



**Female breast cancer in the UK: Understanding the process of
familial disclosure and considering hair loss experiences**

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Contents

<i>Acknowledgements</i>	2
<i>Contents</i>	4
<i>Introductory chapter: Thesis overview</i>	7
<i>Chapter 1: Empirical paper *</i>	9
<i>Abstract</i>	10
1. Introduction	11
Women's experiences of breast cancer	11
Hair loss and breast cancer	12
Cancer and age	13
Hair loss and women of colour	15
Cultural influences and psychological impacts	16
Research aims	18
Research question	19
2. Method	20
Study design	20
Epistemological position	21
Participants.....	21
Inclusion criteria	21
Exclusion criteria.....	22
Sample	22
Ethical considerations.....	23
<i>Potential distress</i>	23
<i>Informed consent</i>	24
<i>Anonymity</i>	25
<i>Data storage</i>	25
<i>Ethics amendments</i>	25
Interview procedure	26
Data analysis and interpretation	27
<i>Reflexivity and validity</i>	27
<i>Reflexive statement: Position of the lead researcher</i>	27
Quality in IPA	28
3. Results	30
GET 1: Hair journey	30
<i>Hair loss</i>	30
<i>Regrowth</i>	35
<i>Identity</i>	36
<i>The hair they don't talk about</i>	38
GET 2: Support and connection	40

<i>Peer support</i>	40
<i>Community support</i>	42
<i>Responses from others</i>	43
<i>Disclosure and non-disclosure experiences</i>	44
<i>Support from family and friends unrelated to hair loss</i>	45
GET 3: Context	46
<i>Cultural perspectives</i>	46
<i>COVID context</i>	47
<i>Experiences of private vs. NHS treatment</i>	48
4. Discussion	50
GET 1: Hair Journey	50
GET 2: Support and connection	53
GET 3: Context.....	55
Strengths and limitations	55
Strengths	55
Limitations.....	56
Clinical implications and recommendations	57
Future research	59
5. Conclusions	61
6. References	62
<i>Chapter 2: Systematic review*</i>	75
<i>Abstract</i>	76
1. Introduction	77
Patterns of disclosure	77
The impact of illness on families.....	78
Rationale for the current review	79
Research question	80
Review aims	80
2. Methodology	82
Search strategy and design	82
Studies of interest.....	82
Search methods and inclusion and exclusion criteria	82
Search terms	84
Data extraction	84
Search outcome.....	85
Quality assessment.....	87
3. Results	88
Themes from the literature	88
Theme 1: Maintaining normality	93

Theme 2: Disclosure experiences	94
Theme 3: The impact of the diagnosis on family functioning	97
Theme 4: Sources of support.....	98
Theme 5: Emotive responses to diagnosis	100
4. Discussion.....	102
Strengths and limitations	105
Strengths	105
Limitations.....	105
Clinical implications and recommendations	106
Recommendations for ongoing research	107
5. Conclusion	109
6. References	110
Appendices.....	117
Appendix 1. Author guidelines, Psycho-oncology	117
Appendix 2. Data extraction tool	120
Appendix 3. Central university ethics approval	121
Appendix 4. Study poster	123
Appendix 5. Participant information sheet.....	124
Appendix 6. Debrief form	128
Appendix 7. Consent form.....	129
Appendix 8. Interview schedule.....	130
Appendix 9. Example of annotated transcript with experiential statements and exploratory notes	132
Appendix 10. Example of quotes used to form a subtheme.....	134
Appendix 11. Reflections	136

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Introductory chapter: Thesis overview

This thesis explores women's experiences of breast cancer in the UK. The first chapter of the thesis is an empirical paper exploring the experiences of younger women of colour who have lost their hair due to chemotherapy for breast cancer. Hair loss can change a woman's sense of identity and self, impacting mood and wellbeing. This may be considered within the context of social identity theory. Management of hair loss may be influenced by age, heritage and societal norms resulting in varying narratives around hair. When hair loss occurs it is important that women receive appropriate support.

Due to varying health inequalities, women of colour are less likely to receive equity in healthcare from physical healthcare services, including in relation to breast cancer. This may extend to support offered to manage the impact of treatment, including hair loss. Chapter one captures experiences of women's journey of hair loss, within the context of having a breast cancer diagnosis as a younger woman of colour.

The term 'women of colour' was used following consultation with experts by experience, but also to promote inclusivity. Interpretative Phenomenological Analysis (IPA) was used to explore and analyse data.

The systematic review question was directly generated from the empirical paper, after participants shared their concerns and experiences of disease disclosure and what informed the decisions they made regarding disclosure. Some participants chose to share their diagnosis very openly with their loved ones, whilst others did not feel comfortable to do so and shared their reasons for doing this. This prompted chapter 2, a systematic review exploring experiences of women in the UK when sharing their diagnosis of breast cancer with their families. The systematic review followed 'The Enhancing Transparency in Reporting the Synthesis of Qualitative Research' (ENTREQ) statement.

It was important this the present review specifically focused on the UK context for appropriate recommendations to be made. Included studies explored the experiences of adult women communicating their breast cancer diagnosis to family members, and the experiences of family members hearing about the diagnosis and managing its impact. Familial perspectives included the experiences of children and spouses. One study focussed on the experiences of women sharing both their diagnoses of breast cancer and their BRCA gene status.

The results were analysed using thematic analysis and reported using a narrative summary. Clinical implications and recommendations for future research are discussed.

Chapter 1: Empirical paper *

‘The pain I felt from the cancer was not up to the pain I felt losing my hair’: **Experiences of younger women of colour who have lost their hair as a result of chemotherapy for breast cancer.**

*To be submitted to: *Psycho-Oncology*, Journal of Psychological, Social and Behavioural Dimensions of Cancer (see Appendix 1 for author guidelines). The word count for this journal is 4000, however, when writing this paper, to provide adequate detail for viva examination, this has been extended.

Abstract

Background: Research highlights the difficulties experienced by women managing hair loss due to chemotherapy. Younger women have reported variations in breast cancer experience, and the experiences of minority groups and women under the age of 40 have not been explored widely in the literature. This study explores the perspectives and experiences of younger women of colour who have experienced hair loss due to chemotherapy for breast cancer.

Method: Nine women of colour who had experienced hair loss due to chemotherapy for breast cancer between the ages of 26 and 35, participated in qualitative interviews that were transcribed and analysed using Interpretative Phenomenological Analysis (IPA).

