hospital Inpatient wards.	Purposive sampling	Descriptive Quali design	TA	Loss of femininity and womanhood. Loss of roles. Body image and appearance identity. Stigma and threatened social identity. Emotional identity – shock, fear and self-blame. Functional identity loss. Existential identity hope vs despair.
Adler (2019)	USA	63 women ages 29-71 mean 53.9	Metastatic Breast	Community based clinic and Hospital.	Purposive Sampling	Phenomenological Quali study	TA	Identity as 'useful' 'independent' 'provider' is threatened. Identity as "less-worthy", internalised stigma. Feeling invisible in society. Threatened caregiver and relational identity. Identity reconstruction and meaning making.
Dumas (2021)	UK	15 women ages 68-89, Mean at diagnosis 75.0.	Advanced Ovarian cancer	Specialist Cancer Hospital.	Purposive sampling (to ensure variation in disease severity Stage II – IV)	Qualitative Phenomenological	Inductive TA	Identity and aging, Threat to identity; shock, overwhelm and loss of control. Threat to functional identity: fatigue and loss of independence. Stoicism and identity preservation. Relational identity family

								motivation and burden, and avoidance.
Visovsky (2023)	USA	16 women ages 29-73, mean age 55.62.	Metastatic Breast	National Cancer Institute (hospital)		Phenomenological Quali	TA within a phenomenological framework	Shock and identity collapse. Fear and threatened identity. Endless treatment eroding identity. Quality of life and identity loss. You are not the person you once were. Positive identity reconstruction. Diminished self-worth.
Lewis (2016)	Australia	18 women ages 42-74.	Metastatic breast.	Hospital outpatient oncology clinics and online.	Purposive sampling via an existing study cohort.	Qualitative using social constructionist approach.	TA	Identity preservation, reevaluating identity, constrained identity (symptom driven limitations), emotional identity and self-worth. Social identity changes.
Milagres (2016)	Brazil	18 women	Mixed incl. Breast/lung/intestine/cervical.	Hospital	Purposive	Qualitative using life story methodology.	Content Analysis.	Altered self-image and changed perception of body. Withdrawal and social identity disruption. Threats to femininity and sexual identity. Loss of autonomy and independence. Disrupted domestic and caregiver identity.

Ginter (2022)	USA	9 women (ages 28-40 at time of metastatic diagnosis)	Metastatic Breast Cancer	Online – social media.	Purposive sampling.	Cross-sectional Quali study with phenomenological orientation.	Phenomenological thematic analysis.	Dual marginalised identity (being young, being metastatic). Shifting social identity. Changing intimacy in relationships related to identity and bodily changes. Maternal identity changes. Disruption of future identity (maternal). Strong collective identity in MBC community.
Esquives (2024)	Norway	22 women ages (34-84), mean age 60.3.	Metastatic Breast	Hospital outpatient and patient homes.	Purposive sampling – across clinical lists, support groups, community cancer organisations.	Qualitative study using focus groups.	General inductive analytic approach. COREQ and SRQR used for reporting codes.	Identity integration, Body image, femininity, womanhood. Role and relational identity. Illness meaning and existential self-concept. Avoidance of cancer related identity.
Natuhwera (2021)	Uganda	10 women ages 40-71, mean age 53.4.	Advanced Cervical	Hospital.	Purposive sampling	Qualitative, exploratory descriptive.	TA	Fear of loss of identity. Disruption of social identity. Loss of relational identity. Identity threat form inability to perform expected roles. Existential identity disruption. Identity reconstruction and coping.

Quality Appraisal

All studies included were of high quality when appraised using the CASP Qualitative checklist. All studies clearly articulated aims and employed qualitative designs appropriate for exploring experiences of women living with advanced cancer. Across all eleven papers data collection methods were well aligned with aims and the choice of most studies to use in-depth or semi-structured interviews allowed participants to narrate complex and sensitive experiences. Most studies also presented findings clearly offering valuable contributions to the very limited qualitative evidence base addressing identity in women with advanced cancer.

Table 2*: Outcomes of the CASP checklist quality assessment for the 11 included studies.*

	1	2	3	4	5	6	7	8	9	10	11
Was there a clear statement of the aims of the research?	1	1	1	1	1	1	1	1	1	1	1
Is a qualitative methodology appropriate?	1	1	1	1	1	1	1	1	1	1	1
Was the research design appropriate to address the aims of the research?	1	1	1	1	1	1	1	1	1	1	1
Was the recruitment strategy appropriate to the aims of the research?	1	1	1	1	1	1	1	1	1	1	1
Was the data collected in a way that addressed the research issue?	1	1	1	1	1	1	1	1	1	1	1
Has the relationship between researcher and participants been adequately considered?	CT	CT	0	CT	0	CT	1	0	1	1	0
Have ethical issues been taken into consideration?	1	1	1	1	CT	CT	1	CT	1	CT	CT
Was the data analysis sufficiently rigorous?	1	1	1	1	1	1	1	1	CT	1	1
Is there a clear statement of findings?	1	1	1	CT	0	1	1	1	1	1	1
How valuable is the research?	1	1	1	1	1	1	1	1	1	1	1
Total score	9.5	9.5	9	9	7.5	9	10	8.5	9.5	9.5	8.5

Yes (1) Can't tell (CT 0.5) No (0)

Attention was paid to ethical considerations in most studies. Studies based in hospital settings also referred to formal ethical processes for their location. However, less detail was given by studies based in the community or online to safeguards around participant vulnerability. A further limitation was that four studies only partially addressed ethical issues in practice. These papers mention gaining ethical approval but do not explain how issues such as emotional distress, ongoing treatment burden

or power imbalances were managed during data collection. In addition, concerns relating to analytical rigour were present in three studies, where descriptions of analytic process lacked depth making it unclear how coding was conducted and themes were derived, making it challenging to appraise the analytic process. Finally, four studies offered limited information about their recruitment strategy, this may affect assessments of transferability or obscure any sampling bias present.

Despite overall high quality, several methodological limitations were identified in studies. Notably in nine studies, there was limited consideration given to the researcher/participant relationship. It was unclear whether researchers had reflected on their own positionality, and whether they may have any unconscious influence over data generated in interviews or the assumptions they may bring to analysis. As reflexivity is a core element of qualitative rigour, the limited reporting in these studies reduces transparency.

Overall, the studies included were methodologically robust, scoring highly on the CASP (ranging from 7.5-10), demonstrating clear aims, appropriate methodologies, coherent findings and provide valuable contribution to understanding self-identity in the context of advanced cancer in women. The identified limitations primarily relate to incomplete reporting rather than flaws in the study conduct and therefore do not substantially undermine confidence in the synthesis presented in this review.

Table 3: *A summary of Meta-Ethnography findings including contributing studies to third order construct development.*

Construct	Components	Studies contributing constructs (first and second order)
1.Performing Normality to Protect Identity.	-Normality as an existential defence against identity erosion. -Performative wellness and the concealment of suffering. -Moral obligation, gendered roles and endurance.	Studies 1,5,10 and 11.
2.Temporal reorganisation in the face of mortality.	-Diagnostic rupture and the collapse of future timelines. -Living in compressed and conditional temporalities. -Temporal anchoring. -Oscillating emotions.	Studies 2,5,6,8,9 and 11.
3.Emotional regulation amid shifting priorities	-Regulating emotion to contain fear and distress. -Shifting priorities towards emotional energy conservation. -Managing social expectations and compulsory positivity. -Reframing emotions.	Studies 2,5,8,10 and 11.
4.Meaning making and reclaiming the narrative.	-Illness as reinterpretation. -Reclaiming control through narrative and rituals. -Meaning making, spirituality and faith. -Meaning making through legacy	Studies 1,2,6,7,8,10 and 11.

Meta-Ethnography

The line of argument generated through this meta-ethnography posits that women living with advanced cancer engage in ongoing identity work that is simultaneously protective yet costly. Across diverse cultural and socioeconomic contexts women are required to manage the tension between physical symptoms and decline, amidst social expectations of femininity, productivity, normality and caregiving. A full summary of findings including contributing studies to each third order construct can be found in Table 3.

Identity is actively performed by women, who regulate and reconfigure according to their life. Women frequently perform normality to maintain social belonging and protect a valued sense of self, even when this has negative consequences such as invisible suffering or invalidating expectations from those around them. This appears to be closely tied to temporal reorganisation, whereby future horizons become contracted, reprioritised or anchored to immediate values-based goals in the short term. Emotions are similarly regulated, with women engaging in selective expression of their emotions, instead adopting forced positivity, humour or avoidance to manage relational expectations.

Finally meaning making emerges as a central process through which women reclaim narrative authority over illness, reframing cancer as a site of moral growth, building legacies and experiencing spiritual transformations. The synthesis reveals identity in women with advanced cancer as a form of moral and existential labour, shaped by gendered responsibilities, structural inequalities (healthcare systems) and cultural narratives of illness.

Construct 1: Performing Normality to Protect Identity

Across the included studies women described a sustained effort to perform everyday normality to preserve a coherent sense of self. This construct captures how normality was actively produced, functioning as a form of identity labour that enabled women to resist reduction to enforced

identities such as ‘cancer patient’. This pattern was evident across cancer types, age groups and socio-cultural contexts, although the form and intensity of this performance varied according to gendered expectation and structural conditions.

Normality as an existential defence against identity erosion

Women across studies articulated the importance of continuity of ordinary daily activities as central to maintaining their sense of self. In Study 5, one woman described how completing everyday domestic routines restored her sense of normality and purpose.

“*I get the vacuuming done... all the normal household things” (Study 5)*

Emphasising how productivity acted as an existential defence against the dominance of cancer in her life. Similarly in Study 11 women described daily routines as enabling continuity of pre-illness identity.

“I look normal... people don’t realise I still have stage IV cancer” (Study 11)

Across studies, normality was framed as something that had to be actively worked at, with women focusing on periods of relative physical stability to preserve identity coherence in the face of ongoing uncertainty.

Performative wellness and the concealment of suffering

A key dimension of this construct was the performative nature of wellness with women concealing physical symptoms, fatigue and emotional distress to meet social expectations and avoid

being identified solely through illness. In Study 11 women described appearing healthy to others despite significant internal suffering at times resulting in their needs being overlooked.

"People don't believe that you're terminal" (Study 11)

This participant reflects that the cost of performative wellness can be invisibility of illness undermining social understanding or support. The cost of performative wellness for women is also noted in Study 10, with women describing pushing themselves to physical limits to maintain an image of strength

"I continued working even though I couldn't really breathe" (Study 10)

These comments highlight that societal expectations are to supress vulnerability to be more acceptable socially, reflecting the tension between lived suffering and socially constrained ideas around resilience.

Moral obligation, gendered roles and endurance

The performance of normality was shaped by gendered expectations specifically around caregiving and productivity. In several studies motherhood emerged as a dominant driver of endurance.

"I can't give up I must be here for my kids" (Study 11)

Maternal identity remained central, survival for mothers became a moral obligation rooted in their responsibilities. In differing contexts of economic or structural vulnerability, women described continuing physically demanding labour despite advanced illness often driven by poverty and gendered expectations of responsibility for dependents.

"I have to do casual labour.... even when sick" (Study 1)

This performance of normality illustrates that 'performance' may be compelled by survival needs in addition to identity preservation. Across studies, endurance was frequently moralised regardless of cultural or socioeconomic status, with women describing their efforts to 'carry on' as necessary to protect others around them from distress, often at significant personal cost.

"I fake happiness to make them smile" (Study 10).

Encapsulating the emotional labour embedded in this construct. This construct also intersects closely with all three other contracts. Normality is often anchored in the present moment (Construct 2) and with women's careful emotions regulation (Construct 3). Through their active performance of normality women are also meaning making and reclaiming the narrative of advanced cancer (Construct 4).

Construct 2: Temporal reorganisation in the face of mortality.

This construct captures how awareness of mortality disrupts women's pre-existing life plans and future trajectories, leading to a new temporal framework. Women describe moving away from linear life planning instead shifting towards compressed timelines and present focused temporalities allowing them to maintain identity.

Diagnostic rupture and the collapse of future timelines

The moment of diagnosis represented a rupture for many women. This rupture caused destabilisation. In Study 6 one participant described the moment as being completely overwhelming.

"You can't really absorb what they are saying... you're in shock" (Study 6)

The impact women described, functioned as a catalyst for the rupture of future timelines, with their previous horizons instantly collapsing. Cultural understandings also impacted on women's

experiences of diagnostic rupture, in Study 9, women articulated how cancer was viewed as a death sentence, with one participant stating: *"Breast cancer is the end of someone" (Study 9)*. This reflects the moment of diagnosis being the rupture which immediately reconfigures women's expectations of lifespan and future possibility.

Living in compressed and conditional temporalities

The response of women across studies to this diagnostic rupture was to adapt to new temporal frameworks of living. These were often based on short term goals dictated by treatment cycles or scans. Women used normalising and reframing of death at times, away from the cancer narrative to build tolerance around the uncertainty they were facing.

"I could get hit by a bus tomorrow" (Study 5).

By shifting external temporal frameworks to universally be unpredictable, they are normalising their unique and sudden shift into this compressed timeline. In Study 11, women described other strategies which hint at denial or avoidance as a coping mechanism.

"Life goes on... staying busy gives me a sense of control" (Study 11).

This example is echoed in other studies and reveals how present focused living can restore some agency in this new temporal framework, whilst also supporting women to maintain or reconstruct their sense of identity.

Temporal Anchoring

Identity was also shaped via women finding meaningful short-term goals to anchor to.

"I've got to stay healthy for my son's wedding" (Study 5).

In studies where women describe concrete emotionally powerful goals, this became a new way of framing hope, survival became tethered to specific events not longevity. Similarly in Study 2, women described goal setting as essential to living.

"Having goals gives you meaning, purpose and something to live for" (Study 2).

Goals became a coping strategy in temporal uncertainty. In some studies women describe striving for stability in daily life moments through ritualisation.

"We had a ceremony for medications" (Study 5)

This description of ritualisation of treatment reveals attempts to create agency and find meaning in illness which is a disrupting reminder of cancer treatment and decline.

Oscillating emotions

Temporal reorganisation for many women was not linear or stable with women describing oscillation between hope, fear and anticipatory grief. These fluctuations were attributed to symptoms, treatment or scans and the emotional weight of facing mortality. In Study 6 one participant refers to life with metastatic cancer as:

"..a physical and emotional rollercoaster" (Study 6)

Another participant likened the daily feelings of fear as similar to being hunted and unable to see the predator.

"The sharks are circling" (Study 6)

There is a sense for women of being pursued by cancer but also by their own uncertain future. In Study 8, women reflected on the feeling of chasing time.

"Every single thing is precious now" (Study 8)

Women's intensified appreciation of time offers some explanation of sharpened experiential focus for women with advanced cancer. However, this heightened awareness did at times coexist with fear and anxiety.

"...it's a dark cloud...always there" (Study 6)

This participant's description of death highlights that temporal meaning making, or goal setting are marred by the fragility of life. The second construct, *'Temporal reorganisation in the face of mortality'* explores how women living with advanced cancer actively reconstruct their relationship with the time, reorganisation was not static or uniform. It shifted for women, who at times lived in the moment, at other times moving fluidly between planning for immediate futures and legacy building for the possibility of imminent death.

This construct links closely with the other constructs. Performing normality to protect identity as present focused routines support temporal stability and identity continuity. Similarly in Construct 3 'E*motional regulation and shifting priorities*' women are actively managing attention towards what remained meaningful. Temporal reorganisation functions as a central mechanism for women with advanced cancer to negotiate survival, meaning and selfhood.

Construct 3: Emotional regulation amid shifting priorities

Women with advanced cancer across all studies described the extensive ongoing emotional work aimed at regulating distress and protecting both themselves and others. This construct '*Emotional regulation and shifting priorities*' captures how women actively managed their emotions, largely through prioritising relational engagement. Emotional regulation became more than an internal coping process, instead reflecting women prioritising individuals or relationships which positively reinforced their sense of identity.

Regulating emotion to contain fear and distress

Throughout all studies women described deliberate strategies to contain their emotions, predominantly fear, anxiety and despair. In Study 2, women spoke of keeping busy to prevent emotional spiralling.

"I keep myself occupied so that my mind doesn't wander into this area of anxiety" (Study 2)

Similarly in Study 5 women described actively cognitive avoidance as a survival strategy:

"I try not to think about it.... I keep myself busy so that the mind, I'm not sitting around feeling sorry for myself" (Study 5)

This active regulation was frequently framed not as denial or avoidance but as intentional emotional management, necessary when living with advanced cancer.

Shifting priorities towards emotional energy conservation

For many women the reorganisation of their priorities was an active task, in which emotional energy was a precious entity that had to be actively protected. In Study 5 women discussed carefully curating their social worlds.

"I'll only talk to people who can go the distance" (Study 5)

Women noted that ending friendships became about survival and protecting their own emotional capacity. This prioritisation was also seen in other studies with women linking it to their identity as caregivers, prioritising this role above others.

"Like a battery if you're not charged, you don't have anything to give to anybody else" (Study 8)

The delicate balance between caregiving and self-care reflected in this metaphor reveals that emotional regulation through protecting their limited psychological capacity, was an active move by

women to reduce exposure to emotionally draining interactions. This active self-preservation may have also acted as a defence to enforced reminders of illness or illness identity.

Managing social expectations and compulsory positivity

A consistent finding across studies was women feeling pressure to regulate their emotions in line with societal expectations of positivity, strength and remaining hopeful. In Study 5 participants described feeling guilty when they experienced despair or fear and could not maintain positivity.

"Try not to feel the guilt of being positive... that really to me is very painful" (Study 5)

Reflecting societal pressure as an additional burden to women already under immense strain. Comparably, in Study 10 women articulated frustration when expected to remain positive:

"They want me to always be positive" (Study 10)

Similarly in Study 11, women described wearing a "mask of wellness" (Study 11), actively working on emotional regulation to reduce suffering of others, particularly for children and partners. This form of emotional containment often came at personal cost, with women describing it as contributing to isolation and unseen distress.

Reframing emotions

Alongside both containment and suppression of emotions, women in several studies described reframing their emotional experiences through gratitude, humour and seeking meaning. Some participants described gratitude as a coping strategy.

"I'm thankful I'm still here" (Study 2)

For other women using humour became a method of resisting despair when facing death:

"Laughter...sick humour" (Study 2)

It could be argued that this may be emotional ambivalence but across all studies, ambivalence was not encountered by women facing their own mortality. In contrast, emotional regulation was closely linked to moral and existential reframing, with some participants describing heightened experiences of gratitude or kindness as their illness progressed towards hospice care. One woman reflected:

"*The time I have left is a gift.... I need to make the most of it and be as kind as I can" (Study 8)*

This suggests that for some women, emotional regulation becomes a process of reshaping moral priorities in response to mortality. Emotional regulation and shifting priorities capture how women with advanced cancer actively manage their emotions, specifically their outward emotions, to remain functional, prioritising others, often to their own detriment, and maintaining a sense of agency over their lives. These findings reflect a deeper underlying gendered and societal expectation that women remain caring and protective of others even when faced with their own mortality.

Construct 3 closely overlaps with the others 3 constructs, performing normality to protect identity is arguably emotional masking and temporal reorganisation is emotional regulation via present focused attention. The findings of construct 3 posit that emotional regulation is a moral and relational labour central to women's experiences of living with advanced cancer and a central part of their identity preservation.

Construct 4:Meaning making and reclaiming the narrative.

The concept of meaning making was present across all eleven studies, women engaged in an active and ongoing process of meaning making to counter the existential disruption and identity threat which advanced cancer poses. This construct captures how women resisted biomedical, cultural and social narratives that position advanced cancer as simply decline or death. Meaning making functioned to preserve dignity, agency, moral worth and a coherent sense of self identity.