Results: Findings are presented through three Group Experiential Themes (GETs) which are then divided into subthemes. The GETs are 1) Hair Journey, 2) Support and Connection and 3) Context. The findings explore breast cancer experiences of younger women, with emphasis on hair, whilst considering age and cultural background.

Conclusions: Participants reported high levels of distress in relation to hair loss. Participants managed hair loss by using a combination of wigs and hair coverings, with some leaving their heads uncovered, and described hair loss from other parts of their body (for example, their faces) making them look more unwell. Participants sought support from friends, family and community groups, and their breast cancer experiences were mediated by their individual contexts. Recommendations are made for ongoing research and clinical implications are discussed.

KEYWORDS: *Breast cancer, younger women, women of colour, hair loss, experiences, UK*

1. Introduction

Women's experiences of breast cancer

Breast cancer is the most prevalent cancer diagnosis in the UK, with 55,900 (2016-2018) new cases being reported each year (1). Diagnoses normally affect women, with 55,500 cases a year reported in women in the UK, compared with 370 male cases reported per year (2016-2018) (1). Additionally, the risk of being diagnosed with breast cancer increases with age (2). The impact of receiving a breast cancer diagnosis and going through treatment is widely documented throughout the literature with diagnosis and treatment being associated with psychological distress, body image problems, intimacy difficulties and ongoing health anxieties (3, 4). Research findings describe the overall experience of receiving a breast cancer diagnosis and treatment as akin to trauma (5), not only impacting a woman's emotional wellbeing, but also presenting challenges to one's idea of femininity (6-9) and potentially leading to women experiencing feelings of guilt, isolation and mistrust (10). There are individual differences in relation to the response and impact of receiving a diagnosis, and reactions may also be shaped by wider contextual factors (11).

Breast cancer is the most common cancer effecting women across the globe (12). Treatment typically involves chemotherapy, a lumpectomy or mastectomy and radiotherapy (13). One of the side effects of chemotherapy is alopecia, which involves losing hair from the head, but extends to hair loss all over the body (13-15). In the medical literature this is often termed chemotherapy-induced alopecia (16), however, it is typically referred to by patients as hair loss, hence this language being used in this study. Hair loss remains one of the most prominent concerns of patients when they receive a diagnosis (17-19) and is a source of considerable distress for (18, 20).

Hair loss and breast cancer

Hair loss and changes in appearance are linked to female breast cancer patients feeling unattractive, less feminine, and having decreased self-esteem (21-24). These negative body image perceptions can have an impact on psychological wellbeing and wellness, as well as self-perception and identity (20, 25). In order to manage some of these experiences, patients may use wigs or head coverings (20), and may be encouraged by other people to conceal their baldness (26, 27). Patients may also try and keep their hair during treatment through scalp cooling which involves freezing the hair follicles by wearing a cold cap during chemotherapy treatment (28). There are varying levels of success with scalp cooling (29) with patients experiencing higher levels of distress when this intervention is unsuccessful (28).

Individuals' identities develop within historical, cultural, familial and circumstantial contexts which inform norms for living (30). When normality is disturbed, people may experience challenges to their sense of self, which in turn may impact psychological wellbeing and engagement with others (31-33). Ideas about body perception directly relate to levels of self-esteem, with individuals who feel better about themselves reporting increased levels of self-esteem (34). Studies suggest that, within Western culture, psychological wellbeing and functioning can be affected by hair loss (32, 33). Hair loss can also impact an individual's sense of self (32). These factors are particularly relevant for younger women (35). Research has found that women with breast cancer experience distorted body image and a decrease in self-esteem which can have a detrimental effect on wellbeing (36), with individuals experiencing emotional, behavioural and cognitive changes that challenge one's sense of self (37).

In the literature, the hair loss process within the context of cancer treatment, is described as traumatic, due to changes in self-esteem, self-confidence, and psychological wellbeing (33, 38, 39) when people experience hair loss. Hair is significant in relation to people's identities in part due to existing religious, personal, societal and cultural narratives around hair and appearance (40). A full head of hair is often representative of gender, and youthfulness (41). Pergament (40) asserts that, universally, hair can be indicative of an individual's beliefs or lifestyle and people may make inferences based on an individual's hairstyle (40). In some Western societies (such as the United States of America) certain ideas and attitudes are held towards women who are bald or have a shaved head (32). Such hairstyles may be associated with incarceration, the military or illness. However, different interpretations may exist for such hairstyles within minority communities, and cultural perceptions of hair from minority ethnic groups living in the UK may differ from the majority Western view (40).

This study uses both terms 'scalp cooling' and 'cold cap' interchangeably to describe the scalp cooling process. This is in line with the language used by participants.

Cancer and age

Research suggests that, although when someone is diagnosed and treated for cancer they may have similar treatment experiences, these can be mediated by their life stage and the age at which they are diagnosed (42, 43). There are a number of services that have been developed to work with the adolescent and young adult population who have cancer (42), with specific services for children up to aged 18 and young adults aged 19-24. However, age specific services for adults above the age of 24 are less common.

There are a number of cancers that are more common in younger women, one of which is breast cancer (44), followed by lung, cervical and thyroid cancer (45). There has

been a reported global increase in the number of cases of breast cancer in women under the age of 40 (44, 46), and age has been documented as a contributing factor in late diagnosis and misdiagnosis (45).

There are significant age differences described in breast cancer presentation in British women of colour and White British women (47, 48). It is reported that the overall incidence of breast cancer is lower in Black women than that of White women in the UK. However, the risk of developing breast cancer is higher in Black and minority women under the age of 45 than their White counterparts (49). One study found that, in the UK, 16% of South Asian women diagnosed with breast cancer during 1986-1990 were under 40 years old compared to the national statistics where 5% of women were under 40 (48). Another study reported that, on average, Black British women present with breast cancer symptoms 21 years younger than their White British counterparts (47). Moreover, tumours were more aggressive in the Black population, and younger Black women were more than twice as likely to die due to the disease than their White equivalents (47). This fits with more recent research which reported that ethnic minority women are at greater risk of breast cancers with less favourable tumour characteristics than their White British peers (50).

Literature highlights variation in needs for women with cancer dependent on age. Typically, younger women with a diagnosis may experience higher levels of distress trying to manage the implications of diagnosis and treatment within their developmental, social, and emotional contexts. (35, 51). Additionally, literature suggests that the younger demographic manage the aftermath of cancer treatment differently to their older counterparts, with physical appearance being more of a concern. Altered appearance may serve as a reminder of a cancer diagnosis and can prevent younger women from reaching desired normality. Older women report more concerns around transitioning into later life

(52). Further research of experiences of women across the lifespan is important, and services should consider age as a factor when offering support to patients (35, 52).

Studies reporting on cancer experiences vary in relation to what is defined as 'young'. One study classified 'younger women' as being pre-menopausal or having children of primary school age (35), and another considered women of 'fertile age' (15-50) as being 'young' (53). Another study classified 'younger women' with breast cancer as being under the age of 50 (54). What is common in the literature is to see studies that focus on the experience of 'young women' reporting on the experiences of women towards the top of the 50-year-old bracket, with little representation from women in their later 20s and early 30s (51). Victorson, Garcia (51) describe the experiences of young adults with breast cancer. Whilst young adulthood is typically defined as being between the ages of 18-25 (55), the age range for young adult participants taking part in the study was between the ages of 28 and 39.

Hair loss and women of colour

Studies exploring the impact of chemotherapy related hair loss do not exclusively explore the experiences of women from minoritized groups, despite research reporting deficits in culturally appropriate services for this group, especially in regard to physical appearance (56, 57). There is existing variation in salience and symbolism of hair across cultures, which may influence the hair loss experience during the breast cancer journey (58).

There are many examples of the significance of hair across cultures. The Black community have used hair as a means of self-expression, political messaging and symbolic representation for a number of years (58, 59). The significance of hair and creativity within this community has been documented within literature (60). Within the

Orthodox Jewish community, hair is typically indicative of marital status, with modesty being protected by women covering their hair (40). Showing hair may be seen as sexually appealing (40), which is similar within Tunisian-Muslim communities. Although women covering their hair is common in the Tunisian-Muslim community, women who have lost their hair may be identified as being different or standing out (39). There are reported poorer psychological outcomes for younger, unmarried women who lose their hair when compared to their married peers (39).

It was reported in the 2016 Cancer Patient Experience survey that minority ethnic groups have fewer positive experiences of cancer-related services (61) in England than white British groups. It was recommended that services develop a better understanding of the specific needs of ethnic minority patients (61) to improve satisfaction with cancer care within minority groups. This includes consideration of specific cultural factors that may be relevant for the side effects of treatment. Disparities in treatment can be attributed to systemic medical racism, where inequalities in treatment between people from ethnic minorities and their white counterparts have been highlighted across services. This exists for individuals across the lifespan with a range of presentations including cancer (62).

This study uses the term 'women of colour' to describe women from minority backgrounds. This was decided by the research team and experts by experience with the aim of maximising inclusivity during recruitment.

Cultural influences and psychological impacts

Despite physical health disparities between women of colour and White women with breast cancer, psychological outcomes and treatment experiences of women of colour have not been widely explored in the UK. Studies have been conducted in relation

to the experiences of women in other countries, such as Thailand (6), Ghana (53), Jordan (12), Turkey (63) and Pakistan (64). Research highlights the importance of providing culturally sensitive treatments and interventions when working with women breast cancer (12). Additionally, there are reported differences in psychological outcomes and self-perception (of physical appearance) between White women and women of colour following cancer (20, 65). Two UK based studies suggest that Black and South Asian women experience cancer through a cultural lens, with both groups drawing on religion for both explanations of illness and sources comfort (57, 65) and with Black women, in particular, accessing culturally relevant community support (57, 65).

The research picture is similar when looking at international studies. In a study exploring experiences of Thai women, the importance of cultural beliefs and practices, emotions, and the body were recognised as being important for healing (6). This study recommended that culturally appropriate interventions and therapeutic strategies should be employed when working therapeutically with diverse groups of women who have a breast cancer diagnosis. In another study exploring the experience of Ghanaian women who have been treated for breast cancer, it was reported that diagnosis and treatment impacted women's social and spiritual life, and women felt that their comfort and ability to parent was also affected (53). This group of women experienced feelings of loss regarding hair loss and found side effects of treatment relating to their appearance distressing (for example, darkening of skin and gums). A study considering the experiences of Jordanian women reported similar themes around sources of distress for participants, which included concerns about 'my body falling apart' or physical wellbeing, 'broken heart' or changes in emotional wellbeing, 'broken future' or changes in social wellbeing and 'repairing what has been broken' or ways that they were able to cope (12).

Whilst some of these themes or experiences may not be unique to women of colour, such experiences may be influenced by cultural factors. This aligns with a study that specifically considered south Asian and Black women's experiences of breast cancer in the UK (57). Like their White counterparts, they shared concerns about altered appearance, social support, and femininity issues, but these worries were viewed through a cultural lens. For example, women that shared concerns about their appearance expressed dissatisfaction with the limited range of prostheses, and unsuitable lymphoedema sleeves (a compression garment worn to help manage swelling) that did not match their complexions (57). Additionally, there were reported differences in quality of life between White women and Black and south Asian women being treated for breast cancer in the UK, with Black and south Asian women reporting higher levels of body image concerns and holding stronger beliefs about God's role in their diagnosis (65). Furthermore, south Asian women identified God as a source of a support more so than Black and White women included in the study (65). These studies are the only two that have explored the breast cancer experiences of women of colour in the UK, with a focus on south Asian and Black women. They do not consider the impact of age on diagnosis and have a generic focus on the overall breast cancer sequelae, rather than considering specific factors.

Research aims

This research seeks to gain an understanding of the experiences of women of colour who have received treatment for breast cancer at a young age, and who lost their hair due to chemotherapy. It aims to explore the impact of hair loss on self-perception and the perceived perceptions of others. It also aims to explore sources of support accessed by this group of women in relation to their hair, ethnicity and their age, and the perceived

support available to them. The study focuses on the intersection between young women and cultural background in relation to breast cancer, a perspective that is rarely considered in the cancer literature.

Research question

What are the experiences of younger women of colour who have lost their hair because of chemotherapy for breast cancer? What is the impact of hair loss on self-perception, and how do they understand other people's perceptions of them?

2. Method

Study design

This study used Interpretative Phenomenological Analysis (IPA), as described by Smith, Flowers (66) to explore the world as experienced from the viewpoint of participants (67). It focused on exploring experiences of hair loss due to chemotherapy in young women of colour, with the intention of allowing for an in-depth understanding of participants' experiences, their relational contexts, and ways in which they interact with others. This study aimed to reflect individuals' experiences authentically and meaningfully, and make relevant, general recommendations for practice. The aim was to have a homogenous sample, in line with the IPA approach (66).