Illness as reinterpretation

Women's meaning making across studies often began with reframing. Advanced cancer prompted women to reflect or reorientate their values. One woman in Study 2 describes how others with cancer have opened her eyes to cancer being transformative.

"Everybody seems to have taken cancer to be a teacher as opposed to a nemesis to be feared" (Study 2)

By situating illness as a catalyst for positive change suggests that meaning making begins with perspective change or reframing of narratives, allowing cancer to become more than a negative rupture. This reframing is more than naive optimism, instead it represents a concerted effort by women to retain narrative agency in the face of threat. In Study 6 women described metastatic cancer as a "*rollercoaster"* and a *"dark cloud"* whilst also articulating the subsequent shifts in their perspectives *"I appreciate the little things now" (Study 6).* These women's accounts begin to suggest meaning making allows women to hold both suffering and values simultaneously seemingly resisting narrative collapse.

Reclaiming Control through Narrative and Rituals

Women in some studies also described reclaiming meaning by transforming aspects of illness which were experienced as overwhelming or uncontrollable into symbolic or meaningful. In Study 10 young women describe reconstructing their own illness narratives through moral and psychological frameworks.

"I had to change my personality to beat cancer" (Study 10)

In some cases, women attributed illness progression to their mindset reflecting how meaning making could also take the form of moralisation, reflecting an attempt at reclaiming agency over a life disrupted by uncertainty.

Meaning making, spirituality and faith.

In some studies women's relationship with their own spirituality or faith played a role in their meaning making. This was more prevalent in women living in low resource communities or highly religious cultures, who often used spiritual frameworks as central to their meaning making.

"God brought hospice like manna" (Study 1)

In Study 1, women interpreted access to hospice care through religious metaphor, positioning palliative care as divine provision and relief. Another woman explained:

"God is the one who has your life" (Study 1)

Highlighting that acceptance through faith for some women is core to their meaning making of existential threat. Similarly in Study 7, older women with ovarian cancer placed outcomes into religious context.

"The only thing I can do is put my hand in the hand of God" (Study 7)

By leaning into religious belief, some women effectively surrender control over outcomes as a coping strategy for prognostic uncertainty. Across contexts, spiritual surrender functioned as a method of redistributing responsibility for outcomes, alleviating self-blame and despair in women's lives when living with limited control.

Meaning making through legacy

A prominent focus of meaning making across studies was narrative reclamation through legacy building, particularly seeking meaning through contribution to others. In Study 8 women described altruism as central to their sense of purpose.

"As a way to pay it forward... you never know, there's always somebody out there that needs help" (Study 8).

Legacy building was especially salient for women who had dependent children. Across studies women expressed fears of being forgotten and engaged in intentional memory making.

"They might not remember me" (Study 11)

In Study 11, some women contrastingly described emotional reassurance derived from knowing their children would be care for after their death, reframing mortality through ongoing maternal influence. Meaning making in this context extends beyond the self, and beyond the lifespan.

Meaning making and reclaiming the narrative represents a core process for women living with advanced cancer. Within Construct 4, women resist narrative foreclosure and assert agency over how their lives and illness are understood, supporting a more coherent sense of self in an unstable life of unknowns. Meaning making emerges as a dynamic ongoing survival practice central to identity preservation. All four constructs come together to form a coherent line of argument: women living with advanced cancer actively negotiate identity, time, emotion and meaning to live.

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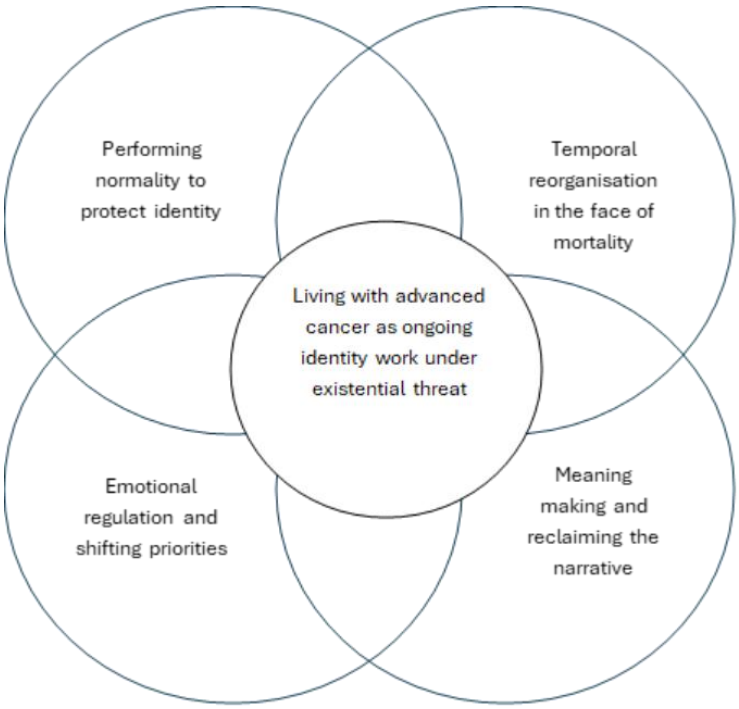


Figure 3 *Visual representation of the identity work of women living with advanced cancer*

Discussion

This meta-ethnography synthesised qualitative evidence of women's experiences of identity whilst living with advanced cancer. Through reciprocal and refutational translation of 11 studies, a line of argument was developed demonstrating that identity in advanced cancer is actively negotiated through ongoing relational, temporal, emotional and narrative work. Women sustain a sense of self in the face of unknowns by performing normality, reorganising time, regulating emotion and priorities and reclaiming meaning and authorship over their illness narratives. This synthesis advances understanding of advanced cancer in women as a prolonged existential condition which instigates ongoing identity labour.

The included studies were predominantly of high methodological quality and offered in-depth, first-person account of women's lived experiences of advanced cancer. The synthesis collated studies from a wide range of settings, spanning contexts, age groups of women, cultures, socioeconomic backgrounds and both maternal and non-maternal identities. This heterogeneity limits the extent to which conclusions can be drawn about any specific subgroup or cancer diagnostic type,

but it strengthens conceptual transferability of its findings. The similarities and repetition of core constructs across a multitude of contexts suggests processes identified in this synthesis reflect fundamental aspects of living with advanced cancer as a woman and the subsequent impact on a woman's identity.

The developed line of argument from this synthesis demonstrates women living with advanced cancer engage in four interrelated methods of active identity work: *Performing normality to protect identity; Temporal reorganisation in the face of mortality; Emotional regulation and shifting priorities;* and *Meaning making and reclaiming the illness narrative.* These processes operated simultaneously and dynamically, uniquely to the individual women, reflecting the impact on a woman's identity. These findings are consistent with existing theories of chronic illness (Charmaz, 2014; Williams 2018) demonstrating that identity disruption in advanced cancer is not resolved over time but continuously managed in response to fluctuating symptoms, side effects of treatment, scan cycles and ongoing prognostic uncertainty. In addition, the findings further extend existing literature on identity in advanced cancer by illustrating how identity work is shaped by gendered expectations for women. For many women, survival in the short term became a moral responsibility to others, especially in the context of maternal roles and relational obligations.

Performing normality

Across studies women described performing acts of normality to preserve a coherent sense of self and resist illness identity. This aligns with work on stigma and identity (Goffman, 1963; Chaudoir et al, 2013) which suggests that there is a tension created between the visibility and invisibility of incurable or chronic illness and the subsequent psychological impact of this on a person's identity (Carel 2016; Eassey et al, 2020). Women were found to conceal fatigue, pain and emotional distress to avoid burdening others, maintain social roles or avoid causing distress to those close to them. The synthesis demonstrates that the act of performing normality is an act of determined agency and self-preservation. This strategy, however, comes with a steep psychological cost for women. The performative nature of maintaining normality can lead to feelings of isolation and unmet needs, particularly when women's externally portrayed wellness obscured internal suffering. Our synthesis

suggests that young women and mothers appear to be especially vulnerable to these pressures, reflecting global cultural norms that equate femininity with caregiving, resilience and productivity (Ginsberg et al., 2023).

Temporal reorganisation

A key finding across studies was women's reorganisation of time following an advanced cancer diagnosis. Women described altered future horizons and focused more closely on the present. This correlates with existing literature which posits that temporality in serious illness becomes more pronounced and anticipated futures are renegotiated following life limiting diagnoses (van Laarhoven et al, 2021; Joshi et al, 2025). However, this synthesis extends recent work by illustrating how temporal reorganisation functions as identity work, enabling women to maintain meaning and agency. Findings from this synthesis suggest that women adopted flexible temporal orientations which oscillated between present focused living and carefully selected future planning. This temporal fluidity appeared to support psychological coping but was easily destabilised by treatment failure and disease progression.

Emotional regulation and shifting priorities

Women across all studies described the substantial emotional labour of living with advanced cancer. Emotional regulation was shaped by external expectations dependent on cultural norms but was often influenced by women feeling they needed to stay strong, positive and hopeful. This resonates with Hochschild's (2012) theory of emotional labour, along with more recent literature on moral regulation of emotion in cancer care (Bell & Ristovski-Slijepcevic, 2020). This synthesis further extends these findings by illustrating that emotional regulation for women with advanced cancer is not an act of avoidance or solely intrapsychic, it was also relationally reinforced. Women frequently supressed distress to protect loved ones, leading to emotional silencing and isolation. Thus, the act of emotional regulation became both preservation but destructive and detrimental.

In addition, women's careful employment of emotional regulation led to shifting priorities, friendships were ended, time with children and close family became prioritised. This suggests a redefining of quality of life, through relinquishing of long-term ambitions or goals, shifting values and prioritising relational presence. These are all adaptive response to the existential threat but also reflect constrained choices within the realities of living with advanced cancer.

Meaning making and reclaiming the illness narrative

The final construct captures how women sought to reclaim authorship over their illness narratives through meaning-making, spirituality, self-advocacy, humour and legacy work. This closely aligns with narrative theories of illness which emphasise storytelling as a means of restoring coherence and moral identity (Frank 2013; Hydén 2018). However, the synthesis demonstrates that meaning making in advanced cancer is not necessarily redemptive or linear in quality, it coexists with suffering, fear and occasionally ambivalence. In several studies women reframed their illness as transformative, or morally significant while others resisted imposed narratives, which included disliked narratives of 'bravery' or 'positivity'. Crucially, meaning making often served a relational purpose, allowing women to maintain dignity and reduce perceived burden or bias, thereby extending capacity to perform their caregiving roles, including beyond death through legacy planning. Thus, through meaning making, women are enacting agency over their illness narrative and restructuring of their identity.

Together all four constructs cohesively form the line of argument which conceptualises identity as an ongoing relational, moral project which is actively sustained. Bury's (1982) concept of biographical disruption has been influential in framing serious illness as a rupture. While this framework is supported by the diagnostic shock described across the included studies, this synthesis extends this model by demonstrating that, for women with advanced cancer, disruption is not a temporary or singular moment. This synthesis instead demonstrates that identity negotiation becomes

a part of women's living, happening whilst women navigate the unknown of living with advanced cancer, they are also navigating the space between their identity before cancer and who they are now living with cancer. Therefore, this synthesis challenges linear interpretations of disruption and recovery, suggesting that advanced cancer produces an enduring state of existential instability which women use all four constructs to navigate requiring continuous adaptation.

In addition to challenging existing identity theories in advanced illness, this synthesis also reframes other key work on chronic illness. Charmaz's (1981, 1991) conceptualises loss of self as emerging through restricted lives, diminished agency and social devaluation. While elements of loss were evident across the eleven included studies, this appeared to be limited to physical decline and social invisibility. Women in the eleven studies, actively resisted identity erosion through performing normality, regulating emotional expression and reclaiming narrative authorship. Identity was therefore not passively lost or eroded, instead women strategically protected and rebuilt their identity in the face of advanced cancer. This suggests that identity and selfhood in advanced cancer is better understood as precarious yet agentic.

A central contribution of this synthesis is the illumination of the potentially gendered nature of identity work in advanced cancer. Across contexts, women described regulating their emotions to protect loved ones. This aligns with feminist theories of emotional labour, which position women as disproportionally responsible for managing affect within relationships (Lutz & Abu-Lughod, 1990; Usher, 2011; Erickson & Stacey, 2013). Survival in the short term emerges as more than personal hope, it is also a relational duty, especially for mothers. This extends existing literature such as Fisher & O'Conner (2012) which argue that motherhood intensifies responsibility of women to present a maintained appearance of normality and adds argument to the impact of caregiving identities into the domain of incurable illness in addition to the moralisation of endurance for women.

Clinical Practice Implications

The findings from this meta-ethnography have potential implications for clinical practice across oncological and palliative care for women. Primarily, clinicians may wish to recognise that women living with advanced cancer actively perform normality as a strategy to protect identity, supporting their relationships and family stability. Whilst this may be an adaptive coping strategy, it also puts them at risk of distress, emotional fatigue and unmet needs which are potentially invisible in clinical encounters. Consequently, routine psychosocial assessments should move beyond surface indicators of functioning and explicitly invite discussion of concealed emotional and physical labour.

Furthermore, the identification of potentially gendered moral labour and emotional regulation highlights the need for clinicians to actively challenge cultural and relational pressures that compel women to remain positive and strong. By offering women explicit permission to express fear, guilt, anger, ambivalence and exhaustion, and normalising these may reduce the burden of emotional labour and support women to feel contained and safe.

Finally, recognising women's ongoing meaning making and narrative work suggests that clinical care should support opportunities for identity reconstruction including legacy work, relational continuity and values-based living interventions. Psychological support or intervention with a focus on narrative, relational and values-based approaches are likely to be more supportive according to the lived realities illuminated by this synthesis.

Strengths and Limitations

A key strength of this synthesis was the choice of meta-ethnography which offered a breadth of exploration of women's experiences across diverse ages, cultures and health systems. However, the

strengths of this choice also introduced important considerations regarding transferability and analytic scope. The heterogeneity of included studies meant that the synthesis prioritised conceptual resonance over contextual specificity. The generalisability of findings to a specific diagnostic group or healthcare setting is limited, however, the synthesis offers theoretically informed insights into shared identity processes among women living with any form of advanced cancer, these therefore should be considered as analytical propositions.

Additionally, as meta-ethnography relies upon second order constructs as reported by original study authors, rather than re-analysis of primary data, all analysis is shaped by interpretive lenses and reporting practices of individual studies. Variability in the depth of reflexive reporting may have influenced how participant experiences were framed. This synthesis attempted to mitigate this limitation by prioritising conceptual transparency in both second and third order constructs, preserving original metaphors and meanings and using constant comparison during translation process (Phase 5, Noblit & Hare, 1988).

A further strength was that all included studies were of high quality, despite this, there were inconsistencies in the reporting of participant characteristics, inducing ethnicity, sexuality and disability status. Consequently, the synthesis may be limited in its ability to fully explore how intersecting axes of identities shape experiences of advanced cancer. Furthermore, although the CASP checklist provided a structured approach to quality appraisal, it relied upon the level of methodological detail reported in the studies. Several studies provided limited reflexive accounts, which made it problematic to assess how researcher's perspectives may have influenced analysis and interpretation. This highlights a key gap for future research, use of an additional checklist such as consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury and Craig, 2007) which focused greater attention on comprehensive reporting of participant characteristics and researcher reflexivity would enhance transparency and rigour of qualitative findings, particularly important for meta-ethnography.

A further strength was the careful attention to methodological rigour through researcher reflexivity. Steps were taken by the primary author to enhance analytic rigour (systematic documentation of translation, engagement with refutational cases and explicit statement of the line of argument). As with most qualitative synthesis, analysis is inevitably shaped by the interpretive position of the reviewer. In line with interpretivist epistemology, this is understood not as bias to be eliminated but as an analytical standpoint that has been grounded in explicit theory.

Conclusion and Future Directions for Research

In conclusion this meta-ethnography demonstrates that women living with advanced cancer engage in sustained relational identity work that challenges existing narratives of decline. Identity is actively negotiated through performances of normality, temporal reorganisation, emotional regulation and narrative meaning making. By integrating findings across diverse contexts this review extends existing psycho-oncological theories and feminist health literature, reframing advanced cancer as a relational and moral identity process. This synthesis therefore provides a robust conceptual foundation for future research and clinical practice, recognising the essential need for developing care approaches that honour personhood in living not survival.

This review highlighted the need for future research which explores longitudinal identity in women living with advanced cancer, mapping the nuances of its reconstruction. The differences of experiences between mothers and non-maternal women may also offer further insight into the impact of motherhood and maternal roles on the experiences of identity for women living with advanced cancer. Furthermore, the review focused on peer reviewed, published studies available in the English language, this was to ensure methodological quality and analytic depth, however, it may have excluded relevant insights from non-English publications, or unpublished works that could further illuminate women's lived experiences, particularly in underrepresented populations. A future study could collate and explore women's experiences as described via social media comments or posts, to offer a new and different insight into lived experiences.

Finally, this synthesis highlighted to need to explore existing cultural differences in emotional regulation for women and how this shapes their sense of self when they may not be able to meet societal expectations or standards for this.

Conflicts of Interests

There are not conflicts of interest for any of the authors of this study.

Author Contribution

Amelia Smith was Lead Author, completing the full systematic review and meta-ethnography. Stephanie Stubbs independently checked the studies for eligibility and quality.

Dr Amy Carroll and Dr Lauren Hickling acted as research supervisors and supported writing through discussion and review.

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Chapter Three

Bridging Chapter

Word Count: 599

Chapter Three: Bridging Chapter

The purpose of this bridging chapter is to provide a clear link between the systematic review and the empirical research paper within this thesis portfolio. Specifically, this chapter outlines how the findings of the systematic review informed the focus and design of the empirical study.

The systematic review findings revealed that across diagnoses women engaged in sustained efforts to preserve continuity of self. These findings are consistent with existing psychological and sociological theories which understand identity as constructed through social roles and narrative meaning making (Bury, 1982; Charmaz, 1995). The review also highlighted processes of adaptation and reconstruction, echoing narrative theories of identity which emphasise individuals' efforts to integrate illness into a coherent life story (Ricoeur, 1992; Frank, 1995, 2002).

While the systematic review included women with a broad range of advanced cancer diagnosis, a substantial portion of the qualitative literature focused on metastatic breast cancer (MBC). This is reflective of the prevalence of breast cancer among women and the distinctive illness trajectory associated with metastatic disease. Advances in treatment have resulted in many women living for prolonged periods with MBC, often described as a chronic but incurable condition (Swain, 2018; Park et al., 2022). This prolonged trajectory creates a unique psychosocial context for women which is characterised by ongoing treatment, scan cycles, fluctuating health and side effects of treatment all whilst facing persistent prognostic uncertainty and nearing end of life.

The review findings indicated that this extended state of uncertainty may be particularly significant for women's identity. Drawing on existing anthropological concepts of liminality (Turner, 1969, Wells et al, 2011) women with MBC may be understood as occupying an in-between position: neither fitting dominant cultural narratives of survivorship nor aligning themselves with aspects of end-of-life care. Breast cancer survivorship discourse was found to often include emphasis on finding a cure, recovery and positivity which marginalised women living with metastatic disease (which remains at the time of writing incurable), due to feelings of invisibility and isolation (Kaiser, 2008; Bell, 2014). Additionally, existing research indicates that women with MBC experience a conflict between external expectations to remain hopeful and internal experiences of fear, loss, guilt and grief

(Vilhauer, 2008). The systematic review therefore indicated that this subgroup of cancer patients may exist in a context in which identity work is especially pronounced and psychologically complex due to the potential longitudinal nature of their condition.

Although identity related themes were evident across studies from the review, identity was rarely positioned as the primary focus of the analysis, often being embedded in broader constructs such as coping or quality of life. This is reflective of broader psycho-oncological literature which prioritises symptom burden and psychological outcomes over experiential and meaning based processes (Ecclestone et al., 2016). In addition, systematic reviews of existing research on breast cancer experiences reveal research often excludes women with metastatic disease, subsequently, women with metastatic disease cannot be assumed to have the same experiences of women in curable stages of cancer (Heidary et al., 2023; King et al., 2024).