IPA involves the detailed examination of an individual's lived experience and personal meanings, and is well suited to understanding an individual's physical health experiences (68). The methodology was used in this study because it concentrates on the interpretative aspect of an individual's experience, focusing on their understanding of a phenomena (66). By using IPA it was hoped that the experiences and behaviours of young women were captured and their social, cultural and economic contexts considered (69).

Typically, IPA focuses on the detailed experience of a small sample, exploring individuals' personal narratives and closer exploration of individual participants' words, hence the smaller sample size of nine participants in the study (70). Additionally, IPA holds in mind the ontological position of the researcher and allows them to consider their position in relation to the area of study throughout the research process. This was particularly relevant for the lead researcher who has lived experience of being a younger woman of colour who was treated for breast cancer in the past.

Epistemological position

IPA adopts both a constructivist and realist epistemological approach (71), considering personal meanings within the context of reality. It encourages the double hermeneutic approach, where the researcher interprets participants' personal interpretations of their experiences (66). IPA adopts an idiographic perspective considering the individual experiences of participants before looking closely at similarities and differences in perception and understanding of participants (66).

Participants

A purposive sample method was used, in line with the IPA approach (66) with the aim to recruit between six and ten participants in order to interpret the data meaningfully, observing patterns in the data (72). Participants were younger women of colour who had previously been treated with chemotherapy for breast cancer, and self-identified as experiencing a significant degree of hair loss as a result. They were between the ages of 21 and 35 when diagnosed and treated. Experts by experience supported the development of the study and were not included in the sample. The study team recruited from third sector and charity organisations only.

The eligibility criteria for the study were as follows:

Inclusion criteria

- Women of colour who self-identify as being from a minority ethnic background.
- Women between the ages of 21 and 35 when treated for breast cancer.
- Women who have had breast cancer treatment within the last 10 years.
- Women who have experienced hair loss due to chemotherapy.
- Women who have received treatment in the UK.

To ensure homogeneity in the sample it was important to focus on a specific cancer diagnosis and experiences of diagnosis and treatment in the UK, considering the NHS context. Due to the common side effects of hair loss when being treated with chemotherapy drugs, it was decided that experiences of breast cancer specifically would be explored (13, 14).

Exclusion criteria

- Women who are still undergoing chemotherapy or other cancer treatment.
- Women who have experienced alopecia for another reason related to their physical health.
- Women who pre-emptively shaved their hair prior to hair loss because of chemotherapy.
- Women who do not self-identify as being from a minority ethnic background.
- Women who were over the age of 35 or under the age of 21 when they were treated for breast cancer.
- Women who have not had breast cancer treatment within the last 10 years.
- Women who have not experienced significant hair loss due to chemotherapy for breast cancer.
- Women who have not received treatment in the UK.

Sample

Nine women of colour were recruited via purposive sample between June and December 2022. The women were between the ages of 30-38 at the time of the interview and had been between the ages of 26-35 at the time of diagnosis. Time since diagnosis ranged from one to seven years, and participants were from across the UK. Participants

were from a range of cultural backgrounds which included British Caribbean, British African, British South Asian, British Caribbean and White Scottish (dual heritage), East Asian and African.

The lead researcher recruited through cancer charities and set up a dedicated Twitter account and Instagram page to advertise the study and recruit. Tweets and Instagram posts included the study poster (Appendix 4) and the contact details of the researcher. Three cancer charities, Black Women Rising, Maggie's and Breast Cancer Now, retweeted the poster. Additionally, Maggie's Cancer Charities advertised the physical poster in their charity buildings. Eighteen women responded to the social media advertisements. The Participation Information Sheet (PIS) (Appendix 5) was circulated to women who expressed an interest in taking part in the study. Nine women who contacted the lead researcher did not participate in the study due to them either meeting the inclusion criteria or not opting in.

Ethical considerations

Ethical approval was granted from the University of Liverpool's Committee of Research Ethics (CORE) (Appendix 3). (Reference 10652, granted on 06/05/2022). Various ethical considerations made throughout the study, which included:

Potential distress

Participants were made aware of the topic of the interview, and other relevant information prior to the interview through the PIS. The PIS provided information about the study, participants' rights to withdraw and explained anonymity and where and how participant data would be stored. They were also invited to discuss this with the researcher. They were informed that should they become distressed, the interview would be stopped. Following the interview, participants were offered a debrief where they could

share concerns and reflect on how they found the interview. They were also offered a debrief form (Appendix 6) with information about useful organisations that could offer support. None of the participants highlighted any concerns during or following the interview.

The lead researcher had regular meetings with her research supervisors to debrief following the interviews. A clear plan was put in place with her supervisors prior to interviews, should the lead researcher become distressed by the content in the interviews, which included the offer of psychological support.

Informed consent

Potential participants who expressed an interest in the study were sent the PIS which provided further details about the study. They were also encouraged to ask questions about the research to make an informed decision whether they wanted to take part. Participants that expressed an interest were asked to answer the following questions to check eligibility and to inform planning around interviews.

Age:
Age at diagnosis:
Were you treated with chemotherapy for breast cancer?
Did you experience hair loss as a result of treatment?
What treatment do you continue to have?
Describe your ethnic identity?
Where did you have treatment for breast cancer?
Should you wish to take part, would you prefer an in-person or remote interview?

Participants that met the inclusion criteria were provided with a consent form (Appendix 7) that they were required to sign before taking part and an interview date and location was confirmed.

Anonymity

Participants were informed that their demographic information and any other personal identifiers would not be linked to any direct quotes included in the research. They were also told that pseudonyms would be used throughout the research to maintain anonymity. The researcher chose an alias for all nine participants.

Data storage

Participants were informed that data would be stored on securely on the University of Liverpool's M Drive (a secure location on the university's server), and that audio data would be removed from the recording device used for the interviews as soon as possible and would be stored securely alongside any Zoom recordings obtained. Transcript data were stored under unique participant numbers. Data was kept in accordance with the University of Liverpool's regulations and will be destroyed after a period of ten years.

Ethics amendments

Initially the inclusion criteria for participants included women up to the age of 35- there was no distinction between the age at treatment and diagnosis and the age at which

they participated in the study. This prevented women over the age of 35 sharing their experiences retrospectively. Therefore, an ethics amendment was submitted and approved to increase the upper age limit (at time of participation) of participants to 45years. An additional inclusion criterion was also introduced stating that participants must have been diagnosed and treated within the last ten years.

Interview procedure

An interview schedule was developed with Experts by Experience, who were younger women who had been treated for breast cancer. In line with IPA, one opening question was used to explore participants' experiences (66);

“Tell me about your experiences of losing your hair as a younger woman of colour who was treated for breast cancer”.

Subsequent prompt questions included were informed by Experts by Experience and the relevant cancer literature (see interview schedule, Appendix 8).

Two participants were interviewed in person in Maggie's Centre buildings, providing a confidential, but comfortable space for participants. Those who opted for remote interviews were interviewed via Zoom. Interviews lasted between 25 minutes and 90 minutes. The interviews were transcribed; three by a transcription service and six by the researcher. The researcher listened to all the interviews a number of times alongside the transcripts to ensure accuracy. Three transcripts had to be reviewed by the transcription service as they were inaccurate. A reflective diary was kept by the researcher throughout.

Data analysis and interpretation

Analysis of the data was completed, following the process outlined by Smith, Flowers (66). The approach has been described as one that is iterative and inductive (73).

Initially, the researcher started analysis on an individual level, becoming immersed in the data by reading and re-reading transcripts and listening to interviews. Following this, each transcript was analysed individually and coded with exploratory descriptive, linguistic, and conceptual comments to develop an understanding of potential themes arising in the data. Exploratory ideas and thoughts were consolidated through making experiential statements, based on the exploratory notes. These not only reflected participant statements, but also the researcher's interpretation of such statements. Connections between experiential statements in the transcript were then made and were added to a table, displaying participants' Personal Experiential Themes (PETs). This process was repeated across transcripts, before patterns and similarities between personal themes were generated across the group (Group Experiential Themes). These themes were captured in a table, which included both PETs and experiential statements and verbatim quotes from a range of participants (66). Examples of the analysis are provided in Appendix 9 and Appendix 10.

Reflexivity and validity

IPA allows for reflection on one's own perspectives and conceptions in relation to the data (66). Reflexivity can increase awareness of unconscious biases and motivations, and the researcher's relationship to the topic of the study.

Reflexive statement: Position of the lead researcher

I am a woman of colour who experienced a breast cancer diagnosis and hair loss because of treatment in my late twenties, and my experiences directly informed the research question. Initially participants were not made aware of my previous experiences

of breast cancer, but after completing two of the interviews, this was reviewed with the research team, and it was decided that this would be disclosed to participants at the end of the interview.

Throughout the research process I have reflected on my position in relation to this study. Whilst I have had my own personal experience of breast cancer diagnosis and treatment, it was important that I remained consciously aware of that which I was yet to learn about the experiences of other women taking part in the study. Additionally, the research team includes clinical psychologists who have personal and professional experiences of breast cancer (although not having received diagnoses themselves).

Two of the experts by experience involved in the study were younger women who had been treated for breast cancer and experienced hair loss, one of whom is a woman of colour. During the process of data collection, one of the experts by experience unfortunately passed away but had made a significant contribution to the study up until this point. When this happened, it felt important for me to step back from the research to process the impact of losing her, and to seek support for myself. This was mainly through my research team. It did not feel appropriate to seek input from a new expert by experience at this point, therefore the study continued with input from one expert by experience.

Quality in IPA

Throughout the research it was important to maintain a reflexive position including keeping a reflexive diary as a tool for reflection. Additionally, reflexive bracketing was used by holding the researchers' experiences in mind throughout, with particular emphasis during analysis, and by remaining open and curious, and mindful of the research team's positioning in relation to the research.

It is important that transparency is maintained throughout the IPA process in relation to the positionality of the researchers (66), therefore this was acknowledged at every step of the research. Supervision was used throughout the research process which helped maintain quality and validity throughout. A proportion of the analysis was shared with the wider research team. Initial results were also shared with the expert by experience involved with the project.

3. Results

Nine participants were interviewed with the aim of exploring the experiences of younger women of colour who experienced hair loss due to chemotherapy for breast cancer. Three Group Experiential Themes (GETs) were generated with 12 group-level sub themes, outlined in table 1.

Table 1: GETs and group-level sub themes

	GETs	Group-level sub themes
1.	Hair journey	<ul style="list-style-type: none"> • Hair loss • Regrowth • Identity • The hair they don't talk about
2.	Support and connection	<ul style="list-style-type: none"> • Peer support • Community support • Support from family and friends • Response from others • Disclosure and non-disclosure experiences
3.	The importance of context	<ul style="list-style-type: none"> • Cultural perspectives • COVID context • NHS vs. private

GET 1: Hair journey

Participants described their journeys with hair loss, anticipating the hair loss experience before it had begun, the actual hair loss experience, hair regrowth, and their relationship with their hair once it had grown back. They reflected on the impact of hair loss on their feminine identities, within their individual, societal and cultural contexts. They also reflected on their experiences of losing body hair.

Hair loss

'It almost came away like it was never attached to you in the first place. It sort of comes off in your hands.' (Monica)

Participants shared their experiences of hair loss. Whilst they had expected to lose their hair, some felt that they were not adequately prepared for the experience. Parisha stated that even though she understood that hair loss was inevitable, she had hoped that she would not be faced with it. Luna described having a similar sense of hope as she was told by her medical team that it wasn't a certainty that she would lose her hair.

'I was going through they said it's not 100%, it's like 50/50 chance so they said oh you probably wouldn't lose your hair and then I, I, yeah, I started losing hair' (Luna)

For Florence, her sense of frustration when she lost her hair felt acute and she described becoming angry with her medical team. It felt like the guidance that she was given regarding hair loss was inaccurate and gave her false hope.

'I transfer a lot of aggression to my doctor cause he was like okay, first he gave me hope that mine would not be...when I started losing and lost the amount, I got angry with him' (Florence)

Many women shared their initial experience of losing their hair, and then *'braving the shave'*. Women turned to members of their community to support them with this; Gina's brother shaved her hair at an early stage. Anna repeated the fact that she felt scared when she was about to shave her hair, highlighting her heightened emotion.