Therefore, a gap remains in the literature for in-depth qualitative research exploring how women make sense of who they are following a metastatic diagnosis, how identity evolves as illness progresses and how women negotiate continuity of self in the face of uncertainty. The systematic review therefore highlighted a need for research which explicitly focused on identity as a phenomenon of interest, using methodologies capable of capturing lived experience. In response to this gap in the literature, the empirical study focused on women living with MBC and used Interpretive Phenomenological Analysis to explore identity. IPA is well-suited to examining how individuals make sense of their life experiences and has been widely used in health psychology previously to explore chronic and incurable illness (Smith et al, 2011).

Chapter Four

Empirical Research Paper

Exploring Women's Experiences of Identity Whilst Living with a Diagnosis of Metastatic Breast Cancer: An IPA study.

Prepared for submission to The Journal of Health Psychology
(Author Guidelines found in Appendix D)

Word Count (7923)

Exploring Women's Experiences of Identity Whilst Living with a Diagnosis of Metastatic Breast Cancer: An IPA study.

Abstract

Women living with metastatic breast cancer (MBC) face an incurable illness characterised by ongoing treatment, prognostic uncertainty and disruption to daily life. While the psychological impact of breast cancer has been widely studied (Tang et al., 2024), women with metastatic disease remain underrepresented in research, particularly in relation to their lived experience. This study aimed to explore how women make sense of their identity while living with MBC.

Thirteen women diagnosed with MBC living in the UK participated in semi-structured interviews, which were analysed using Interpretive Phenomenological Analysis. Analysis identified four interrelated superordinate themes: "*Rupture: The shattering impact of diagnosis"; "Ripples: Unnerving changes"; "Fragmentation: Challenges Living in the Shadow of Mortality";* and "*Who Am I Now? Reconstruction and Reclaiming of Identity".* Findings showed diagnosis was experienced as an existential rupture, destabilising assumptions about self, future, and roles. MBC treatment and uncertainty generated disruptions to relational, maternal, professional and social identities, alongside heightened awareness of mortality and anticipatory grief. Despite these challenges, women were found to actively engage in processes of meaning-making and identity reconstruction, negotiating loss alongside agency, continuity, and legacy building.

These findings highlight identity as a dynamic and relational process for women living with MBC, shaped by healthcare interactions, societal responses and existential uncertainty. The study underscores the importance of psychologically informed communication at diagnosis and identity focused psychosocial support throughout the illness trajectory

Introduction

Approximately 56,000 people are diagnosed with breast cancer annually (NHS England, 2022), with 11,400 women dying from the disease (Breast Cancer UK, 2019). Breast cancer is widely recognised as a psychologically significant illness with a substantial body of research documenting elevated levels of distress, anxiety, depression and difficulties with adjustments (Tang et al., 2024). Psychological responses to breast cancer are shaped not only by physical effects of disease and treatment, but also by disruptions to roles, relationships, body image and future expectations. However, much of this literature focuses on women with non-metastatic breast cancer, with comparatively limited attention given to those living with metastatic disease.

Metastatic breast cancer (MBC) is an incurable condition in which cancer has spread beyond the breast and surrounding tissue to other sites and organs (WHO, 1993). Unlike early-stage breast cancer, where treatment is orientated towards cure, women with MBC typically undergo ongoing treatment aimed at disease and symptom control, accompanied by repeated monitoring and prognostic uncertainty (Palmieri et al., 2022). Survival outcomes for women with MBC are significantly poorer than for those with non-metastatic disease (Palmieri et al., 2022), and the knowledge that the illness is life-limiting distinguishes MBC psychologically from primary breast cancer. Despite these differences, women with MBC have frequently been excluded from research resulting in limited understanding of their specific psychological needs (Jasim et al., 2023).

Emerging qualitative research has begun to address this gap, highlighting the distress associated with living with prolonged uncertainty, repeated scan cycles, and ongoing treatment alongside experiences of fear, isolation and altered relationships (Ginter, 2020; Alfieri et al., 2022). Women often describe living in a liminal state, balancing hope and fear while attempting to maintain everyday life in the context of an uncertain future (Alfieri et al., 2022). Visovsky et al., (2023) further identified experiences of identity disruption among women with MBC, noting that identity changes

were not uniformly negative and could involve personal growth or re-evaluation of meaning. However, while these studies offer valuable insights in emotional and relational experiences, less attention has been given to how women make sense of identity while living with metastatic disease.

Identity is a central construct within health psychology, encompassing how individuals understand themselves in relation to roles, relationships, values and anticipated futures. Traditional models of adult identity development emphasise continuity, role stability, and future orientated goals (Erikson, 1963; Marcia, 1966). A diagnosis of metastatic cancer may abruptly destabilise these assumptions. Sociological and psychological theories of chronic and life-limiting illness conceptualise such experiences as biographical disruption, in which illness fractures an individual's life narrative and sense of identity (Bury, 1982; Charmaz, 1995). Research suggests that these disruptions can evoke existential distress and profound challenges to identity (Currin-McCulloch, 2011). Furthermore, identity is increasingly understood as dynamic, relational and shaped through ongoing processes (Kroger & Marcia, 2011).

For women living with MBC identity disruption may be particularly salient given the intersection of illness with gendered roles and expectations. MBC is often diagnosed during adulthood stages associated with parenting, partnership and professional development, meaning illness related changes may carry significant implications for identities linked to motherhood and femininity (Mosher et al., 2013). Additionally, physical changes may disrupt women's capacity to enact valued roles, while heightened awareness of mortality introduces additional existential threat. Existing studies of advanced cancer suggest individuals may engage in active processes of identity renegotiation, including re-evaluating priorities, shifting values and redefining roles (Ginter, 2020; Visovsky et al., 2023). However, how these processes are experienced and understood by women with MBC remains underexplored.

Given the routine exclusion of women with metastatic disease from psychosocial research, it cannot be assumed that findings derived from non-metastatic breast cancer populations adequately reflect the psychological and identity-related experiences of this subgroup (Fortin et al., 2021; Visovsky et al., 2023). There remains a lack of qualitative research examining how women with MBC make sense of their identity. The present study aimed to explore the lived experience of women living with metastatic breast cancer in the UK, with a specific focus on how diagnosis and ongoing illness shape identity.

Methodology

Design

An Interpretative Phenomenological Analysis (IPA) design was used to answer the research questions. IPA is idiographic in nature, prioritising an in-depth exploration of individual experiences (Smith et al., 2022; Braun & Clarke, 2013). This approach involves a double hermeneutic, whereby participants interpret their own experiences, and the researcher interprets these accounts. A critical realist epistemological stance (Willig, 2013) was adopted which aligns with the study's aims of developing a nuanced psychological understanding of women's lived experiences of MBC. From an ontological perspective Critical Realism assumes that a reality exists independently of human perception, while recognising that this reality cannot be accessed directly (Braun & Clarke., 2013). In the context of metastatic breast cancer, this position acknowledges that physical changes, illness progression and mortality are real phenomena with tangible consequences yet also considers that individual's experiences of these phenomena are shaped by their personal history, contexts and social and cultural narratives. Additional details on this can be found in Chapter 6 Extended Methodology and Additional Information.

Patient and Public involvement (PPI)

In line with guidance for good practice in research (NIHR) PPI was used to inform the design and development of this study. PPI was sought from a local MBC charity. The PPI group participated in online focus groups to review the study proposal, all documents and advised on interview questions and topics. Details of this process are discussed further in Chapter 6: Extended Methodology and Additional Information.

Participants and Recruitment

The sample comprised of thirteen women diagnosed with MBC, living in the UK. Eligibility criteria required participants to be aged 18 years or over and to have received an MBC diagnosis at least six months prior to participation. This timeframe was to allow participants some opportunity to process the diagnosis given that the period immediately following recurrence or metastatic diagnosis may be particularly distressing (Hall et al., 1996; Davies & Sque, 2002). Participants were excluded if participation seemed likely to pose a significant risk to their physical or psychological wellbeing, if they were not fluent in English, or if they identified as male. Recruitment was conducted via social media using a poster (Appendix E) distributed by two charities with a social media presence in the East of England.

The sample comprised of thirteen women all living in the UK with a diagnosis of MBC. Participants ranged from 26 to 74 years old with the majority aged between 35 and 54 years. Time since diagnosis ranged from 11 to 72 months (Table 1). Around three quarters of the sample were mothers, and just under half had dependents still living at home. Threewomen in the sample were carers.
Ten participants had ceased working. The sample comprised primarily of married women, with the remainder categorising themselves assingle. Although participants varied in demographic details, all shared experience of adapting to an incurable cancer diagnosis and ongoing treatment.

Table 1: Participant Information

(Participant age was categorised to support anonymity)

Participant PIN	Age	Time since diagnosis
Aoife	45-54	15 months
Bella	35-44	24 months
Claire	35-44	13 months
Danny	26-34	24 months
Eloise	35-44	17 months
Frankie	35-44	22 months
Georgia	55-64	11 months
Holly	35-44	72 months
Isla	45-54	12 months
Jackie	55-65	28 months
Kelly	65-74	24 months
Laura	55-64	23 months
Mia	35-44	13 months

Measures

Participants completed an online consent form (Appendix F) and demographic questionnaire (JISC, UEA) prior to interview to gather essential information pertaining to participants contextual information (Appendix G). Semi-structured interviews were used to explore participant experiences. In accordance with guidelines for conducting semi-structured interviews in psychological research (Smith, 1995), these contained only a few questions and were supplemented with prompts to allow for participant led exploration. Topic areas were initially developed based upon existing research alongside PPI groups (Visovsky et al., 2023; Alfieri et al., 2022). Questions asked in the interview covered topics including impact of diagnosis and self-perception (Appendix H).

Procedure

Interested participants were provided with a participant information sheet, consent was obtained electronically prior to participation. Participants completed a brief online demographic questionnaire before taking part in a semi-structured interview conducted remotely via Microsoft Teams. Interviews were conducted by the first author and lasted between 28-84 minutes (mean=48 minutes). Interviews were video and audio recorded and transcribed verbatim. Identifying information was removed and participants were offered the opportunity to review transcripts for accuracy.

Ethical Considerations

Ethical approval was obtained from the UEA Faculty of Medicine and Health Sciences Research Committee (reference number: ETH2425-0258) (Appendix I). Given the sensitive nature of the topic, interviews were conducted with attention to participants wellbeing, and participants were reminded of their right to pause, or withdraw at any time. All participants were provided with information about sources of support following the interview.

Analysis

Data were analysed following the stages of IPA as outlined by Smith et al (2022). Analysis began with repeated close reading of each transcript individually, alongside detailed exploratory noting. Initial notes attended to descriptive content, linguistic features and conceptual reflections. Emergent themes were developed for each participant, capturing meaningful patterns within their account. At this stage, analysis remained grounded in the individual case with attention given to the individual experiences. Once individual case analysis was completed, patterns of convergence and divergence across participants were examined. Themes were clustered and refined to develop superordinate and subordinate themes that reflected shared experience processes while retaining sensitivity to variation. Throughout the analytic process, emerging interpretations and theme structures were discussed within the research team. These discussions supported critical reflections, challenging of assumptions and aided the refinement of themes. This collaborative process aligned with IPAs focus on transparency and reflexivity. Further details of the analysis process can be found in Chapter 6: Extended Methodology and Additional Information.

Reflexivity was integral to the analytic process, the primary researcher maintained a reflective journal throughout research process to support analytic rigour through acknowledgment of assumptions, emotional responses ad interpretative decisions

Table 2: Example of Analysis Process

Quote	Coding	Emerging theme	Subtheme	Main theme
"I'm no longer the primary caregiver… that really eats away at me." (Holly)	Emotional response around shifting roles within parenting, impact of not being the 'main caregiver' to her child, feeling replaced by partner?	Impact on motherhood	Altered maternal roles	Relationships, roles and societal impact.
"I probably won't be alive to see his 5th birthday." (Jackie)	Reflection on mortality and prognosis, sadness and grief about missing out on motherhood,	Reflections on motherhood	Existential reflection on fertility, legacy and anticipatory grief	Mortality, existential reflection and facing death
"I've chosen who I've told... I didn't want to worry people and I didn't want any drama." (Georgia)	Trying to protect others but also herself from the 'fallout'. This might also be a form of self-protection as well as protecting others around her, she doesn't have emotional capacity to manage the emotions of others at present.	Fear of other's perceptions	Selective disclosure and control	Identity and Role

Findings

Four superordinate themes were developed, each representing a distinct, yet interconnected aspect of participant's lived experience. These are: "*Rupture: The shattering impact of diagnosis"; "Ripples: Unnerving changes"; "Fragmentation: Challenges Living in the Shadow of Mortality";* and "*Who Am I Now? Reconstruction and Reclaiming of Identity".* Each superordinate theme contains subordinate themes that capture the unique elements of these broader experiences. In presenting these findings we sought to balance participants voices with interpretive commentary, reflecting the double hermeneutic of IPA.

Rupture: The Shattering Impact of Diagnosis

This superordinate theme captures the psychological and existential rupture at diagnosis experienced by all participants. The diagnosis signalled a collapse of previously grounded assumptions about health, identity and future plans. The breadth of emotional responses at this point were vast, ranging from shock and disbelief, to anger, identity confusion, fear, and immediate attempts at adaptation.

This theme is comprised of three interrelated subthemes: "*Diagnostic Shock and Systemic Failures", "Delayed Diagnosis and The Professional Divide",* and *"Existential Adjustment and Acceptance".*

Diagnostic Shock and Systemic Failures

This subtheme captures the significant rupture experienced by participants on receiving their diagnosis of MBC.

"It was just a shock… it almost felt empty. You know, I didn't know what to do with myself." (Claire).

This brief and fragmented recollection of the exact moment of diagnosis conveys the life altering nature of MBC, the participant struggles to find words for the overwhelming disorientation in this moment. Emotional paralysis was also experienced by other participants.

"I was just in shock. There was no tears there. It was just processing, processing…" (Holly).

This participant experienced diagnosis as overwhelming, describing a lack of emotional release, it appears from their description they felt detached and struggled to make sense of this rupture in their assumptive world. Shock here symbolises emotional suspension, allowing survival in the face of an unbearable reality, whilst also being frozen in a liminal space. Across participants the disruption of coherence and difficulty processing reflected the moment life ceases making sense; a rupture in the boundary between the known and the unknown. The most significant factor for participants was the healthcare professional delivering the message.

"My consultant actually phoned my husband… asked him to… make sure the children were out of the way… [She] explained the bone scan… there was cancer in my spine, and it had basically eaten the bone away." (Bella).

This participant recalls feeling cared for and contained by the thoughtfulness of her consultant contrasting with the telephonic communication removing human containment in the delivery of diagnosis. Other participants described feeling abandoned and unsupported during diagnosis.

"He didn't ask me if I'd got anybody with me… he just left us pretty much high and dry." (Frankie).

This recollection captures an absence of empathy and emotional containment, being left alone at a moment of vulnerability.

Many participants experienced incidents of systemic discontinuity within diagnosis, leaving them caught between fragmented channels of information which mirror the fragmenting nature of the rupture in life narrative caused by receiving such a difficult diagnosis. These encounters also speak to the dehumanising gap between medical procedure and humane experience, with the patient becoming an object of diagnosis rather than a person in need of support.

Delayed Diagnosis and The Professional Divide

For many participants their road to diagnosis was protracted and distressing.

"I just sneezed and collapsed… diagnosed [with] a pulled muscle… I'd been effectively walking around with a broken back for six months." (Bella).

The abruptness of this account conveys disbelief and anger. The imagery of "*walking around with a broken back"* powerfully embodies the literal and metaphorical consequences of delayed diagnosis. The trivialising diagnosis of a "pulled muscle" is juxtaposed with the severity of cancer that has metastasised to the spine, symbolising a catastrophic failure of recognition which compounds the shock of diagnosis for this participant.

"I felt very not heard and not taken very seriously… I flagged concerns repeatedly and was told it wasn't that." (Laura).

This succinct yet emotionally charged statement encapsulates a recurring feeling of speaking into the void. The repetition of "not" emphasising the absence of professional recognition. The medical system which should provide certainty and clarity, instead amplifying confusion and distress. The uncertainty that characterises participants pre-diagnostic experiences echoes the existential uncertainty of diagnosis, suggesting that diagnostic delays launched a psychological template of unpredictability.

Existential Adjustment and Acceptance

This final subtheme captures participants gradual reorientation and sense making in a moment of rupture.

"You're like, oh crap… I felt very alone. I felt very fragile." (Eloise)

The raw immediacy of the rupture is captured here. The informal exclamation "oh crap" captures an attempt to give a voice to the speed of realisation of what is occurring in her reality. The participant moves quickly from acknowledgement into awareness of her vulnerability, encapsulating the beginning of existential adjustment, the moment during rupture where meaning making has not yet occurred.

"It was quite a shock at the beginning… I literally asked the oncologist the question: how much do I have left to live?" (Isla).

This participant quickly moved from shock to articulation of mortality, she asks for answers, seeking to quantify her remaining life. This may represent a search for boundaries in a moment that feels unbounded and chaotic, or an attempt to re-establish narrative coherence. This further supports the concept that diagnosis functions as an existential rupture. She attempts to regain agency, seeking knowledge to anchor herself which also symbolises early existential adjustment, preferring a painful certainty over intolerable uncertainty.

Ripples: Unnerving Changes.

This superordinate theme captures the relational and social consequences of living with MBC. All participants experienced MBC as causing relational disruptions and reshaping their emotional intimacy, familial roles and social positioning. The theme contains three superordinate themes: "*Relational Shifts and Emotional Intimacy"; "Maternal and Family Role Disruption";* and "*Social Judgement and Stigma*".

Relational Shifts and Emotional Intimacy

This subtheme encompasses the emotional impact of reconfigurations in women's close relationships. Participants describe both losses and gains in intimacy, whilst also experiencing disconnection. Women often experiencing the additional emotional burden of managing the emotions of others around their cancer.

"With my mum, seeing her heartbreak still gets me… we've had to reassess how we are." (Danny).

The participant describes an inversion of the mother-daughter bond. The ellipsis "still gets me" suggests the enduring emotional impact of witnessing a loved one's pain. For some participants illness reconfigured intimacy through shared suffering.

"We're probably closer than we've ever been." (Mia)

When speaking about her own mother, this participant's simple statement illustrates how facing mortality can strip relationships of pretence or superficial burden. The qualifier *"probably"* suggests tentative evaluation, closeness may be a surprising outcome for this participant.

Maternal and Family Role Disruption

This subtheme captures the destabilising impact of MBC on participants identities as mothers and within the family unit. Many described changes forced on deeply ingrained caregiving roles, with women experiencing this as a loss of purpose. For mothers the impact on their core identity as a caregiver evoked feelings of inadequacy and loss of meaning.

"I'm no longer the primary caregiver… that really eats away at me." (Holly)

This participants phrase "eats away" conveys an ongoing internal erosion of self-worth. Caregiving was pivotal to who she identified as and has been displaced by dependency on others. This represents a rupture in the embodied experience of motherhood for her.

"I don't have a bucket list… I just want to walk the kids to school." (Laura).

For this participant, a simple wish encapsulates the yearning for the normality or mundane elements of motherhood. Her rejection of a "bucket list" reflects her reorientation of values towards being present. The "walk to school" becomes a metaphor for her desire to maintain connection and her maternal role. Many mothers described guilt surrounding their inability to parent their children how they imagined, expressing worries about illness framing their child's memories of them.

"She's only ever known me with cancer."(Isla)

The participant's identity here is as a mother with cancer. She reflects with sadness on her child's understanding of the maternal relationship being illness. Several participants describe painful shifts in other family dynamics due to caregiving shifting across generations or partners.

"Where I thought I'd be taking care of her [mother]… there's a fair chance she'll be taking care of me."(Eloise).