'Erm...oh man, erm...so shaving my hair was, gosh, I was terrified before I was going to shave my hair...but there's still something, you know, a bit frightening...so so I was really really really scared...so, I was really frightened.' (Anna)

Other participants also experienced fear and were concerned about what they would look like without hair. Additionally, shaving their hair often served as a way of women gaining some control over their experience of both breast cancer and hair loss, as described by Kamille.

'I took that control, and I wanted to have the control, to be honest. If, if I couldn't control anything, then I would have liked to be able to control my hair and like the length of it and stuff.' (Kamille)

Participants frequently reflected on the lack of choice that they had in relation to the hair loss process, with options for alternative hairstyles removed. Despite Black participants (in particular) in this study describing being experimental with their hair prior to hair loss, they explained how unjust it felt when changes to their hair were imposed upon them because of chemotherapy.

'that option was taken away from me basically...so it did feel different even though I would wear my hair different kind of ways anyway.' (Gina)

For many participants hair loss served as a reminder of how unwell they were. Monica described developing an understanding of the severity of her diagnosis once she started to lose her hair, and experienced the impact of the strong treatment that she was being given.

'it sealed for me that I was going through quite intense treatment...that for me felt like the turning point that I knew I had cancer pretty bad.' (Monica)

Some participants used scalp cooling (wearing the cold cap) to preserve their hair. Whilst the majority did not continue throughout treatment for a range of reasons, including discomfort and ineffectiveness, two participants wore the cold cap throughout chemotherapy.

'the cold cap worked for me really well. So, while I lost some hair, I didn't lose much.'
(Parisha)

A number of the Black women in the study felt that the scalp cooling process was not suitable for their hair type and that there needed to be more information provided regarding efficacy of scalp cooling for women with afro hair.

'I think it's really like it's not for – it, it, it is for Black women as well, but maybe for it to be used differently.' (Kamille)

'Yeah, so they did kind of warn me that erm...there isn't, there wasn't a lot of examples of erm...of it being used with like afro hair' (Anna)

The participants in this study described using a combination of wigs and scarves to cover their hair. Several Black participants shared their experiences of using wigs prior to chemotherapy, and their ability to be able to draw upon some of their previous experiences of this. Anna described the cultural significance of wigs within the Black

community, and highlighted how this may have shaped perspectives around wearing wigs for women who have experienced hair loss due to chemotherapy.

'the thing with the wigs as well, like wigs are already very much embedded into like Black everyday life, so you just know how to wear a wig, or we've done, we've gone in leaps, come in leaps and bounds with making them look realistic so, and also it's normal to wear a wig, so you don't have to be ill to wear wig, right, right so, so if you're wearing a wig, even if people can tell it's a wig whatever it's just like the assumption is you're fine' (Anna)

Participants spoke about their experiences of being offered wigs through the NHS, but most felt that these were not suitable for their needs.

'So, she's bringing out these wigs, and I'm looking at the wigs, and I'm thinking, what makes you think, woman, that this wig is going to look good on me as a Black woman? Maybe on a White woman, but not on me' (Kamille)

Whilst Anna wore a wig throughout treatment, others shared experiences of wearing wigs in an experimental, humorous way, for example:

'my mum actually who brought it...a White, blonde wig and it was like a bob, or it was like cropped. And I put it on, and we found it hilarious...like we messed around with it, and it was just a bit more fun to it...if you're going to have no hair you may as well have the fun of being able to choose a few weird wigs' (Monica)

Two participants described becoming fed up with covering their hair, mainly due to discomfort.

'I just got to a point where I'm just like, I'm fed up of hiding myself, I don't want to keep wearing these scarfs because they're hurting my head. The wig is itching my scalp.' (Kamille)

'I used to wear a lot of wigs at first, then I was like oh fuck it...this is the shit I survived this, so I'm going to work with it.' (Florence)

Kamille alluded to not feeling like herself when wearing scarfs, and Florence articulated a sense of pride for having survived her experience, her bald head being synonymous with this survivorship.

Regrowth

'the growth process of it coming back is a weird one' (Monica)

Participants shared their experiences of hair regrowth, describing feeling happy when their hair started to grow back. Monica described a sense of rebirth and regeneration, and new growth signifying her body healing and coming out of a difficult experience.

'I was grateful that my body was repairing and giving me hair back' (Monica)

Tara found the process 'fun' and 'exciting', and a chance for her to experiment with her hair. Monica also experimented and embraced her natural afro, contrasting with the chemically straightened hair style she had prior to having cancer.

Despite regrowth of body hair being experienced by participants as inconvenient, Tara explained experiencing a sense of '*normality*' when hers grew back.

Identity

'I think a lot of our identity is within our hair and how we look' (Gina)

The participants in this study shared how intrinsic their hair was to their various identities, and as they lost hair, they felt that they looked more unwell.

'It's kind of the biggest sign to the outside world that you're sick' (Tara)

Monica described having had the same hairstyle for many years, that friends and family would associate with her, and she used metaphor to describe her younger self dying alongside losing her hair. Whilst she mourned losing her hair, this process was also representative of her old identity pre-cancer.

'it felt like younger me that had just been like killed off in the process of my hair coming away and it was yeah, it was quite emotional at the time.' (Monica)

When participants spoke about how they looked without their hair, many of them used metaphor, either likening themselves to animals, fictional creatures or inanimate objects. Words used to describe how they looked without hair included '*potato*' and

'gollum'. Additionally, they described losing their sense of femininity that they often associated with their hair.

Through the language used, participants implied that there was a connection between their humanness and their hair, and hair loss compromised their humanness. Florence spoke about changes to her personality and mood, and her changing from being a person with hair into a 'monster' without hair. The sense of frustration that she felt about being bald and losing her hair, which she described as '[her] crown' was palpable. She also described how she felt that others perceived her differently when she lost her hair. Whilst she wore wigs and hair coverings at times, after a while she stopped covering her hair and exposed her bald head in public. She felt that strangers that she interacted with did not associate her hair loss with a cancer diagnosis, and didn't show sympathy, but instead she used warrior imagery to describe what she believed to be strangers' perceptions of herself.

'I know for sure they wouldn't have thought I'm a cancer patient. So maybe they're laughing, 'oh, look at this African warrior, look at this Wakanda princess' (Florence)

Tara also described how she felt she was perceived by other people once she had lost her hair. She covered her hair with a scarf most of the time when she went out. She noticed that people who did not know that she had been diagnosed with breast cancer would increasingly look at her. She suspected that people were questioning whether she had converted to Islam, due to her wearing a head covering coupled with her complexion.

'it's just an identity thing. It was very...it was a very strange journey to go on as an Indian woman who is Hindu to then realise that after I started wearing you know, a head wrap, I potentially was being confused for a Muslim woman.' (Tara)

As the participants in this study lost more hair, they felt like they were not themselves. They described not recognising themselves when they saw their reflection, but also not feeling attractive without hair. This was particularly pertinent once they lost hair from their faces.

'Because obviously my hair was gone, I had no eyelashes, from the steroids as well, your face goes really puffy and round, so and that's when it really hit me. I was like, I looked in the mirror and I was like who is this person?' (Gina)

The hair they don't talk about

'when it was like completely bald and when I had like no eyebrows no eyelashes, that's when it was really just too much' (Anna)

Participants described their experiences of losing body hair. Some aspects of this were convenient describing losing hair from their legs and other parts of the body as one of the *'benefits of chemo'*.

'I'll be real with you; I didn't mind the armpits...I found it bloody fantastic. The hairs on my arms, legs, beautiful...even like, my butt crack. I was like, whoa, no more waxing...I was in my element.' (Kamille)

However, some of the practicalities of having body hair were also described, and women experienced discomfort due to losing facial hair, specifically eyelashes and nose hair.

'Like losing my eyelashes was not only hard from a 'I look like a potato' perspective, an identity perspective, but genuinely painful. Like, my eyes were dry, they were sore, shit would get into them so much more. Like, your eyelashes are powerful things, it's not just something to flutter, like. And you don't appreciate that until they're not there anymore. But I cried the first day I saw an eyelash' (Tara)

When talking about some of the benefits of hair loss from certain areas of the body, participants were able to identify some of the positive experiences that they associated with chemotherapy. This aspect of the conversation was often prefaced with humour, and for many it seemed that it felt easier to talk about these experiences. Additionally, participants described that they looked the most unwell when they had lost hair from their faces, and this was often hard to disguise.

'but the eyelashes, oh my gosh, I feel like you look really unwell when you don't have facial hair, like you really look ill. Like I remember I'd look at myself and I would just be like gosh you look, you look unwell' (Anna)

GET 2: Support and connection

Participants shared their experiences of accessing support through community spaces, healthcare professionals and the charitable sector. Peer, friend, and family support were described as important.

Peer support

'I did go to a fantastic event by...Breast Cancer Now...and I met some amazing, amazing women. And like four of us have become really good friends.' (Tara)

Participants shared a number of perspectives about the value of peer support. Many found it helpful, especially when connecting with women who were of a similar age and had similar experiences to them. Tara described the significance of age when connecting with women who had a breast cancer diagnosis through breast cancer charity, Breast Cancer Now.

'I think a lot of women who I now know or share a similar opinion is that breast cancer traditionally is an older woman's disease, so it was really hard to like try and enter, like virtual especially, but try and enter any sort of group setting where it's like 50, 60-year-old women and you're like, cool, like, we have nothing in common except for breast cancer...women of my age...the worries were just really different' (Tara)

Additionally, Florence met with other cancer patients at her local Maggie's Centre exercise class. Gina and Kamille connected with women from similar backgrounds to them, and comparable experiences, through Black Women Rising, a charity specifically focussing on the experiences of Black women who have a cancer diagnosis. Kamille

shared the importance of this in relation to cancer awareness, especially amongst younger women.

'Genuinely speaking, I thought it was an elderly White woman's disease, you know, erm...just because I never saw, I never Black people come forward. I never saw young people come forward with their stories, so, I think it's about changing the narrative' (Kamille)

Participants valued perspectives of people who had been in the same position as them, rather than individuals who did not have lived experience of breast cancer. Luna talked about her frustration when people who had not experienced cancer tried to reassure her that things would get better. She described hearing the perspective of another younger Korean woman who had a similar experience as being helpful.

Anna did not connect with many women who also had experienced breast cancer during her cancer journey and shared her thoughts about the positives and negatives to this.

'I think the good thing is obviously having that sense of I'm not alone and that other people going through similar thing, and being able to obviously draw on their experiences, but...I would say the bad things about it is that everyone's experiences can be quite different... watching videos with people talking about their experience of chemo, and it's all just so awful and just so terrible and I was just getting like worried and fearful about a lot of things that didn't actually happen to me' (Anna)

Community support

'church supported me, came over, spoke to me, and I love the way they spoke to me.'

(Florence)

Participants shared their experiences of seeking support and finding their faith and spirituality helpful in the face of their cancer diagnoses and treatment. This included finding comfort in prayer, but also accessing support from their faith communities. Women accessed support from community spaces such as churches and hairdressers.

Esther described her hairdresser guiding her throughout her hair journey, making sure she was *'prepped'* before chemotherapy started and advising her in relation to hair loss from her head and the rest of her body. Esther's hairdresser was knowledgeable about the hair loss process and gave her advice, specifically for managing her hair texture (afro hair).

'she kind of got me ready in terms of I guess the aesthetic' (Esther)

Luna described her church community coming together to drive her to appointments and offering gestures such as care packages. Florence talked with her pastor about her experience. She valued how honest and open he was with her, and she felt that in turn she was able to be open about her experiences and feelings in relation to her diagnosis. Others described their communities praying for them and they experienced this as supportive.

'we're quite strong in our like...Christian and so I just, we just had so much like external support in the form of like prayer' (Anna)

Responses from others

'sometimes I'll walk around and, you know, people kind of pity you. Oh, dear, she must have cancer or alopecia or whatever it is like, you know, people just make the assumptions and then start to feel sorry for you, and it's like, oh please, did I ask for your sorry?' (Kamille)

Participants shared how other people responded to them following hair loss. Responses varied amongst group and was dependent on the amount of information about diagnosis that had been shared. The majority of participants reported that their age played a factor in how other people responded to them, and some also felt that people did not always attribute their hair loss to chemotherapy, with alternative suggestions for hair loss being made.

'I just found this lump...and the doctor was like we don't think it's, we don't think it's anything like that...you're too young.' (Gina)

'they were aware that I had like a quite a stressful job so they were like oh are you stressing because of work, so that's, that's pretty much what they associated the hair loss with' (Esther)

Family responses to breast cancer were described. Two participants talked about their families encouraging them to carry on and *'fight'* the cancer. Participants explained family narratives and relationships to cancer affecting familial attitudes to diagnosis. Monica described members of her family previously having been diagnosed with a range

of cancers and having beat their diagnoses. This gave her hope, and it also provided her with a reference point in relation to treatment and outcomes.