The phrase *"fair chance"* conveys resigned awareness. This shift reveals how illness disrupts embedded cultural scripts about generational continuity and caregiving. Similarly in intimate partnerships, shifts led to emotional distance and identity confusion.

"We've got a relationship more like a brother and sister now."(Holly).

The participant signals the lack of sexual intimacy and redefinition of the relationship's identity. The romantic bond has transformed into something platonic. This reflects how illness forces caregiving to overtake romantic or sexual intimacy.

Social Judgement and Stigma

An experience echoed across participants was the social discomfort, misunderstanding and stigma surrounding MBC. Participants described feeling isolated as objects of pity. Social interactions were often experienced as awkward or avoidant, drawing an invisible line between themselves and those who were "well".

"People don't want to talk to you because they don't want to know the answer… you feel very lonely." (Claire).

This extract highlights the atmosphere of avoidance and denial faced by this participant. She experienced illness as unspeakable, it becomes a societal threat to the shared illusion of control and permanence. The rejection felt by the participant suggests that stigma operates through absence; the withdrawal of conversation and connection resulting in isolation and loneliness.

"You get people look at you. They don't say anything, but they stare… and that gets to you." (Claire).

The contrast between silence and staring, underscores the contrast here between feeling exposed as a woman with MBC and being isolated concurrently. Participants who faced stigma responded in differing ways, some using dark humour to reclaim agency and connection.

"I say, 'Oh, well, you could be lucky too. All you've got to do is get cancer and then you get a free tummy tuck.'"(Aoife)

Here humour operates as defence and defiance in the face of stigma. The ironic tone exposes the absurdity of assumptions made whilst allowing her to invert the power dynamic of feeling dehumanised through use of satire. Humour can be used to preserve identity, dignity and a sense of control, here the participant used it as a defence to pity. These narratives reveal the social cost of MBC; the erosion of belonging and a loss of social identity, instead becoming a forced identity of the "ill person". Participants navigate a complex social terrain whilst also managing their own identity.

Fragmentation: Challenges Living in the Shadow of Mortality.

This superordinate theme captures participants experiences of profound existential awareness when facing one's own mortality. Many women articulated a sense of tension between living in the present whilst anticipating loss, uncertainty and time limitation. This theme encompasses subthemes of *"Temporal Living", "Legacy, Fertility and Anticipatory Grief"* and *"Existential awareness and Reframing Mortality".*

Temporal Living

This subtheme addresses the altered experience of time in the context of terminal illness. Participants describe a shift from future orientated planning to present focused living, reflecting how illness reshapes temporal perception and necessitates a reconfiguration of priorities.

All participants found the temporal scaffolding of treatment cycles and surveillance scans as disruptive which resulted in time no longer being experienced as linear but in medical intervals.

"We try to live our life in three-month plans." (Isla)

This disrupted temporality of illness leads women to experience the shifting of time from open-ended linear progression, into a series of finite segments defined by medical intervention or surveillance. The reliance on clinical markers to structure time was experienced as unilaterally protective and constraining, one participant describes this vividly.

"It's like you've got a time bomb… one day the scans will be the bad news." (Laura).

This metaphor encapsulates the emotional volatility of living in cycles of hope and dread, the language of "time bomb" evokes a feeling of countdown. This reflects a thread which was present across participants, of anticipatory living as an impossible attempt at normality when every reprieve carries the shadow of its own ending.

Legacy, Fertility and Anticipatory Grief

This subtheme explores participants experiences of mortality, for many participants living with MBC forced a re-evaluation of what it meant to be a mother and how to nurture beyond their own lifetime. Participants spoke of wanting to leave tangible and emotional traces of themselves for loved ones, particularly children and for some participants, the treatment for MBC led to grieving the fertility and motherhood they would be denied.

"The cancer's aged me… it's picked the worst things it could do to you as a woman." (Mia)

Participants articulated grief not only for the physical changes but the imagined futures those bodies made possible. The sense of theft here also speaks to the experience of biographical disruption in which a coherent life story is fractured by illness and leads to existential protest. For many participants legacy building became a grounding exercise for this sense of fractured self and loss of future. Some legacy acts focused on immediate family, while others extended to a broader impact for remembrance.

"I'm putting things in place… making a bucket list." (Jackie)

"I'm making a memory box for my son." (Kelly)

Memory boxes and collaborative bucket lists gave many participants a sense of agency through goal setting. Through these acts participants transformed anticipatory grief into purposeful activity. For mothers this grief was felt particularly sharply with some participants expressing deeply emotional realisations during interview.

"I probably won't be alive to see his 5th birthday." (Jackie)

This brief disclosure highlights that participants are living with the shadow of mortality. For mothers their future planning became acts of temporal caregiving, mothering across time redefined motherhood into a symbolic presence beyond material traces of themselves.

Existential awareness and Reframing Mortality

This subtheme captures participants heightened awareness of mortality and their attempts to reframe death within an ongoing search for meaning. Participants offered varying viewpoints oscillating between fear, acceptance, uncertainty and reflection on moments of clarity.

"It's the unknown more than anything… I just don't know what's going to happen." (Claire)

For many participants living with the unknown emerged as a defining emotional experience of existential reflection. In this quote the participant surrenders control to the unpredictability of MBC. There is a sense of unease in her language, yet others experienced wisdom and enlightenment.

"You've been shown a secret level… you see things for what they really are." (Mia)

This metaphor captures the transformative aspect of living in proximity to death; the participant offers existential insight into the life's lack of permeance. The phrase 'secret level' suggests privilege and isolation. It portrays a sense of clarity that co-exists with a feeling of alienation; that once enlightenment of deaths inevitability is gained it cannot be unseen. Participants adopted different metaphors for their experiences of slowly dying.

"Other people… may one day get hit by a bus… Whereas we're already trapped underneath the bus, being dragged along and over all the bumps and around the corners… and one day, that bus is going to kill us." (Bella)

This visceral metaphor encapsulates this woman's experience of MBC as slowly dying. She distinguishes between those unaware of mortality and those forced to live in its constant shadow "already trapped". The imagery of being dragged evokes suffering and instability. This metaphor transforms the abstract quality of mortality into a relatable process. It highlights that those with incurable illness don't await death, they endure it gradually. The bus becomes a symbol here of fate. Ultimately for participants, the awareness of death became intertwined with affirmation of life itself, the pain of exposure to truth being the humanising aspect of facing death.

Who Am I Now? Reconstruction and Reclaiming of Identity.

This final superordinate theme regards transitions in identity experienced by participants as they navigate living with MBC. Participants describe the changes to their bodies and capacities which challenged their femininity, autonomy and values. This theme combines two sub-themes: *"Impact of Treatment on Identity"* and *"Identity Fragmentation and Role* Loss".

Impact of treatment on Identity

The physical and psychological consequences of MBC cancer treatment can be devastating. There was a cruel paradoxical experience of being both saved and harmed by treatment experienced by all participants.

"It tried to kill me… I'm not being dramatic… I had immune toxicity.... within a few weeks of that I was hospitalised… I came home on oxygen, I came home in a wheelchair." (Danny).

This participant's need for the researcher to understand she's "not being dramatic" emphasises the severity of treatment. Her description conveys the vulnerability and loss of autonomy

experienced by other participants through treatment. For all participants, the impact of treatment on their femininity had a dramatic impact on their identity. Treatment for MBC may involve women being put through medical menopause, for many, holding onto their femininity afterwards became performative.

"You try and put wigs on, you try and get makeup… but you don't feel sexy." (Holly)

This reflection encapsulates the emotional distance between appearance and embodiment, fighting for femininity in a body that no longer feels like one's own. The impact of treatment was also felt on identity in an emotional context.

"I've lost a bit of spark… I used to be really funny." (Mia)

This reflection moves beyond physical impact to express a deeper, inner sense of diminished identity. Her *"spark"* is a symbol for her of personality. The loss of her spark becomes a metaphor here, conveying a disconnection from the person she recognises. This interruption of her life narrative gives the sense that her identity feels suspended. The impact of treatment on identity for all participants was monumental, not only altering physical appearance but the foundations of femininity and self.

Identity Fragmentation, Role Loss and Rebuilding.

Many participants described illness interrupting roles through which their identity was anchored. The impact on ability to maintain professional or social participation represented a loss of self-definition and purpose.

"*I felt absolutely robbed… you lose the identity in the workplace, but you lose your identity professionally and your value." (Danny)*

This choice of the word 'robbed' also seen in other interviews, depicts cancer as a thief, highlighting a sense of violation, and revealing the loss of identity and belonging.

"I've lost my job, the way I feel, the way I look, my future, my way of parenting… I've lost everything." (Kelly)

Similarly, this participant's list of losses is revealing of the core parts of herself which form her identity. For others, loss of professional status symbolised a collapse in external validation and therefore led to questioning value and purpose.

"I wish I could fly. I can't. So if I'm a bird and I can't fly… what can I do?" (Eloise)

The metaphor ("bird") elicits feeling of disconnection and worthlessness. She appears to retain her core sense of identity yet is unable to express it in action, feeling restricted in her roles and therefore questioning her purpose.

This sub-theme illustrates how MBC fractures a woman's sense of self through inability to maintain professional roles through which identity is anchored. The recurring language of "robbed" conveys the depth of violation and helplessness felt as though women's identities had been taken against their will. For many this fragmentation to their identity was accompanied by grief and loss, for others this sparked a resistance to being a passive bystander to their own identity though continuing to work or finding purpose through adaptation, with identity becoming an ongoing negotiation.

Discussion

To the authors' knowledge, this is the first study to investigate the impact of living with MBC on women's identity. Thirteen participants were interviewed, and four main themes identified from their experiences; *Rupture: The shattering impact of diagnosis"; "Ripples: Unnerving changes"; "Fragmentation: Challenges Living in the Shadow of Mortality";* and "*Who Am I Now? Reconstruction and Reclaiming of Identity". Rupture: The Shattering Impact of Diagnosis* was conceptualised as the moment of external rupture for women, with the delivery of this news laying the groundwork for the ongoing process of existential reconstruction of identity. It highlighted the role of healthcare professionals in delivery of life-altering news which aligns with existing literature (Sobczak et al., 2018). In *Ripples: Unnerving Changes* participants voiced the erosion of belonging

and a loss of social identity, becoming a forced identity of the "ill person". *Fragmentation: Challenges Living in the Shadow of Mortality*"; captured participants heightened awareness of temporality and the challenges in finding meaning while living in proximity to death. Finally, "*Who Am I Now? Reconstruction and Reclaiming of Identity"* illustrated the ongoing reconstruction and adaptation of identity amid the instability of living with MBC. Together these four themes map the profound ways in which MBC reshapes how women understand their identity.

Links to Theory and Literature

The themes identified in this study resonate with existing conceptualisations of chronic and life-threatening illness. Firstly, Bury (1982) posited that life threatening illness acts as a biographical disruption. For the women in this study, the diagnosis of MBC represented an existential rupture in their continuity of identity, social roles and future orientation. This shares similarities with Janoff-Bulman's (1989) theory that life threatening illness is a trauma which may destabilise deeply held beliefs. However, whilst both frameworks offer some contextualisation to participants experiences of rupture, the current study extends them by illuminating the existential reconstruction in the aftermath of diagnosis. Women in this study did not resign themselves as passive bystanders, instead they experienced their identity to be dynamic and negotiated.

The first theme, *Rupture: The shattering impact of diagnosis"* reflected the moment of rupture experienced by participants and reinforces earlier research that indicates the point of diagnosis is a psychologically defining moment that forces reassessment of an individual's assumptions about self, future and mortality (Fortin et al., 2021; Visovsky et al., 2023). For participants, diagnosis represented a collapse in understanding of their life narrative and sense of embodied security. This is consistent with findings by Palmieri et al., (2022) and Ginter (2020) who described MBC as uniquely destabilising due to its incurable nature and subsequent ongoing uncertainty,

Participants descriptions of how their diagnosis was delivered adds an important dimension to this rupture. Encounters which were experienced as relationally containing and emotionally attuned were recalled as grounding. Whereas rushed or detached delivery and fragmented communication intensified distress. The importance of compassionate communication is not novel (e.g. Baile et al., 2000; Clayton et al., 2007; Sobczak et al., 2018). However, the clinician's delivery of participant's diagnosis became tied to the meaning of diagnosis itself, where communication felt rushed or procedural, women described feeling dehumanised and abandoned, when it felt attuned and emotionally supportive, they experienced a fragile sense of safety and support.

Through the lens of diagnosis being a rupture for participants, the emotional trajectory of women was also observed across subsequent themes. When women had experienced systemic failures during this moment, they were more likely to be mistrusting of healthcare systems and professionals which is seen captured in *Ripples: Unnerving Changes* Conversely, when participants described feeling contained by professionals at the point of diagnosis, they later described greater capacity for adjustment, suggesting that earlier relational containment with healthcare professionals may buffer against future psychological difficulties. This interconnection between diagnostic experience and later identity reconstruction underscores the clinical importance of psychologically informed patient care at all stages of contact (Baile et al., 2000; Clayton et al., 2007).

The findings related to the theme *Rupture: The shattering impact of diagnosis*" deepen understanding of the diagnostic encounter and propose it to be the first site of identity reconfiguration for women with MBC. Our findings bridge previous psycho-oncological research emphasising distress at initial diagnosis (Fortin et al., 2021) with phenomenological accounts of meaning making in chronic illness (Bury, 1982; Charmaz, 1995) showing that the quality of communication can either compound the sense of existential rupture or provide the first scaffold for reconstruction.

The theme *Ripples: Unnerving Changes* captured the shifting and reshaping of women's relational worlds. Findings corroborated previous research suggesting that severe illness's impact is felt far beyond the individual, affecting relational systems and social positioning (Palmieri et al., 2022; Ginter, 2020). Our findings went further in capturing the meaning behind the relational shifts and exploring them as an existential disturbance in identity.

The relational ruptures identified align closely with the existing qualitative research on MBC. Visovsky et al., (2023) highlighted similar experiences around altered roles, however, the present study extends these findings through an idiographic focus on how women interpret disruption to their relationships as a part of their identity. Participants narrated the shifts in their relationships as moving pieces of a larger puzzle, within the frame of existential uncertainty. Shifting roles and relationships were seen as part of the ripple effect initiated by diagnosis.

Participant's experiences of relational recalibration somewhat mirror Charmaz's (1995) description of "the social loss of self", a process of illness altering a person's perception of their social worth. However, our findings complicate this conceptualisation. Whilst Charmaz (1995) posits a unidimensional loss, participants in this study describe a complex simultaneous grieving process for lost roles alongside reclaiming agency. This further suggests that the internal fragmentation caused by changing roles for women leads to an existential reconstruction, via re-evaluation. These findings also suggest that identity for women with MBC is not wholly characterised by depletion and loss, instead involving purposeful renegotiation which aligns with existing theoretical understandings of identity as relational and under continual reconstruction (Kroger & Marcia, 2011).

The theme of *Fragmentation: Challenges Living in the Shadow of Mortality* is pivotal to the identity processes uncovered by this study. Existing literature recognises that living with cancer intensifies distress and evokes anticipatory grief (Ginter, 2020), though, as with much breast cancer research such studies often exclude women with metastatic cancer. Our findings are consistent with Toombs' (1990) conceptualisation of illness temporality, building on this to illustrate how women rebuild identity amidst temporal disruption caused by treatment cycles, scans and unpredictable prognosis.

The 'three-month cycles' of temporal living described by many participants offers an example of this temporal process. Similarly to Toombs (1990), participants described their lives to be defined by medical events, demonstrating the difficulty for women in rebuilding a future narrative in the face of constant reorientation. Furthermore, participants oscillated between present-focused living and anticipatory grief. Understanding this 'in-between' where women are both living and dying was supported by IPA's double hermeneutic quality which enabled exploration of how women often held contradictory experiences simultaneously, such as gratitude and grief or fear and acceptance.

Practices which revealed the reclamation of agency and identity rebuilding such as legacy making activities also extend existing literature on anticipatory grief (Johnson et al., 2017). Our

findings reveal the active identity work involved in these acts, exploring how they serve as both anchors to the present and continuations of self, suggesting that the legacy building acts themselves serve as part of women's identity reconstruction. This concept is supported by ideas of generativity (Erikson, 1963) but in this case is reframed through the lens of incurable illness, a unique contribution of this study.

The final theme "*Who Am I Now? Reconstruction and Reclaiming of Identity"* synthesises the threads of the preceding themes into a broader narrative of identity transformation. Whilst existing literature acknowledges the distressing impact of the physical changes of cancer (Mosher et al., 2013, Hamer et al., 2017) this study expands current understanding by demonstrating how these experiences for individuals, whilst unique, share the nature of being an accumulative ongoing process of identity work.

The perspectives offered in this study support Charmaz's (1995) argument that chronic illness can erode sense of self through disability and loss of autonomy, yet our data highlights the rebuilding aspect of this process. Participants recalibrated priorities and adapted meaningful roles demonstrating identity reconstruction. These findings challenge deterministic narratives of decline in illness (Shields et al., 2015) instead aligning with studies of identity which focus on its position as negotiable, and relationally and contextually embedded (Kroger & Marica, 2011).

A novel finding of this study is that identity fragmentation was not simply internal but perceived as social discourse. Narratives of being labelled by others as a "warrior" or to manage societal expectations of embodying strength and positivity in the face of incurable cancer, left many participants feeling misunderstood and isolated. This builds on survivorship discourse in literature which critiques societal expectations of "fighting" cancer (King, 2006; Broom et al., 2022) and positions MBC as a context in which such narratives may be particularly harmful.

This study contributes methodologically by its use of IPA to an underexplored population, and in doing so demonstrates the value of ideographic enquiry for understanding experiences of those living with incurable illness. The double hermeneutic was particularly relevant in this study given the existential experiences of participants. Their metaphors, contradictions and emotional tone required close interpretive engagement to illuminate deeper identity processes beneath the descriptive content. This adds to calls within IPA literature (Smith et al., 2022; Smith & Nazza, 2021) for studies which move beyond surface thematic description.

Implications for Clinical Practice and Future Research

These findings have implications for psychology practice, oncology services and healthcare communication training. The themes suggest that clinical support must begin at diagnosis, attend to relational and societal dimensions of identity and recognise the ongoing existential reconstruction occurring for women with MBC. Our findings suggest the moment of diagnosis represents an existential rupture, indicating the importance of psychologically informed communication training across oncology teams, such as Level 2 psychological skills training as recommended in NICE guidelines (NICE, 2004) alongside supporting guidelines such as the SPIKES protocol for delivering bad news (Baile et al.,2000). Additionally, the use of reflective practice within oncology teams to recognise the relational and existential weight their communication carries may extend and improve upon existing protocols such as SPIKES (Baile et al., 2000).

More specifically this study highlights the importance of early psychological contact at or shortly after diagnosis, acknowledging diagnosis as a psychological event for some, as opposed to a solely medical event. Early psychological support may serve as a protective factor against later identity fragmentation. It is important to note that not all oncology patients require psychological support, and some may not have equal access to psychology within services, however findings

suggest that while not all patients would require psychological support, this subgroup may have a higher need given the impact of the diagnosis and prognostic uncertainty.

Psychological intervention of a systemic or family nature including psychoeducation to reduce misunderstanding and stigma around MBC, may help patients and families to navigate shifting roles and support women with the turmoil of social narratives and negotiating their own identity (Charmaz, 1995). Furthermore, the benefits of group based psychological support for women with cancer are already established (Cipolletta et al., 2019; Joblotschkin, 2022). Group support may validate identity change and relational shifts for women potentially normalising identity struggles.

Existing psychological therapeutic frameworks which integrate existentially informed work such as Acceptance and Commitment Therapy (ACT) may provide support to women in navigating the bodily changes in relation to femininity and identity. Specifically, findings suggest that psychological therapy in MBC should be identity focused, encouraging values-based living and meaning orientated goal setting even within limited futures.

System implications from this study align with participants accounts that identity is relationally and socially constructed and thus implicated by healthcare interactions. Future oncology or psychology service developments for women with MBC should consider equitable access to psycho-oncology embedded within cancer care.

Strengths and Limitations

Several methodological and conceptual strengths enhance the contribution of this study. Foremost, the use of Interpretive Phenomenological Analysis (IPA) enabled an in-depth, idiographic exploration of identity processes in a population that is frequently underrepresented in psycho-

oncology research. The analytic approach allowed for close engagement with participant's narratives, including their use of metaphor, contradiction and emotional expression, facilitating a nuanced understanding of identity as a dynamic and relational process in the context of incurable illness. This methodological choice fits the research questions well given their existential and meaning orientated nature.

This study also benefited from its use of Patient and Public Involvement (PPI) at the design stage which strengthened the sensitivity and accessibility of the research. Close engagement with PPI alongside MBC charities ensured all aspects of the research were grounded in lived experience and ethically attuned to the needs of participants.

The recruitment strategy represents a further strength. Utilising social media and charitable networks enabled access to women across a wide geographical area within the UK and reduced barriers associated with travel, fatigue and participant's fluctuating health. This approach enhanced the inclusivity of the sample, subsequently, the sample size (n=13) is at the upper end of recommendations for IPA studies supporting both depth of individual analysis and richness of data.

Despite these strengths, several limitations must be considered when interpreting the findings. Firstly, the sample was relatively homogenous, comprising predominantly White British women engaged with online communities or charities. This may reflect a degree of self-selection bias, limiting generalisability as individuals who are digitally connected or more comfortable discussing their experiences may have been more likely to participate (Benedict et al., 2019). Consequently, the findings may not fully capture women who are more socially isolated, from minoritised backgrounds or experiencing more severe physical or cognitive impacts of MBC (Bender et al., 2011)

The exclusion of men or non-binary individuals was implemented in this study to specifically capture the meaning of identity to women with MBC. This does not diminish the importance of gender related analysis in this area, but the gendered meaning-making around motherhood, sexuality and social identity is likely to be experienced differently by those who identify more strongly with other genders (Ginsberg et al., 2023). Therefore, findings should not be assumed to represent the full spectrum of identity experiences even within those who identify as women, but especially across all people with MBC.

A further limitation recognised is the cross-sectional nature of this study design, which captures participant experiences at single point in time, limiting insight into how identity transforms across the illness trajectory. Longitudinal qualitative methods may be valuable in capturing life-limiting illness experiences, where changes in symptoms and treatments may lead to an ever-evolving identity development (Lewis et al., 2014). However, the method was appropriate for the research questions and analysis, and the study offers value through its deep cross-sectional perspective.

IPA acknowledges the role of the researcher within the meaning making during analysis (Smith et al., 2022; Larkin, Shaw & Flowers, 2019). The lead researcher's position as a white female, doctoral trainee as well as her broader social identities may have shaped the analytic lens through which participant accounts were interpreted (Finlay, 2002). Although reflexive journalling, supervision and collaborative discussion were used to support analytic rigour, complete bracketing of assumptions is neither possible nor consistent with the epistemological position of IPA.

A further limitation is posed using through use of online interviews as this may have reduced access to subtleties in communication including non-verbal cues or embodied expressions of the experiences described (Hanna, 2012). This was mitigated by familiarisation with the data and exploratory note taking during the transcription process to assist interpretation. Existing literature

presents a mixed view on disclosure in interviews via video call, with some suggesting technology allows for further disclosure, others suggesting inhibition by technological barriers, potentially limiting accounts (James & Busher, 2009).

Overall, these limitations are consistent with qualitative, idiographic research and do not detract from the value of this study. The study offers a rich and clinically meaningful contribution to understanding identity processes in women with MBC, addressing a notable gap in the literature.

Directions for Future Research

Future research may consider exploration of longitudinal identity in women with MBC from diagnosis across disease progression. Additionally, future research should include investigation into identity and intersectionality across race, class, sexuality and age-dimensions currently underrepresented in MBC research. Cross-cultural research would also illuminate how differing illness narratives, stigma and societal expectations shape identity. Given the role of online communities in recruitment for this study, and the role of online communities in the lives of women with MBC, future research could examine the role of digital networks in contributing to identity and social belonging for women with MBC.

Finally, further research into healthcare professionals' communication around diagnosis and across the treatment process may support with development of training and policy. The findings of this study indicate that clinical practice should focus across all stages of illness trajectory. Future research should build on these findings exploring specific areas of identity including motherhood and intimate relationships with the aim of developing interventions and service pathways which honour the complex, fluid nature of identity for women living with incurable cancer.

Conclusion

This study's findings offer an in-depth exploration into how women with MBC understand their identity as they live, knowing they will die, but not when. Identity was revealed to be a dynamic process which involved a "rupture" at diagnosis, social "ripples" which destabilise roles and belonging, and internal "fragmentation" created by anticipatory grief before shifting towards ongoing "reconstruction" of self-amidst uncertainty. Findings extend existing understandings of incurable illness by highlighting that women's identity is continually regenerated through acts of agency, meaning making and relational recalibration.

Declaration of conflict of interest

The lead author had no pre-existing relationship with participants. Primary research supervisor, Dr Amy Carroll, had previously worked within a palliative care team as a Clinical Psychologist but had no pre-existing relationship with any of the participants. Secondary research supervisor, Dr Lauren Hickling, was employed in an acute hospital as a Clinical Psychologist working one day a week with Breast Cancer patients but had no pre-existing relationship with participants of the study. The author declares there were no other conflicts of interest.

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Chapter Five

Discussion and Critical Evaluation of Thesis Portfolio

Word Count: 4100

Chapter Five: Discussion and Critical Evaluation of Thesis Portfolio

This chapter provides a critical discussion and evaluation of the thesis portfolio with a focus on integrating the author's learning across the systematic review and empirical study through reflection on the combined theoretical, methodological and clinical contributions. This chapter also considers strengths and limitations of the portfolio and implications for clinical psychology practice and future research.

The overarching aim of the portfolio was to explore women's experiences of identity while living with advanced cancer. By bringing together a qualitative meta-ethnography and idiographic IPA study, the portfolio sought to develop a nuanced understanding of identity as it is lived, negotiated and reconstructed under conditions of incurable illness. This chapter reflects on what is gained through considering these studies together and how this integrated approach contributes to psychological knowledge and practice.

The portfolio comprises two complimentary qualitative papers addressing women's identity in the context of advanced cancer. The systematic review synthesised qualitative literature across diagnoses and cultural contexts, generating higher order conceptual understandings of identity processes. The empirical study focused more narrowly on women living with metastatic breast cancer, offering an in- depth exploration of lived experience within a specific clinical subgroup. Across both papers, identity is positioned not as a static attribute which is simply disrupted by illness, but as an active, fluid, relational and dynamic process. The portfolio moves beyond symptom focused or outcome-based accounts of psychological distress to foreground the often-invisible work women undertake to preserve continuity of self, manage relational expectations and make meaning of facing their own mortality. This shared focus facilitates a portfolio where two papers together provide both

breadth and depth to furthering the understanding of women's identity when living with advanced cancer.

Discussion of Findings

When considered together the findings of the systematic review and the empirical study converge on a shared understanding of identity as something continually negotiated in response to advanced cancer. Across both papers, women described identity as being shaped through relational roles, temporal orientation, emotional regulation and narrative meaning making.

A key point of integration lies in the concept of identity as labour. In the systematic review, women were found to engage in sustained efforts to perform normality to meet the needs of others, regulate emotions and preserve their valued identities, such as mother, wife and professional, often at significant personal cost both physically and psychologically. Similarly in the empirical study, participants described managing the emotional responses of others, concealing vulnerability and stiving to maintain their roles despite psychical and existential challenges. These parallel findings suggest identity preservation in advanced cancer is not passive but require ongoing psychological and emotional work.

Temporal reorganisation also emerged as a unifying theme across the portfolio. The systematic review highlighted how women recalibrate their relationship with time in the face of mortality, often shifting focus towards the present or redefining future goals. This was echoed strongly in the empirical study, where participants described living in cycles shaped by scans, treatment milestones or setbacks and prognostic uncertainty. Time was no longer experienced as an open-ended trajectory but as fragmented and contingent, with identity anchored to immediate values and relationships instead of long-term goals or milestones.

Relational identity formed a further central point of convergence. Across both papers, women's sense of self was deeply embedded in their relationships, particularly caregiving and maternal roles. Participants in the empirical study spoke vividly about the pain of altered family dynamics, role reversals and fears about how or whether they would be remembered by their children after death. Their lived accounts brought depth to the systematic reviews' finding that identity is morally situated and shaped by gendered expectations or care, endurance and emotional containment.

Finally meaning making and narrative reconstruction emerged as critical processes through which women reclaimed a sense of agency. Both papers illustrated how women sought to re-author their life stories, whether through legacy building activities, reframing values or integrating their illness into a coherent sense of self through methods such as humour or ritualisation of treatment. When considered as a whole, the portfolio suggests that identity in advanced cancer is best understood as an ongoing narrative project for women, negotiated within social, cultural and existential constraints.

Theoretical and Conceptual Reflections

The themes across both papers are strikingly similar, with the integrated findings of this portfolio also echoing existing theories of illness and identity. While concepts such as biographical disruption (Bury, 1988) and loss of self (Charmaz, 1995) provide a useful foundation, the portfolio findings suggest a need to move beyond disruption focused models alone. Rather than being simply fractured or disrupted by illness, women with advanced cancer were found to actively reconstruct and perform roles which were integral to their identity in ways which maintained their dignity, relational belonging both socially and within family dynamics, and their moral worth.

Narrative theories of identity might add to our understanding of meaning making and storytelling in maintaining continuity of self. A recent study by Devuyst et al.(2025) found narrative story telling to be a powerful took for reclaiming identity and developed a conceptual model which further suggests narrative work may serve to mitigate the existential threat of life limiting illness through reaffirmation of identity (Devuyst et al., 2025). Although not specifically focused on women's identity this recent breakthrough in identifying the complexities of narrative identity dimensions at the end of life further highlights the importance of understanding the experience of people living with advanced cancer. The findings of this portfolio highlight how women revised their life narratives to accommodate uncertainty and mortality, often resisting dominant cultural narratives of survivorship, positivity or strength. This resistance underscores the importance of recognising identity as culturally and morally situated and shaped by societal expectations around femininity, caregiving and emotional strength.

The concept of liminality also provides a useful lens for understanding women's experiences across the portfolio. Women living with advanced cancer occupied an in-between position: neither fitting neatly within survivorship discourses nor aligning themselves fully with end of life or palliative care narratives. This liminal state intensified identity work as women navigated the ambiguity, invisibility and marginalisation within both healthcare and social contexts. This unusual state of limbo where women exist in neither realm of societal categories inspired the title of this portfolio. Liminality has also been used historically to refer to people who live 'outside of society' which further supports the 'in-between' position revealed within this portfolio of women living with advanced cancer (Thomassen, 2016). In addition, the individuation process of self-realisation as described by Miller & Jung (2004) suggests that individuation begins with the withdrawal from normal socialisation processes, which was described by women across this portfolio, further recognising the relational role of identity in women with advanced cancer. Jungian based theories of analytical psychology may therefore support the idea that women with advanced cancer may be 'in-between' the process of breaking down and remaking their identity (Beech, 2011).

Reflexive Learning Across the Portfolio

The following reflective section is written in first person to capture author's learning and reflections.

Given the qualitative and interpretative nature of this thesis portfolio, reflexivity was a central, transparent component of the research process. Reflexive engagement occurred throughout the design, data collection, analysis and writing of both the systematic review and empirical study supported using a reflexive journal and regular discussion with research supervisors. This section draws selectively on reflexive material to critically examine how the researcher's positioning, assumptions and emotional responses shaped the knowledge produced across the portfolio.

As a trainee clinical psychologist, and as a woman and mother, researching the experiences of other women living with advanced cancer, I entered the research process with arguably an existing sensitivity to themes such as caregiving and relational responsibility. This positioning facilitated empathy and rapport during interviews particularly where participants spoke about motherhood and emotional containment. However, it also necessitated ongoing reflexive attention to the risk of assumption or over-identification with participants narratives. Early reflective entries in the reflexive journal highlight an awareness of this proximity:

"*I feel as if any of these women could be me or one of my friends. They have normal jobs, they are similar ages to me and my friends. I am noticing a really strong pull towards understanding these women but will need to be careful about assuming shared meanings because their stories resonate or their lives feel familiar to me"*

This reflexive stance and attempt to continue stepping back and looking at the wider picture of the research and analytic process supported me to take pauses during the analysis process, particularly coding and theme development to interrogate where interpretations were grounded in participant accounts versus where they may reflect my own values. In this way reflexivity functioned as a mechanism for epistemic humility and through sharing discussion through the analysis process with research supervisors the process became more than an attempt to simply eliminate subjectivity.

The empirical study involved 13 interviews with women living with MBC, many of whom were close to the end of their lives and spoke candidly about death, uncertainty and the impact of illness on their families. Reflexive journalling during the data collection captured the emotional weight of these encounters and highlighted tensions between my clinician instincts and the boundaries of the researcher role. For example, following one interview in which a participant spoke about protecting her children from the reality of her prognosis, I noted:

"I noticed a strong urge to offer her reassurance, to contain the uncertainty she was feeling and describing. Sitting with that urge in such an emotionally charged interview reminded me my role as researcher is simply to listen and bear witness, I am not here to rescue, or fix, to contain or resolve. Even if I was, I realised today that for these women, there is no rescuing or fixing them from existential mortality, their death is something they must face and this is what makes them feel so alone and isolated even from families at times."

Acknowledging these moments reflexively supported ethical practice by reinforcing the distinction between research participation and therapeutic intervention. It also informed the pacing and structure of interviews, ensuring participants retained control over what the chose to disclose and that emotional containment was manged through clear boundaries and post-interview signposting rather than implicit therapeutic responses. Careful attention was given to ensuring participation in the

interviews was as supported as possible. Informal time was allowed at the end of interviews for participants to ask questions, reflect or take some time to compose themselves prior to debrief information and signposting. It was made clear to participants this was in no way a therapeutic space, but they were given any time they needed before ending the video call. As a result, many women expressed feelings of pleasure, pride, gratitude and accomplishment that they had been a part of the research study. Research suggests participation in research has been associated with psychological benefits including validation and meaning making (Richards et al., 2015; Payne et al., 2005).

Across both the SR and EP, participants and authors frequently described women's efforts to maintain normality, protect others and continue fulfilling emotional roles despite significant physical and existential challenges. Reflexive engagement was particularly important in analysing these accounts, as such narratives risk being read through a culturally dominant discourse. Approximately midway through the analysis I reflected:

"*I keep catching myself admiring participants for how 'well' they are managing or coping with their situation. I need to think more about this because what if that admiration is rooted in my own upbringing and expectations. I think I need to slow down a bit and ask myself what the cost and impact on these women is of 'managing well' and whose needs are being prioritised in these cases"*

This reflexive awareness directly shaped analytic decisions and discussion within the team, supporting interpretations that framed these behaviours as forms of identity labour rather than just indicators of psychological adjustment or resilience. In the SR, this contributed to the conceptualisation of identity as an active process. In the EP, it supported the more critical reading of the participants accounts of emotional containment, selective disclosure and caregiving which foregrounded interpretation of relational and gendered expectations underpinning these practices.

The portfolio also required reflexive consideration of power dynamics inherent in qualitative research, this was especially prudent for participants who may be considered vulnerable due to severity of illness. Reflexive entries highlighted an awareness of how the act of asking questions about identity and future could be perceived vastly differently. One entry noted:

"Today's interview was emotional for the participant, but she wanted to get things across. I was aware that the emotion from her may not be burden but instead relief that she had a space in which to openly speak about the future. I need to be aware that my own uncomfortableness about asking around futures for these women is in fact based on my own feelings and assumptions about what they may find difficult. I need to hold this really carefully and not assume that specific questions will be harder than others, for this woman, the question about future felt like a huge relief for her. Perhaps she felt validated that the question was included in the interview, it makes me think about how important it is to capture each individual voice uniquely and that IPA was a strong choice for this study to do that".

This awareness which I continued to develop throughout the research process, informed the analytic stance taken across the portfolio. Rather than assuming that identity reconstruction is inherently adaptive or desirable, the findings were interpreted with attention to ambivalence, resistance and moment where meaning making felt imposed rather than chosen.

Engaging reflexively across the portfolio supported my development of a more critically aware researcher identity. Through ongoing reflexive practice and open discussion with research supervisors, I became increasingly attuned to the ways in which psychological knowledge is shaped

by social position, power and professional discourse. This process strengthened my capacity to tolerate uncertainty, resist premature interpretation and remain open to complexity.

Critical Evaluation: Strengths and Limitations

This thesis portfolio sought to explore women's experiences of identity while living with advanced cancer and is to the author's knowledge the first systematic review (SR) and empirical paper (EP) to do so. Considered together, these studies provide both conceptual breath and experiential depth. Both papers make a meaningful contribution to psycho-oncological literature by positioning identity as a central psychological process within advanced cancer rather than a secondary outcome of distress or adjustment.

A key strength of the portfolio lies in it's methodological coherence. The systematic review synthesised qualitative literature across diagnoses, healthcare contexts and cultures, generating higher order conceptual insights into identity as an active, relational and morally situated process. The empirical IPA study then offered an in-depth exploration of how these processes are lived and negotiated by women with metastatic breast cancer. This dual approach reflects a robust qualitative design in which synthesis and idiographic analysis are used in a reciprocal and cumulative manner, enhancing both conceptual development and clinical relevance. The use of meta-ethnography (Noblit & Hare, 1998) was particularly appropriate for generating interpretive understandings of identity across studies while IPA enabled a detailed examination of meaning-making within individuals accounts (Smith et al., 2022). Additionally, IPA has been extensively used in healthcare research to accurately capture and preserve the experiences of patients (Behel, 2024, Brocki & Wearden, 2006). Together these approaches align well withing the portfolio's critical realist and interpretive epistemological stance, supporting an account of identity that acknowledges both material realities of illness and the subjective meanings constructed in response. IPA does not aim for statistical generalisability but the importance of theoretical transferability when considering this patient

subgroup means the demographic specificity of the sample must still be considered (Smith & Nizza, 2021).

A further strength of the portfolio is the demonstration of methodological rigour and transparency across both the systematic review and the empirical paper. The systematic review employed structed screening, quality appraisal and reporting procedures, including the use of an independent second reviewer and established tools such as CASP (2018) and PRISMA checklist, enhancing the credibility and auditability of the synthesis. Similarly, the EP adhered to Yardley's (2015) principles of high-quality qualitative research and demonstrates features of strong IPA, including idiographic depth, interpretive engagement and the use of verbatim extracts to ground analytic claims (Smith et al., 2022). The integration of patient and public involvement (PPI) within the EP further strengthened the ethical and methodological integrity of the portfolio, ensuring sensitivity of language, relevance of research questions and accessibility of procedures for participants.

This portfolio is also strengthened by its clinical relevance and its representation of voices which are often unheard in psycho-oncological research. Both the systematic review and the empirical paper highlight the experiences of women who occupy a marginalised position within cancer discourse, often falling outside of the dominant narratives of survivorship or end of life care (Koczwara & Ward, 2015). By foregrounding identity as a central psychological concern, the portfolio moves beyond symptom-based models of distress to illuminate the ongoing psychological and relational work women undertake to maintain dignity, continuity of self and relational roles. This has clear implications for psycho-oncological and palliative care services, suggesting a need for psychologically informed approaches and training that attend to identity, meaning making and relational context.

However, the portfolio is also characterised by several limitations which reflect both methodological constraints and broader structural issues within the literature. In terms of the systematic review, despite comprehensive database searches (CINAHL Plus, APA PsycINFO, MEDLINE and SocINDEX) and hand searching procedures, the available body of qualitative literature exploring identity in women with advanced cancer was limited. This scarcity constrained the synthesis and reflects a wider tendency to exclude advanced cancer from research. Additionally, this scarcity of research may reflect a wider research tendency to prioritise symptom burden and psychological outcomes over experiential and identity-based processes (King et al., 2024). Furthermore, the studies included in the review were drawn from a heterogeneous range of cultural and healthcare contexts, with uneven geographical representation. While this diversity enhances transferability, it limits the ability to draw context specific conclusions, as identity is shaped by culturally situated norms, healthcare systems and social expectations (Helman, 2007; Kagawa-Singer & Blackhall, 2001).

The empirical paper also presents limitations relating to sampling and inclusivity. The requirement for participants to be fluent in English may have excluded individuals from diverse linguistic, and cultural backgrounds, potentially limiting the representation of minority experiences (Willig, 2013). Recruitment via online platforms and charitable networks may have also resulted in a sample who are more socially connected or able to engage in research, potentially underrepresenting those who are more socially isolated or who do not have access to such systems. While the idiographic focus and relatively small heterogeneous sample are consistent with IPA methodology, these factors limit the transferability of the findings beyond the specific group represented. Furthermore, across both studies, the issue of representation and voice require consideration. Within the empirical paper, practical constraints such as variability in participant's verbal expressiveness meant that some accounts were more prominently represented than others. This is a recognised tension within qualitative research between idiographic depth and representational balance (Braun & Clarke, 2013; Smith et al., 2022). Similarly in the systematic review, the synthesis necessarily

privileged commonalties across studies which may obscure culturally specific or divergent identity experiences. It was also weighted toward studies from Western cultures, resulting in this perhaps being the prominent voice heard within the synthesis.

This portfolio also raises important ethical and relational considerations, particularly regarding power dynamics inherent in qualitative research with individuals living with life-limiting illness. It is acknowledged that power imbalance is somewhat unavoidable in qualitative research (Aluwihare-Samaranayake., 2012) and while the empirical paper incorporated PPI informed procedures (more detail in Chapter 6: Extended Methodology and Additional Information) alongside flexible interviewing practices and clear ethical boundaries, the asymmetry between researcher and participant cannot be fully resolved. Additionally, the sample reflected women who were motivated and well enough to participate and who were already connected to MBC networks. Women at more advanced stages of the disease and those less able to access digital or charity support systems may be underrepresented. Digital recruitment, whilst efficient and widely adopted in research may risk excluding vulnerable women (Gelinas et al., 2017) limiting the scope of the identity processes captured. The experiences of these women, including potentially more intense identity disruption or healthcare barriers may differ from findings captured in this study and is unlikely to have been captured. Reflexive engagement throughout the research process was therefore essential in acknowledging how the researcher's professional identity, gender and life experiences shaped both data collection and interpretation. This reflexive stance enhances the credibility of the portfolio while recognising the challenges common with the interpretive and situated nature of qualitative knowledge production (Dodgson, 2019; Finlay, 2017; Roulston, 2010).

A further limitation which requires careful thought relates to the gendered focus of this portfolio. While this focus was theoretically and clinically justified (Ginsberg et al., 2023) it necessarily excludes the experiences of men and non-binary individuals living with advanced cancer. In addition, the use of a 'woman only' framework risks reinforcing binary understandings of gender

and may not capture the experiences of trans or non-binary individuals affected by breast or gynaecological cancers. This was not the position of the author. This portfolio was intended to carefully consider that gendered social structures shape the conditions under which identity work occurs. In other words, this portfolio does not claim that men or non-binary individuals do not experience identity disruption in advance cancer, instead it argues that women's identity labour may be intensified or patterned in particular ways due to gendered expectations. Furthermore, focusing on women as a single category may obscure important intersectional differences related to ethnicity, socioeconomic status, sexuality, disability and age. Although the portfolio acknowledges these issues, the extent to which such diversity is represented within the included studies and empirical sample is limited.

Despite these limitations, the portfolio offers a coherent and clinically meaningful contribution to the field. By integrating conceptual synthesis with lived experiences, it advances understanding of identity as a dynamic, relational and morally situated process within advanced cancer.

Clinical and Service Level Implications

The findings of this portfolio have important implications for clinical psychology practice, particularly within psycho-oncology and palliative care settings. The emphasis on identity highlights the limitations of approaches which focus solely on symptom reduction or distress screening. While such interventions and monitoring are important, they may overlook the deeper identity-related challenges women face when living with advanced cancer. Clinically the findings suggest a need for psychologically informed care that attends to identity, dignity and supports agency for women. This could include creating space for women to articulate who they are beyond their diagnosis, acknowledging the emotional labour involved in maintaining normality and validating experiences that do not align with the dominant narratives surrounding cancer such as positivity or survivorship.

When working with this population, using interventions which support narrative reconstruction and relational identity may be particularly valuable.

At a service level, the findings point to the importance of training healthcare professionals at all levels to recognise the relational and moral dimension of identity work. Communication that acknowledges uncertainty, avoids reductive labels and supports narrative meaning making may help mitigate feelings of invisibility and marginalisation. Clinical psychologists are well positioned to contribute to this work through formulation, consultation and staff training or support. However the current reality of psychological provision in oncology services in the UK is patchy. A mapping report of London psycho-oncology services in 2020 revealed significant gaps in provision in London alone (Pan-London Mapping, 2020). This extends into the third sector where community mental health services were also recommended to develop clearer pathways for oncology patients (Pan-London Mapping, 2020). Therefore, if one of the best served areas of the country (London) has significant gaps in psycho-oncology provision, it is fair to assume there will be gaps in services, training and wider community mental health provision across the country which means that for many women living with advanced cancer, the psychological support they have access to is limited.

Conclusion and Directions for Future Research

The findings of this portfolio highlight a number of important directions for future research which extend both the conceptual and clinical understanding of identity in the context of advanced cancer. While the present work contributes and initial synthesis and in-depth exploration, it also underscores the scarcity of existing research and underscores the need for further research which is more diverse, longitudinal and contextually situated.

A key priority for future research is to expand the diversity and inclusivity of participants represented within this field. The current portfolio, alongside the wider literature identified in the

systematic review, reflets a predominance of participants who are White, English- speaking and engaged with healthcare or charitable networks. Future studies should aim to include women from a broader range of ethnic, cultural and socio-economic backgrounds, as well as individuals with differing levels of health literacy and access to care. Such work would allow for a more nuanced understanding of how identity processes are shaped by intersectional factor in the context of advanced cancer. In addition, there is a clear need for research which explicitly includes trans and non-binary individuals affected by breast and gynaecological cancers whose experiences of identity may be shaped by additional layers of gendered embodiment, marginalisation and healthcare inequity.

Longitudinal qualitative research is a further direction for future exploration. Both papers in this portfolio indicate that identity is dynamic and fluid, shaped by treatment cycles, prognostic changes and shifting relational contexts. However, most existing studies, including the empirical paper within this portfolio, capture experiences at a single time points. Longitudinal qualitative research which followed women throughout their illness would enable exploration of how identity is negotiated across different phases of illness. Such work could illuminate how identity reconstruction unfolds over time and identify critical points where psychological support may be most beneficial.

Future research may also consider the relational nature of identity from the findings of this portfolio and look at systemic understandings of how advanced cancer and identity changes are experienced by those who surround an individual. By exploring this alongside consideration of more culturally situated research, greater understanding could be gained around the culturally and relationally situated nature of identity and how this is shaped and experienced by women, their families and the impact upon this of differing societal expectations of gender, family roles, illness and death. Furthermore, comparative studies across healthcare systems may further illuminate how organisational practices and discourses influence across healthcare systems.

Methodologically there is scope to extend beyond interview-based approaches. Methods which are more creative or participatory including visual methods, narrative diaries or digital story telling may allow participants to express aspects of identity which are difficult to articulate verbally. This would also open up opportunities to individuals experiencing fatigue or cognitive changes associated with advanced cancer, to participate. Participatory approaches may invite more coproduction within research and help to address traditional power imbalances, ensuring future studies are grounded in priorities shaped by those with lived experience.

In summary, future research should aim to build on the foundations of this portfolio by expanding inclusivity, adopting longitudinal and culturally situated designs and developing participatory methodologies. Through such work the field can move towards a more comprehensive and equitable understanding of women's identity in advanced cancer, with direct relevance for improving psychological care, support, training and services.

Chapter Six

Extended Methodology and Additional Information

Word Count (Including Tables): 2181

Chapter Six: Extended Methodology and Additional Information

This chapter provides an extended methodological account of the qualitative approach underpinning the empirical study within this thesis portfolio. Journal limits (8000 words, Journal of Health Psychology) restrict the extent to which methodological detail may be presented within the empirical paper itself, this chapter therefore, offers a more reflective and theoretically informed discussion of the epistemological positioning of the researcher, analytic approach and processes to enhance transparency and support the credibility of the findings. Ethical considerations specific to conducting qualitative research as well as considerations specific to this patient group are also discussed. This chapter aims to demonstrate coherence between the research questions, methodological choices and analytic claims made within the empirical paper, enhancing understanding of how lived experience was carefully explored in the context of advanced cancer within this thesis portfolio.

Ontological and Epistemological Positioning

Qualitative research is underpinned by assumptions about the nature of reality (ontology) and the nature of knowledge (epistemology)(Braun & Clarke., 2013). This portfolio is situated within a critical realism ontological position, alongside an interpretative epistemological stance which together align with the principles of IPA.

As outlined in Chapter Four: Empirical Research Study, from an ontological perspective Critical Realism assumes that a reality exists independently of human perception, while recognising that this reality cannot be accessed directly (Braun & Clarke., 2013).

Constructionism, on which critical realism is based, sits on a proposed continuum of reality somewhere between realism and relativism and posits that individuals' experiences of reality are mediated through biological, psychological, social and cultural processes. Epistemologically, Critical Realism also sits in between positivism and constructionism (Braun & Clarke, 2013). In the context of metastatic breast cancer (MBC), this position acknowledges that physical changes, illness progression and mortality are real phenomena with tangible consequences yet also considers that individual's experiences of these phenomena are shaped by their own unique personal history, contexts and broader social and cultural narratives.

Epistemologically, this portfolio adopts an interpretative position that knowledge is not simply discovered but is instead constructed through processes of meaning-making. Participant's accounts in this empirical paper are considered active interpretations of their lived experience. Similarly, the lead researcher's engagement with the data is acknowledged to be an interpretative act shaped by their prior knowledge and experience. This combined ontological and epistemological positing aligns closely with IPA's emphasis on the double hermeneutic (Smith et al., 2022; Braun & Clarke., 2013). Participants experiences are explored by the researcher who attempts to make sense of the participants sense making through interpretative analysis thus allowing a nuanced exploration of lived experience whilst maintaining epistemological humility regarding the limits of interpretation.

Furthermore, by adopting a critical realist position the study avoids extremes of positivism and relativism. The research does not assume that participants accounts provide direct access to objective truth, nor does it suggest all interpretations are equally valid.

Interpretations are instead grounded in close engagements with the participants accounts supported by careful reflexive awareness of the part of the lead researcher alongside psychological theory. Overall, the framework provided by a critical realism ontological and interpretative epistemological stance provides a strong foundation for exploring both the tangible realties of illness and the subjective meanings individual draw from their experience, which is central to the aims of this thesis portfolio.

Reflection on PPI

The sensitive nature of the subject matter of this thesis portfolio was taken very seriously by the lead researcher. At every possible stage Patient Participant Involvement (PPI) was used to inform the direction of research, development of research questions, interview preparation, interview questions, all research paperwork which would be used to communicate to participants, all questionnaires developed for demographic data collection and research poster design. The inclusion of PPI in the development of research is being increasingly recognised as key to developing thorough and meaningful research (Boylan et al., 2019) yet is still found in cross-sectional analysis of health care literature to be present in only 44.5% of UK studies and 20.6% research papers globally (Lang et al., 2022). It felt important for the lead researcher to consult with patients with lived experience for this project due to the difficult and sensitive nature of the topic but particularly given the nature of diagnosis as life limiting and the exclusion of these women from other breast cancer research. The research team included two clinicians who had extensive combined experience of working with this patient group, and so an understanding was held in commencement of this research about how emotive the subject matter may be for both participant and researchers.

It was understood from early stages of research development that MBC and identity would bring up topics such death, surgery, treatment, traumatic incidents such as treatment failure or physically or emotionally painful experiences related to this. A focus group was formed using social media to recruit via national charity sites. It is understood by the lead researcher that this was shared more widely via group chats and Facebook pages so two focus groups were held online, each with four PPI volunteers. Volunteers were offered payment of £25.00 for their time in line with PPI renumeration guidelines (NIHR, 2020) though all declined to accept, expressing wishes to support and encourage any and all research into MBC they could, through giving their time freely. These individuals were asked to review documents, offering their thoughts on wording, sensitivity of language and terminology and appropriateness of study procedures. Feedback was all noted and changes made in accordance with PPI input. Some specific changes made included a strong feeling by groups that the terminology 'cancer journey' was disliked by the MBC population subgroup as it implies something they have undertaken out of choice, or that there is a pleasant ending awaiting them on completion of the 'cancer journey'. PPI focus groups were also key in guiding the wording of interview questions around mortality and death. The lead researcher was aware of the potential to add unnecessary trauma or emotional burden during interviews to participants and so focus groups guided the phrasing of this specific question in its entirety. Originally the question proposed by researchers was

"How does discussion of death or dying impact you since your diagnosis of MBC?"

Focus groups recommended avoiding any specific mention of mortality, settling on the use of the word future to indicate the direction of open questioning, allowing for the researcher to facilitate the participant to open up about mortality if they wished or felt bale to do so without it being unduly triggering for them. The question was changed to

How has thinking about your future changed or impacted on your sense of self (identity)?

This offers one example of the crucial part PPI played in the research design. The research team was comprised of a trainee clinical psychologist and two qualified Clinical Psychologists. The nature of whose jobs and training is to not avoid difficult subject matter and to name or encourage service users to name difficulties. However, in research, the role adopted by the researcher is not one of a psychologist, therefore due care must be given to protect the participants from additional burden or distress. Despite not including any reference to death in the phrasing of this question, all women went on to speak about it directly when asked about the future suggesting that for some women this question gave them permission to speak about their own death in a way they may not have been able to before.

Following PPI input reasonable adjustments were also made for the interview process. To allow ease of access for participants who may be physically unable to attend interviews due to MBC, interviews were all conducted online. Breaks and freedom to pause and move around were regularly offered to participants. Consideration and flexibility were also given with regards to medication or treatment effects, with interviews being rescheduled when needed or longer breaks splitting up the interview offered. Participants were also reminded they could withdraw at any point during the interview; no participant withdrew from the study.

Analysis

The analysis process followed the steps outlined by Smith et al., (2009) for IPA. The lead author transcribed each interview verbatim after it had been sent to the participants to check accuracy. At this stage data was anonymised and participants referred to by their Participant Identification Number, of which they were aware. All identifiable information was removed or changed where this impacted the recounted experience. The researcher engaged reflexively with the data and an outline of the steps followed is summarised below.

Initial reading, rereading and exploratory notes.

All interviews were transcribed verbatim by the lead researcher to support close familiarisation with the data. Transcript were anonymised at this stage and checked against the audio recordings for accuracy. Transcripts were also sent to participants to check for accuracy at this stage, participants were under no obligation to comment or return them, and were informed if not returned within 7 days, it would be assumed they were satisfied with the transcription. Engagement with the data continued through repeated re-reading and listening alongside listening to the audio recording to retain attention to tone, emotion and emphasis within the participants accounts. This initial stage of analysis also included exploratory commenting by the lead researcher which included initial thoughts on descriptive, linguistic and conceptual notes recorded in the margin of each transcript. Descriptive comments focused on the content of participants accounts and key experiential features. Linguistic comments were centred on language use, metaphors, pauses and emotional expressions. Conceptual comments involved more interpretive reflections drawing on psychological theory and the researchers developing understanding of the account of the participant in relation to identity and advanced cancer.

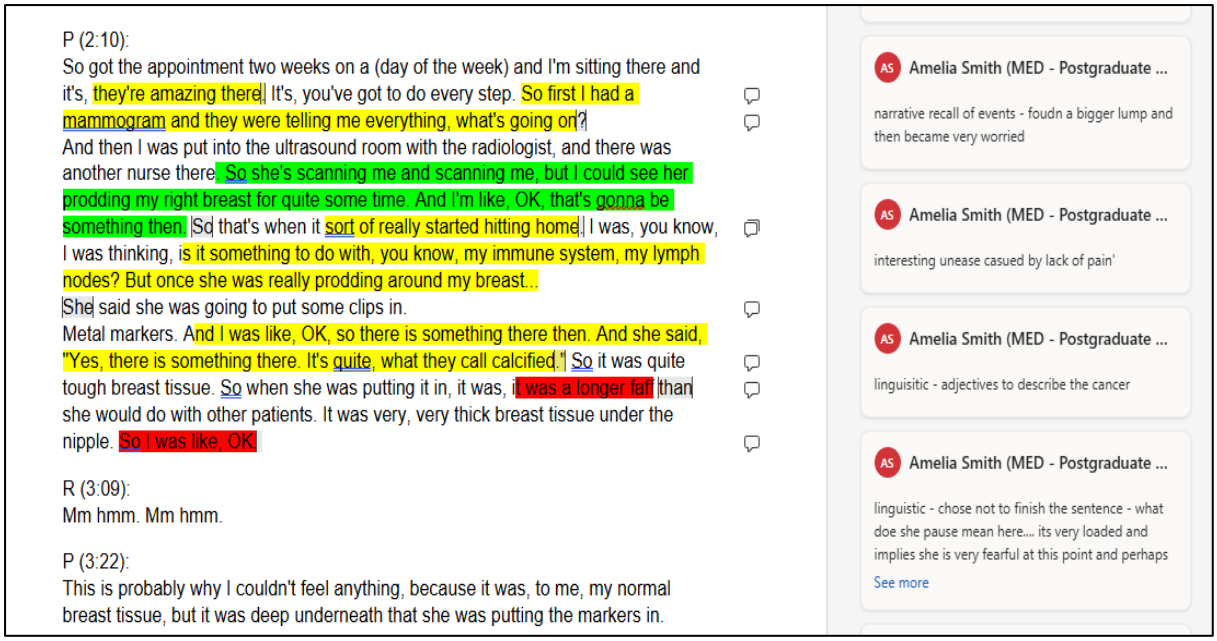


Figure 1 *Shows an extract from transcript (Holly) at exploratory notes stage.*

From these detailed notes, emergent themes were developed for each transcript individually. These themes aimed to capture essential aspects of the participants meaning making while remaining grounded in the data. Themes were expressed at a slightly higher level of abstraction that the original text, reflecting the interpretive nature of IPA. Following the development of emergent themes within each participant's account, the researcher engaged in a process of mapping connections across themes within accounts, clustering themes together and developing superordinate themes for each participant. Techniques such as abstraction, subsumption and polarisation were used to explore relationships between themes, including points of convergence and divergence within each individual transcript.

Superordinate Theme	Subtheme	Verbatim Quote
Friendships and Social Life	Support and adjustment	They've helped me go... Oh, what would it take to? What do you need?
Physical Changes	Loss of strength and mobility	To lose that strength and to lose independence... is yeah.
Disability Identity	Navigating aids and acceptance	You can live so much more richly using them.
Healthcare Experience	Treatment burden and scheduling	That week I've actually got eight hospital appointments across 5 days.
Healthcare Experience	Need for professional understanding	Even things like radiotherapy... it's still going to hit me like a brick.
Future Orientation	Living in short cycles	I've got used to now living in three-month cycles.
Future Orientation	Acceptance and planning	I've sorted out my funeral plan... whatever happens from here.

Table 1 *shows an extract of individual transcript theme development table (Danny).*

Once idiographic analysis had been performed for each participant, a cross-case analysis was conducted to identify patterns across participants while preserving attention to

individual variation. Superordinate themes were compared across cases and organised into a final structure which represented shared experiential processes alongside areas of nuance and difference. Throughout this process, care was taken to ensure that each case was given equal analytic attention.

Superordinate Theme	**Subtheme**	**Participant Pseudonym**	**Verbatim Quotes**
Future Orientation	Imagining life after death	Holly	"I do play out my family without me all the time in the kitchen."
Future Orientation	Living in short-term plans	Isla	"We try to live our life kind of in three month plans which works better than, you know, making long term plans."
Future Orientation	Urgency and uncertainty	Bella	"I feel like I've got to do everything in case I don't get the chance again... It's not comparable to anybody else possibly being hit by that bus one day."
Future avoidance	Theme related to other themes – future avoidance.	Mia	"I rarely think about the future... it's a sort of the future gets more painful to look at.""

Future Outlook	Living with Uncertainty	Kelly	"It's like you've got a time bomb... one day those scans will turn up and be... the bad news."
Future Outlook	Pressure to Create Memories	Kelly	"I feel a lot of pressure... I've got to keep going and keep doing this and make these memories while I can."
Future Outlook	Uncertainty and Planning	Jackie	"If you knew you had two years left, would you bother? But if you've got 10 years left to live... it's important to get some independence back."
Future Orientation	Living with Uncertainty	Claire	It's the unknown more than anything... I just don't know what's going to happen.
Future	Theme related to other themes – uncertainty and fear.	Mia	"You don't know how long you've got left."

Table 2 *shows an extract from the table used to conduct cross-case analysis and begin to group similar themes together.*

To support credibility and rigour, the analytic process involved ongoing discussion with research supervisor at regular supervisory meetings. Supervisors reviewed transcripts, coding and theme development. These discussions functioned as a form of analytic triangulation, supporting reflexive thinking, challenging ideas and refining interpretations. The researcher also kept a reflexive journal throughout the analytic process.

The analysis revealed a wealth of information which due to the nature of Journal word limits had to be carefully selected for inclusion in the final empirical paper. The Master Table of Themes is available for review in the appendix of this portfolio (Appendix J)

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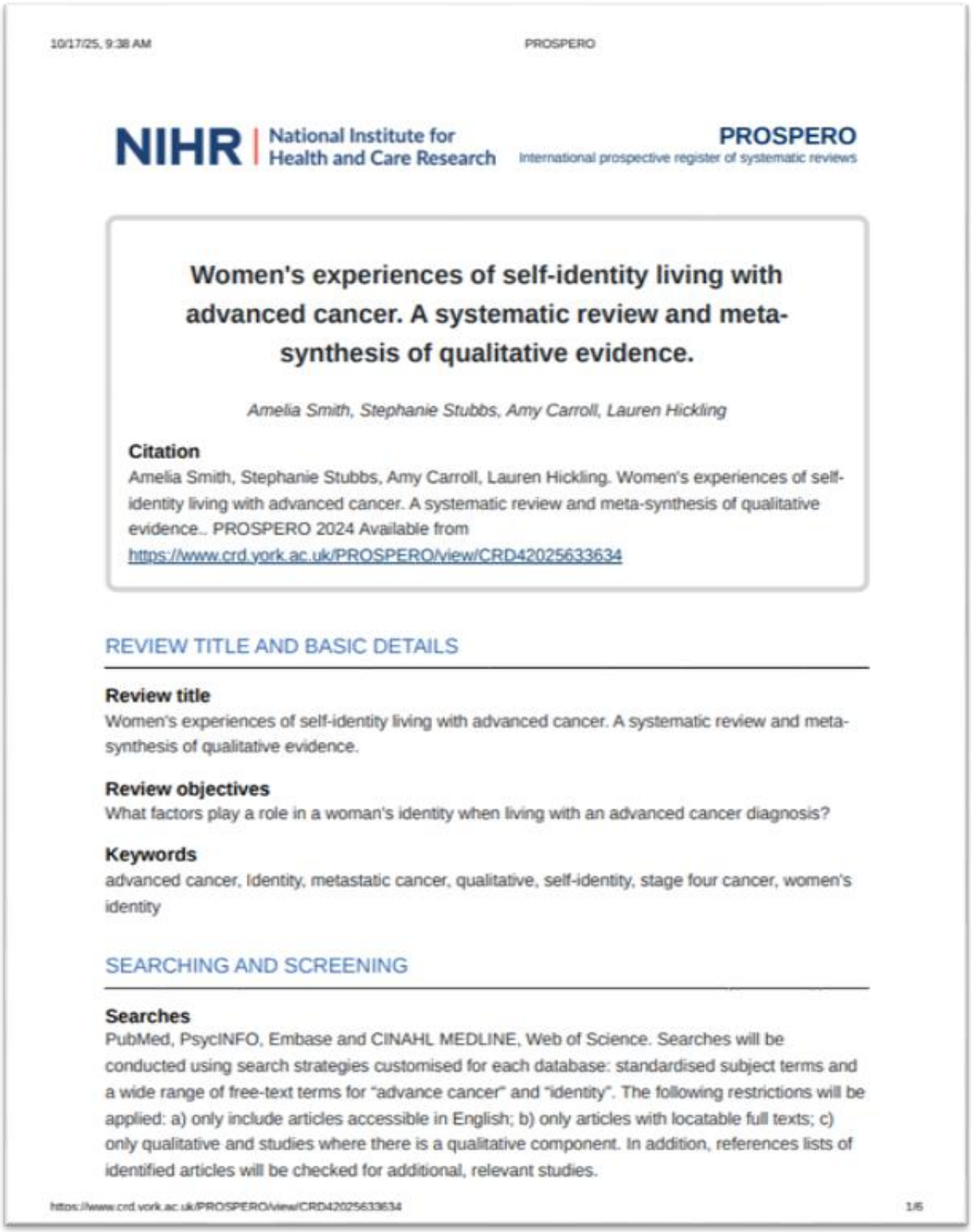
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Appendices

Appendix A: Prospero Registration of Systematic Review



10/17/25, 9:38 AM PROSPERO

NIHR | National Institute for Health and Care Research

PROSPERO
International prospective register of systematic reviews

Women's experiences of self-identity living with advanced cancer. A systematic review and meta-synthesis of qualitative evidence.

Amelia Smith, Stephanie Stubbs, Amy Carroll, Lauren Hickling

Citation
Amelia Smith, Stephanie Stubbs, Amy Carroll, Lauren Hickling. Women's experiences of self-identity living with advanced cancer. A systematic review and meta-synthesis of qualitative evidence.. PROSPERO 2024 Available from https://www.crd.york.ac.uk/PROSPERO/view/CRD42025633634

REVIEW TITLE AND BASIC DETAILS

Review title
Women's experiences of self-identity living with advanced cancer. A systematic review and meta-synthesis of qualitative evidence.

Review objectives
What factors play a role in a woman's identity when living with an advanced cancer diagnosis?

Keywords
advanced cancer, Identity, metastatic cancer, qualitative, self-identity, stage four cancer, women's identity

SEARCHING AND SCREENING

Searches
PubMed, PsycINFO, Embase and CINAHL MEDLINE, Web of Science. Searches will be conducted using search strategies customised for each database: standardised subject terms and a wide range of free-text terms for "advance cancer" and "identity". The following restrictions will be applied: a) only include articles accessible in English; b) only articles with locatable full texts; c) only qualitative and studies where there is a qualitative component. In addition, references lists of identified articles will be checked for additional, relevant studies.

https://www.crd.york.ac.uk/PROSPERO/view/CRD42025633634 1/6

Appendix B: CASP Qualitative Checklist which was adapted into a table for ease of reporting. (see Table 2)

Section A Are the results valid?	
1. Was there a clear statement of the aims of the research?	Yes No Can't Tell
CONSIDER: • *what was the goal of the research?* • *why was it thought important?* • *its relevance*	
2. Is a qualitative methodology appropriate?	Yes No Can't Tell
CONSIDER: • *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants* • *Is qualitative research the right methodology for addressing the research goal?*	
3. Was the research design appropriate to address the aims of the research?	Yes No Can't Tell
CONSIDER: • *if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)*	
4. Was the recruitment strategy appropriate to the aims of the research?	Yes No Can't Tell

CONSIDER: • *If the researcher has explained how the participants were selected* • *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study* • *If there are any discussions around recruitment (e.g. why some people chose not to take part)*	
5. Was the data collected in a way that addressed the research issue?	Yes No Can't Tell
CONSIDER: • *If the setting for the data collection was justified* • *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)* • *If the researcher has justified the methods chosen* • *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)* • *If methods were modified during the study. If so, has the researcher explained how and why* • *If the form of data is clear (e.g. tape recordings, video material, notes etc.)* • *If the researcher has discussed saturation of data*	
6. Has the relationship between researcher and participants been adequately considered?	Yes No Can't Tell
CONSIDER: • *If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location* • *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*	

Section B: What are the results?	
7. Have ethical issues been taken into consideration?	Yes No Can't Tell
CONSIDER: • *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained* • *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)* • *If approval has been sought from the ethics committee*	
8. Was the data analysis sufficiently rigorous?	Yes No Can't Tell
CONSIDER: • *If there is an in-depth description of the analysis process* • *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data* • *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process* • *If sufficient data are presented to support the findings* • *To what extent contradictory data are taken into account* • *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*	
9. Is there a clear statement of findings?	Yes No Can't Tell
CONSIDER: • *If the findings are explicit*	

- *If there is adequate discussion of the evidence both for and against the researcher's arguments*
- *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)*
- *If the findings are discussed in relation to the original research question*

Section C: Will the results help locally?

10. How valuable is the research?	Yes No Can't Tell

CONSIDER:

- *If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature*
- *If they identify new areas where research is necessary*
- *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*

APPRAISAL SUMMARY: *List key points from your critical appraisal that need to be considered when assessing the validity of the results and their usefulness in decision-making.*

Positive/Methodologically sound	**Negative/Relatively poor methodology**	**Unknowns**

Appendix C: Definitions of Meta-Ethnography Constructs (Atkins et al., 2008)

Table 4 Definitions

From: Conducting a meta-ethnography of qualitative literature: Lessons learnt

Term	Definition
1st order construct	Constructs that reflect participants' understandings, as reported in the included studies (usually found in the results section of an article).
2nd order construct	Interpretations of participants' understandings made by authors of these studies (and usually found in the discussion and conclusion section of an article).
3rd order construct	The synthesis of both first and second order constructs into a new model or theory about a phenomenon
Reciprocal translation	The comparison of themes across papers and an attempt to "match" themes from one paper with themes from another, ensuring that a key theme captures similar themes from different papers
Line of argument synthesis	The development of a new model, theory or understanding by synthesising and interpreting first and second order themes found in the text.

Appendix D: Summary of and Link to Journal of Health Psychology Author Guidelines

Link:

https://journals.sagepub.com/author-instructions/hpqournals

Article types

(a) Full-length Reports on empirical studies. The word limit including the reference list and tables/figures for this article type is a maximum of 8,000 words.

(b) Rapid Reports on empirical studies. The word limit including the reference list and tables/figures for this article type is a maximum of 4,000 words.

(c) Review Articles including systematic reviews, narrative reviews, and theoretical contributions. The word limit including the reference list and tables/figures for this article type is a maximum of 8,000 words.

Reference style and citations

The journal follows the Sage Harvard reference style. View the Sage Harvard guidelines to ensure your manuscript conforms.

Every in-text citation must have a corresponding citation in the reference list and vice versa. Corresponding citations must have identical spelling and year.

Appendix E: Recruitment Poster

University of East Anglia

Research Opportunity

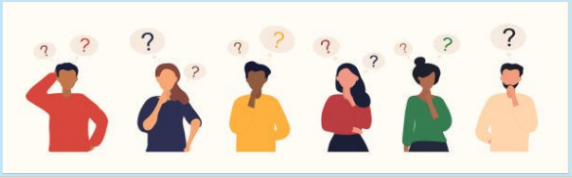
Exploring Women's Experiences of Identity When Living with Metastatic Breast Cancer

We are looking for women who have a diagnosis of metastatic breast cancer. We are conducting research which aims to increase understanding of what it is like for women to be diagnosed with and live with the experience of metastatic breast cancer and any impact this may have on your sense of identity.

There is currently very little research which acknowledges the experience of metastatic breast cancer, and we would like to hear from you about your experiences. The research would involve you taking part in an online interview via Microsoft Teams. You will be asked questions about your thoughts, feelings and experiences related to metastatic breast cancer. The interview is estimated to last up to 1 hour.

If you are interested in knowing more, please email Amelia Smith, the lead investigator on a.smith29@uea.ac.uk, **or scan the QR code below.**

Supervised by Dr Amy Carroll, Clinical Associate Professor (UEA) and Dr Lauren Hickling, Clinical Psychologist(NNUH).



Appendix F: Online Consent Form

Consent Form

Exploring women's experiences of identity when living with a diagnosis of metastatic breast cancer.
Name of investigators: Amelia Smith (Trainee Clinical Psychologist), Dr Amy Carroll (Clinical Psychologist and Clinical Associate Professor) and Dr Lauren Hickling (Clinical Psychologist)

10. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. Please sign name in box to confirm. *

11. I understand and consent for my interview to be audio recorded. Please sign name in box to confirm. *

12. I understand that my data will be stored and handled according to the UK Data Protection Act and the General Data Protection Regulation. Please sign name in box to confirm. *

13. I understand that my participation is voluntary and that I am free to withdraw at any time (up until the data analysis of the study) without giving any reason, none of my rights will be affected. Please sign name in box to confirm *

14. Once the study is complete, I would like a summary of the results to be emailed to me at: *

15. I agree to take part in the above study *

- ◯ Yes
- ◯ No

Appendix G: Online Demographic Questionnaire

Additional Information

18. As a token of appreciation for your participation, we would like to offer you a £10 Amazon voucher. This will be sent to you via email. Please provide an email address (if this is the same as above then please leave blank)

19. Please enter below your age bracket.
(18-25) (26-34) (35-44) (45-54) (55-64) (65-74) (75 and over) *

20. Job role/ Previous role if not currently working *

21. Length of time since diagnosis. *

22. Are you currently undergoing treatment and what type of treatment? (Hormonal, Chemotherapy etc) *

23. Have you received any mental health support since diagnosis and what was the nature of this support (counselling/support group/helpline/sessions with a Clinical Psychologist)? *

24. Do you have any existing mental health conditions and when this condition was diagnosed (prior or post diagnosis)? *

Appendix H: Semi-Structured Interview Questions (Including Prompts)

Introductions and reminder that they are free to stop or leave the interview at any time. Make clear to participants that if there are any accommodations such as regular breaks they may need to support them to take part, we will support them with this.

Prompts will be used throughout the interview to encourage the participant to expand or explore further areas of interest to the researcher. Examples of these may be "can you tell me more about that?" "How did that feel for you?".

Could you tell me about your initial diagnosis and your experience of this?

If they don't mention it go on to ask about any treatments

How have you found any treatments you have undergone?

Can you tell me about any ongoing treatments you are undertaking and how those impact on your day to day life?

How would you say cancer has impacted on you?

T*o ask if not covered in the above questions answer*

How has living with this diagnosis impacted on your relationships with family and friends?

Has your diagnosis and living with this affected how you see yourself?

Prompts;

-family roles

-employment

-physical changes

Are there any aspects of how metastatic breast cancer has impacted your identity that are less well understood by others/professionals?

How has thinking about your future changed or impacted on your sense of self (identity)?

Anything I haven't asked you, that you feel is important for me to know about living with MBC?

Thank participant and end recording. Offer participant chance to ask any questions and send debrief sheet via email.

End of interview

Appendix I: Ethical Approval FMH Ethics Board

EM

EthicsMonitor<no-reply@ethicsreview.uea.ac.uk>

To: Amelia Smith (MED - Postgraduate Researcher)

University of East Anglia

Study title: Exploring experiences and identity with women living with a diagnosis of metastatic breast cancer.

Application ID: ETH2425-0258

Dear Amelia,

Your application was considered on 9th December 2024 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

The decision is: **approved**.

You are therefore able to start your project subject to any other necessary approvals being given.

If your study involves NHS staff and facilities, you will require Health Research Authority (HRA) governance approval before you can start this project (even though you did not require NHS-REC ethics approval). Please consult the HRA webpage about the application required, which is submitted through the IRAS system.

This approval will expire on **1st July 2026**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.

Appendix J: Master Table of Themes from Empirical Paper (IPA)

Superordinate Theme	**Subtheme**	**Interviews**	**Verbatim Quotes**
Initial Diagnosis and Emotional Impact	Shock and disbelief	Interview 1, Interview 2	Interview 1: ““They can't come in with you, [name], because you've got cancer. And that was it. And I thought I was going to... I went into shock and I instantly I couldn't talk.”” Interview 2: “I was convinced it would just turn out to be a cyst or something... I just wouldn't have dreamt in a million years that it would be cancer.”
Initial Diagnosis and Emotional Impact	Guilt and comparison	Interview 1	Interview 1: ““I was upset that I was even thinking of myself when there were other people with cancer holding me back.””
Initial Diagnosis Experience	Shock and Emotional Numbness	Interview 3	It was just a shock... it almost felt empty. You know, I didn't know what to do with myself.
Initial Diagnosis Experience	Shock and rapid escalation	Interview 4	I went from finding a lump in the shower to potentially having metastatic breast cancer within a week, and I wasn't prepared.

Initial Emotional Impact	Shock and disbelief at diagnosis	Interview 5	Felt like being hit by bus is what I would say, so it came as a huge shock to me...
Initial Diagnosis Experience	Dismissal and delay in diagnosis	Interview 7 *Linguistic*	I went to the GP, said, 'I'm absolutely exhausted... your bloods look all right, yadda yadda yadda.'
Initial Diagnosis Experience	Shock and anger at communication	Interview 7	She said, 'you've got cancer in your liver, chest and bones.' I was absolutely gobsmacked... I was furious.
Identity and Self-Perception	Loss of identity	Interview 1	Interview 1: ""I went from all of those things to a cancer patient... I didn't see myself in the mirror.""
Identity and Self-Perception	Reclaiming identity	Interview 1	Interview 1: ""I see like I can just go on the Internet and then my bald head with lots of makeup on will crop up... I'm only just finding my identity again now.""
Identity and Self-Perception	Guilt and loss of independence	Interview 2	Interview 2: "I feel useless... I haven't got the energy to make a cup of coffee or the pain is so bad that I can't put my own socks and shoes on."
Identity and Self-Perception	Striving to maintain normalcy	Interview 9	Interview 9: "I don't want to be a victim, so I try to still look at myself like, you

			know, in a in a good way.”
Identity and Role Disruption	Loss of professional identity	Interview 8	Interview 8: “Losing a job is horrendous, but losing a career… I knew I couldn’t go back.”
Identity and Role Disruption	Shift in family roles	Interview 8	Interview 8: “I was the primary caregiver… now Daddy, Daddy, Daddy, can you help me with this?”
Identity and Role Disruption	Grieving former self	Interview 8	Interview 8: “They live with grief every day because they're grieving their old personality.”
Roles	Impact on Parenting	Interview 11	Interview 11: “I can't do all the school runs... I want to do stuff with her and I want to go camping... I don't know if I'll manage it.”
Loss and Adjustment of Professional Identity	Stepping down from partnership	Interview 10	Interview 10: “I've really struggled with that and losing that part of my identity because I love my job and I love my work.”
Restricted Physical Identity	Loss of fitness and appearance	Interview 10	Interview 10: “I remember looking at myself in the mirror, thinking I feel like shit... and I look hideous.”
Roles	Motherhood and Guilt	Interview 12	Interview 12: “My main focus is my

			child... that's the hardest part of it all... that's what keeps me up at night.”
Roles	Partner and Family Dynamics	Interview 12	Interview 12: “My husband does have a lot of stress on his shoulders... he does do a lot of parenting and been very involved.”
Self-Identity	Changes in Appearance and Confidence	Interview 11	Interview 11: “My hair is so thin and thinning and grey... I don't know what clothes in me anymore.”
Professional Identity	Reduced Confidence at Work	Interview 3	You lose a bit of confidence... maybe not as outgoing sometimes as I should be.
Professional Identity	Loss of work role	Interview 4	You lose your identity professionally and your value.
Identity and Role	Maintaining self despite illness	Interview 7	No, I think I’m me... I’ve had it for a year and I’m fine.
Disrupted Expectations of Motherhood Identity	Diagnosis during pregnancy	Interview 10	Interview 10: “It was pretty awful to then be thinking I'm pregnant... this isn't the instruction to motherhood that I thought it was going to be.”
Identity and Role	Selective disclosure and control	Interview 7	I’ve chosen who I’ve told... I didn’t want to

			worry people and I didn’t want any drama.
Self-Identity	Loss of Spark and Confidence	Interview 12	Interview 12: “I think I've lost like a bit of spark... I think a lot of people used to say I was really funny and I feel like I struggle a bit more to tap into that.”
Motherhood	Theme related to roles – motherhood.	Interview 13	Interview 13: ““She's only ever known me really with cancer.””
Self-Identity	Reinforcement of Values	Interview 12	Interview 12: “Family. Really. Like it's really the simple things... it's more been about experiences and time together.”
Changed sense of self	Theme related to self-identity – changed sense of self.	Interview 13	Interview 13: ““I still don't see myself as ill. It's really weird. I still don't see myself as ill.””
Altered perception of importance	Theme related to self-identity – altered perception of importance.	Interview 13	Interview 13: ““You just see things differently because people are just focused on their day-to-day... and you think it's just so not important.””
Loss of femininity	Theme related to self-identity – loss of femininity.	Interview 13	Interview 13: ““The things that make you feel feminine... are damaged 'cause you don't feel feminine.””

Changed physical appearance	Theme related to self-identity – changed physical appearance.	Interview 13	Interview 13: ““I still look in the mirror now and I think bloody hell, is that what I look like?””
Work identity	Theme related to roles – work identity.	Interview 13	Interview 13: ““I'm still working but part time.””
Future Orientation	Fear of death and its impact	Interview 8	Interview 8: “I don’t want (child’s name) to see me getting sicker and sicker… screaming out in pain.”
Future Orientation	Imagining life after death	Interview 8	Interview 8: “I do play out my family without me all the time in the kitchen.”
Future Orientation	Living in short-term plans	Interview 9	Interview 9: “We try to live our life kind of in three month plans which works better than, you know, making long term plans.”
Future Orientation	Urgency and uncertainty	Interview 2	Interview 2: “I feel like I've got to do everything in case I don't get the chance again... It's not comparable to anybody else possibly being hit by that bus one day.”
Future avoidance	Theme related to other themes – future avoidance.	Interview 13	Interview 13: ““I rarely think about the future... it's a sort of the future gets more painful to look at.””

Existential reflection	Theme related to self-identity – existential reflection.	Interview 13	Interview 13: ““It's like you've been shown a secret... where you can see things for what they really are.””
Future Outlook	Living with Uncertainty	Interview 11	Interview 11: “It's like you've got a time bomb... one day those scans will turn up and be... the bad news.”
Future Outlook	Pressure to Create Memories	Interview 11	Interview 11: “I feel a lot of pressure... I've got to keep going and keep doing this and make these memories while I can.”
Future Outlook	Uncertainty and Planning	Interview 12	Interview 12: “If you knew you had two years left, would you bother? But if you've got 10 years left to live... it's important to get some independence back.”
Future Outlook	Legacy and Memory	Interview 12	Interview 12: “I just want my kids to remember me... not just the actual memories, but who I was and what we had together.”
Future Orientation	Living with Uncertainty	Interview 3	It's the unknown more than anything... I just don't know what's going to happen.
Future	Theme related to other themes – uncertainty and fear.	Interview 13	Interview 13: ““You don't know how long you've got left.””

Future Orientation	Living in short cycles	Interview 4	I've got used to now living in three month cycles.
Future Orientation	Acceptance and planning	Interview 4	I've sorted out my funeral plan... whatever happens from here.
Future Orientation	Ambiguity and shifting perspectives	Interview 5	I can't really see into a future... But I feel I also feel like it will change maybe in another six months.
Future Orientation	Acceptance and perspective	Interview 6	I accept it, I think... I'm just getting on with life and living it to the full.
Future Orientation	Living in the moment	Interview 7	I am quite 'do it now'... I'm going to Japan on Monday.
Healthcare Experience	Feeling dismissed by professionals	Interview 9	Interview 9: "They still weren't paying much attention to me, so I had to call a nurse... and then from there is when I got diagnosed with secondary."
Healthcare Interactions	Poor Communication of Diagnosis	Interview 11	Interview 11: "She started talking about this, that and the other, and I was like, so has it, miss. And she's like, oh, did you not know?"
Healthcare Communication	Receiving Diagnosis Alone	Interview 3	Unfortunately, I'm was on my own at that point, and maybe I should have took someone.

Healthcare Interactions	Lack of Holistic Support	Interview 11	Interview 11: “There's no support there in that way... it's all about the medical.”
Healthcare Interactions	Feeling Unheard	Interview 12	Interview 12: “I felt very not heard and not taken very seriously, which is kind of a theme throughout all of the diagnosis really.”
Healthcare Interactions	Communication and Trust Issues	Interview 12	Interview 12: “It makes me not trust... because I've never been told about any lesions in my left hip... what else haven't you told me?”
Communication from healthcare professionals	Shock and poor communication	Interview 6	He just said, 'OK... We've had these results back. You've got metastatic cancer.' And I just went, 'What? No, it just can't be possible.'
Healthcare Understanding	Prognosis and chronic illness framing	Interview 6	Nobody had ever offered that... we really didn’t want a prognosis anyway, because... it’s like a chronic condition.
Emotional Toll and Coping	Acceptance and legacy	Interview 8	Interview 8: “I made a bear with my voice in it… I want my daughter to go and look back at that account and go my mum was making a difference.”

Impact on Intimacy and Femininity	Loss of sexual identity	Interview 8	Interview 8: “You lose your hair, you take away your femininity… you don’t feel sexy.”
Impact on Intimacy and Femininity	Guilt and humour as coping	Interview 8	Interview 8: “When I’m gone find someone… that will give you that because it’s been deprived.”
Systemic Gaps and Advocacy	Lack of resources for secondary cancer	Interview 8	Interview 8: “Everything is geared up for primary… Mummy doesn’t get better with secondary.”
Systemic Gaps and Advocacy	Desire to educate and support others	Interview 8	Interview 8: “Do I write a children’s book just so there’s something for secondary?”
Navigating Treatment	Managing long-term medication and side effects	Interview 9	Interview 9: “I've been on (drug name) which is chemotherapy for over three years. I imagine that has had some impact in in my body.”
Physical Limitations	Loss of flexibility and joint pain	Interview 9	Interview 9: “I couldn't even, like, open my legs. Well, if I turn my back hurts this and that. So that that was quite, quite tough.”
Emotional Toll of Monitoring	Anxiety around scan results	Interview 9	Interview 9: “The month after I usually have loads of anxiety and I've told my

			office, so now my line manager knows because I'm just not the same person that month.”
Coping Strategies	Avoiding information to manage anxiety	Interview 9	Interview 9: “I actually don't even know... should I not know because I'm just gonna get super paranoid every time I feel something.”
Fertility and Family Planning	Robbed of reproductive choices	Interview 10	Interview 10: “Again, I feel very robbed that the cancer is taking that away from me.”
Preserving Normalcy	Rejecting cancer as sole identity	Interview 10	Interview 10: “I'm not poor. I know I'm unwell... but I'm ultimately still (name).”
Emotional Experience	Shock and Panic at Diagnosis	Interview 11	Interview 11: “I was a bit taken aback by it... my first thoughts to her and how long have I got and you know, and panic.”
Emotional Experience	Anger and Frustration	Interview 12	Interview 12: “I felt very angry. I still feel very angry, to be honest... that's quite tricky because I think a lot of the anger is justified.”
Medical experience	Previous medical experience.	Interview 13	Interview 13: ““It was like, well, no, I beat that. I've done that.””

Treatment impact	Previous medical experience	Interview 13	Interview 13: ““I've had lots of treatment. Loads.””
Treatment Journey	Chemotherapy Side Effects and Fatigue	Interview 3	I was in hospital quite a lot of times with intravenous sepsis... it's draining. It's just draining.
Treatment Journey	Immunotherapy complications	Interview 4	It gave me a lot of hope... and then it tried to kill me.
Treatment Journey	Loss of independence	Interview 4	I came home on oxygen, I came home in a wheelchair.
Impact on Family and Relationships	Maintaining Normalcy for Children	Interview 3	The kids were young at that age as well... just trying to keep normal for everyone as possible.
Identity and Appearance	Loss of Femininity and Physical Changes	Interview 3	I had no hair. One breast... you literally feel like a shell of yourself.
Social Perception and Isolation	Avoidance and Stigma	Interview 3	People tend to shy away from you because they don't know what to say.
Loss of Activities and Hobbies	Exercise Restrictions	Interview 3	I used to do a lot of running... I've just stopped completely.
Family Relationships	Role reversal with mother	Interview 4	Where I thought I would be taking care of her and her old age, there's a fair chance that she'll be taking care of me before that point.

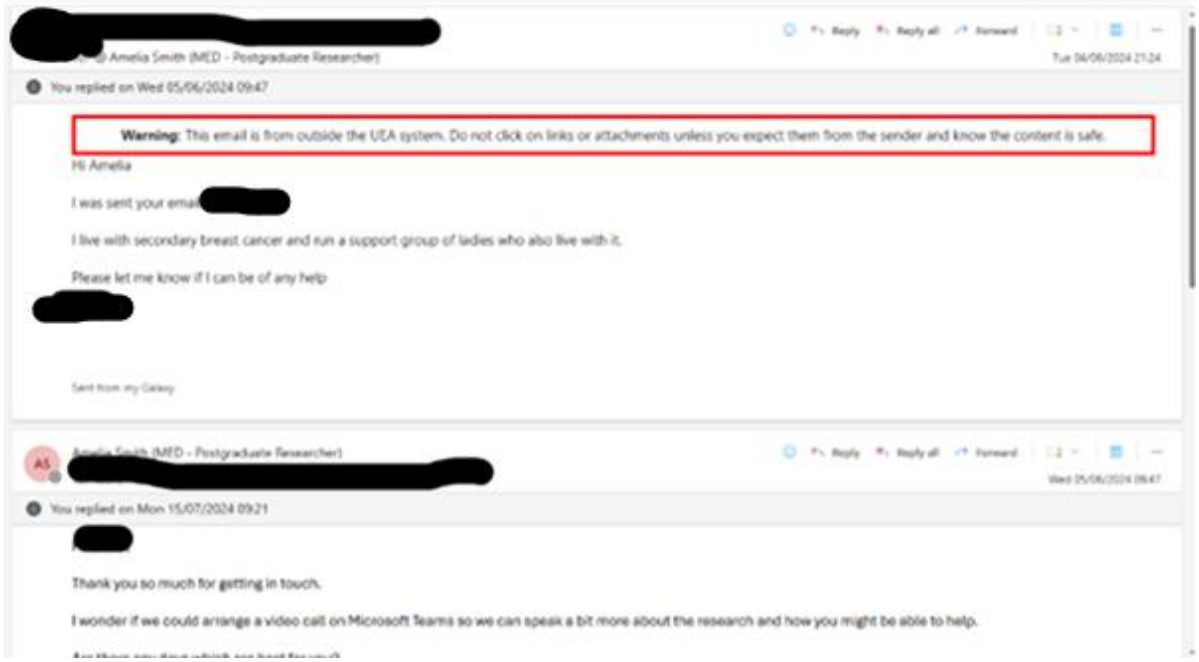
Partner Relationship	Emotional burden and adaptation	Interview 4	The relationship with your partner just changes so much... it's fundamentally changed our relationship.
Support systems	Theme related to other themes – support systems.	Interview 13	Interview 13: ““Everybody's been fantastic... my parents are still around. My nan's still around. Husband's brilliant.””
Relationship Dynamics	Safe spaces and emotional burden	Interview 5	My parents and my partner are my safe people... They experience a very different version of me.
Family Support	Open communication and resilience	Interview 6	We talk a lot, we all, you know, we can talk about anything... I'm just grateful that I've got them, really.
Social Relationships	Maintaining normalcy	Interview 6	Everybody’s just got on with it... some people don’t even know about it, I don’t think.
Physical Changes	Loss of strength and mobility	Interview 4	To lose that strength and to lose independence... is yeah.
Disability Identity	Navigating aids and acceptance	Interview 4	You can live so much more richly using them.
Healthcare Experience	Treatment burden and scheduling	Interview 4	That week I've actually got eight hospital appointments across 5 days.

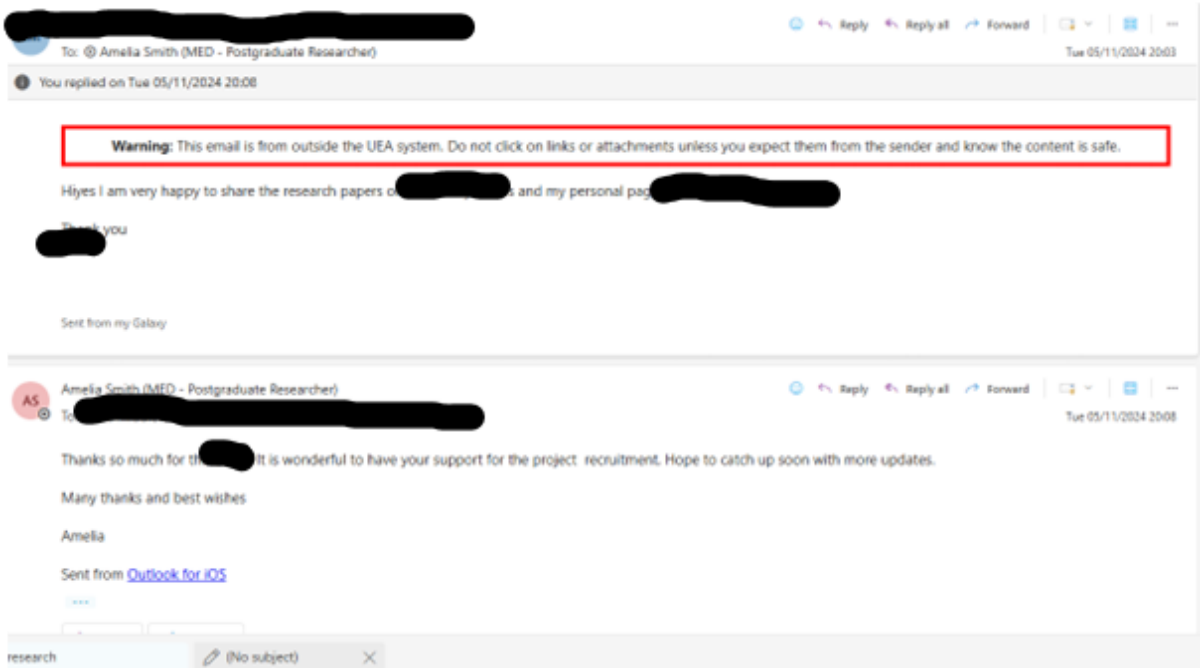
Healthcare Experience	Need for professional understanding	Interview 4	Even things like radiotherapy... it's still going to hit me like a brick.
Healthcare Experience	Lack of support and clarity	Interview 6	He was just really, really, really not very helpful... he just left us pretty much high and dry.
Self-Advocacy	Navigating medical systems	Interview 4	You can feel very trapped... you can't always get the answers that you want.
Self-Advocacy	Financial planning and support	Interview 4	My pension paid out in full... it's meant that we're in a position where I have a bit of financial freedom.
Concept of Unknowns	Medical ambiguity	Interview 4	We don't know what order things happened in... we don't know.
Processing and Disclosure	Scripted communication and emotional detachment	Interview 5	I had a script. In the end, I gave a script... Here's the script. Here's what has happened to me.
Treatment Experience	Managing side effects and emotional toll	Interview 5	There are days when I don't want to take the tablets... I just want to stop living this one.
Treatment Experience	Managing side effects and adapting	Interview 6	I felt like I couldn't swallow... ended up in the hospital a few times... The (name of second drug) is perfect for me.

Identity Disruption	Loss of former self and confidence	Interview 5	I was very confident... I am not that person anymore.
Employment and Purpose	Work as identity and coping mechanism	Interview 5	My job is my life... It's a really important part of who I am.
Systemic Gaps	Lack of support for young women with metastatic cancer	Interview 5	I just feel like there's not really a lot of support for young women who have stage 4.
Grief and Loss	Infertility and stolen future	Interview 5	This has taken children away from me... That has absolutely killed me and killed my partner.
Social Identity	Feeling excluded and misunderstood	Interview 5	I just feel really left out... It's like they're all in the club still and I'm not.
Conceptual Confusion	Mixed messages about remission and identity	Interview 5	I'm technically in remission... But I'm not in remission. It's highly confusing for me.
Daily Life and Limitations	Physical constraints and adaptation	Interview 6	The only thing that it affects is the housework and the heavy, heavy jobs at home... that has to take a back seat because of my back.
Living with Uncertainty	Scan anxiety and emotional cycles	Interview 6	The build-up to the appointment is always nerve-wracking... it was stable. So you know, that’s a relief.

Healthcare System Navigation	Lack of support and coordination	Interview 7	Not, 'Would you like a glass of water, Mrs (name)?' Just, 'Go back in the waiting room.'
Healthcare System Navigation	Self-advocacy and resilience	Interview 7	I got a pen and clipboard and I was starting my complaint letter... I couldn't afford to do anything else other than get mad.
Treatment and Side Effects	Physical limitations and fatigue	Interview 7	I ache. Things ache. I get tired... walking up hills is a pain.
Treatment and Side Effects	Financial and lifestyle impact	Interview 7	It costs me money, because I've got somebody who helps with the garden now.
Conceptual Understanding	Terminology and its impact	Interview 7 *Linguistic*	'Terminal' means you have an end date... 'Incurable' turns it into a long-term condition.

Appendix K: Redacted Gatekeeper Emails from Initial Contact with Cancer Charities


[redacted]
Amelia Smith (MED - Postgraduate Researcher)
Tue 04/06/2024 21:24
You replied on Wed 05/06/2024 09:47
Warning: This email is from outside the UEA system. Do not click on links or attachments unless you expect them from the sender and know the content is safe.
Hi Amelia
I was sent your email [redacted]
I live with secondary breast cancer and run a support group of ladies who also live with it.
Please let me know if I can be of any help
[redacted]
Sent from my Galaxy
AS
[redacted]
Wed 05/06/2024 09:47
You replied on Mon 15/07/2024 09:21
[redacted]
Thank you so much for getting in touch.
I wonder if we could arrange a video call on Microsoft Teams so we can speak a bit more about the research and how you might be able to help.


[redacted]
To: Amelia Smith (MED - Postgraduate Researcher)
Tue 05/11/2024 20:03
You replied on Tue 05/11/2024 20:08
Warning: This email is from outside the UEA system. Do not click on links or attachments unless you expect them from the sender and know the content is safe.
Hiyes I am very happy to share the research papers [redacted] and my personal pag[redacted]
Thank you
[redacted]
Sent from my Galaxy
AS
Amelia Smith (MED - Postgraduate Researcher)
To: [redacted]
Tue 05/11/2024 20:08
Thanks so much for th[redacted] It is wonderful to have your support for the project recruitment. Hope to catch up soon with more updates.
Many thanks and best wishes
Amelia
Sent from Outlook for iOS
research
(No subject)