Disclosure and non-disclosure experiences

'I said...I have just finished chemo and...you know this is what I've been going through, and maybe like a third of the room knew and then so there was a bunch of people that had no idea, and they were just like, Oh my...' (Anna)

Participants shared their experiences of disclosure, what mediated their decisions to disclose their diagnosis or not, and how they managed having disclosure decisions taken away from them. Kamille expressed concerns about hair loss as she believed that if people saw that she was bald, they would guess that she has cancer and her choice around disclosure would be removed.

'I wasn't concerned about how short it would be, but how I would look bald, and then just like, having to explain to people, because at the time, I hadn't told any-the only people that knew I had the cancer was my family; like immediate family' (Kamille)

Anna and Esther kept their diagnosis from many of their friends and family, with Anna choosing to share her diagnosis in a group setting towards the end of treatment. Esther shared that she did not feel that people needed to know whilst she was going through treatment. When her siblings noticed her hair loss, they attributed it to alopecia induced stress from work, and advised her to seek support from her hairdresser. Esther felt that it was only necessary to share her diagnosis with people who would be able to

help support her practically. She also shared her reluctance to manage other people's reaction to her diagnosis, a sentiment shared by Anna.

'I feel like people don't know what to do when you tell them. That's like one thing. People don't know how to react' (Anna)

Support from family and friends unrelated to hair loss

'that's what your friends and family are there to kind of...support you, egg you on if you need to, to get you through that door' (Esther)

For many of this study's participants familial support was essential as part of their treatment and recovery. Family provided both practical and emotional support.

'I think my family, they were supportive. And my partner, he really...felt it. You know, he felt me losing my hair. But I think it was mainly like my immediate family and group' (Gina)

Anna described moving back home to be close to her family. Her mother came to all of her appointments with her, which she described as '*amazing*' and a '*great support*'.

There were occasions when participants shared that their friends and family were not available to support them when needed. This was often dependent on their job roles and other commitments.

'his job was really, really demanding...sometimes he just had to leave me, and there were times...I literally completely broke down because of his situation where he couldn't look after me, and I was like in need of help' (Luna)

GET 3: Context

Participants' contexts were significant in relation to their experiences of breast cancer. This was described in relation to their cultural backgrounds, the wider social climate during which they were diagnosed and treated, whether they were treated within an NHS context and their location in the UK.

Cultural perspectives

'even as an Indian woman, it was like you've got such long and silky black hair and you know, it's so soft, and you know, it's got a bit of a curl to it, and it's wavy and it's just like, "mm-hmm, that's, that's my hair' (Tara)

The experiences of participants in this study sat within their cultural contexts with culturally informed narratives around hair. This was particularly relevant for Black women, and seemed most evident when participants shared their perspectives around their hair. Both Esther and Florence likened women's hair to a 'crown', and Gina and Anna named their experiences of experimenting with different styles and their familiarity with wearing wigs. As hair is such a statement within the Black community, it was unsurprising that Black women's experiences of hair loss were impacted by their cultural backgrounds.

'in the Black community...that whole message about your hair is your crown...you use it to express yourself, you use it to kind of just project whatever you want into the universe... it boosts your confidence... a lot of people say oh your hair will grow back...they think they're being comforting, but actually they're not really giving a lot of thought to...what hair symbolises' (Esther)

A number of participants described how some of the more negative experiences they had during treatment and recovery pertained to issues to do with the colour of their skin. Tara shared that during the breast reconstruction process, it was difficult to obtain a colour match for the construction of her areola. Gina reported having a similar experience, where images of breast reconstruction on women with a darker complexion were not made available to her, making it difficult to visualise how her breasts might appear after surgery. Images provided were all of White women. Both Tara and Kamille experienced radiotherapy burns. Tara felt that she might have been perceived as overreacting, so did not tell her team about this until she was in a lot of pain. Kamille told her medical team, but they misdiagnosed her several times before realising that she had radiotherapy burns. The delay in diagnosis was because the medical team did not know what radiotherapy burns looked like for someone with her complexion.

'They even called the NHS photographer to come and take a picture of the thing because they had no clue what it was. It turned out to be radiotherapy burns, and obviously, because they haven't seen it on Black skin, they weren't aware. Like, they didn't know what it was,'
Kamille

COVID context

'It got slowed down because it was COVID' (Tara)

Half of the participants in this study had treatment during COVID. This impacted the access they had to services such as wig shops, but also meant that they were not able to connect with other women. Groups were not meeting in person but moved to online

and therefore opportunities for connection were limited. Additionally, they were not always able to have family members join them at appointments.

'because it was COVID, there wasn't really any mixing and you had to be particularly careful because we were already immunosuppressed.' (Parisha)

Some participants continued to work throughout their treatment, many of whom had treatment during COVID. They were able to work remotely and, therefore, more flexibly. They were able to hide or obscure their appearance from colleagues due to remote working and were also able to rest when needed.

Experiences of private vs. NHS treatment

'and I guess the difference on the NHS ward would be that there would be maybe eight beds or whatever in the same room...yeah, they were like big rooms with like a double bed and an ensuite bathroom.' (Anna)

Some participants were seen in private settings, and therefore had different experiences to those that were treated in the NHS. The participants who received private treatment described seeing fewer patients when going to appointments. Often, they were treated in individual rooms, or wards were very small so the opportunity to meet other patients was limited.

'I was treated privately so I've never really met any other women through hospital' (Tara)

Participants seen within NHS contexts were satisfied with their care, and the additional support that they received around fertility and decision making from their medical teams. Luna described feeling '*impressed*' with the option that she had to freeze her eggs on the NHS, naming that if she had pursued this privately it would have come at great expense to her.

4. Discussion

This study considered perspectives of women of colour who had received treatment for breast cancer between the ages of 21 and 35. It explored the impact of hair loss on self-perception and the perceived perceptions of others. It also aimed to explore sources of support accessed by this group of women in relation to their hair, ethnicity and their age, and the perceived support available to them.

The transcripts from the nine interviews were analysed using IPA. There were three GETs that emerged from the data: 'Hair Journey', 'Support and Connection' and 'Context'. These themes were shared by all participants and captured not only their experiences of hair loss because of chemotherapy, but their individual journeys through breast cancer as young women, navigating various contexts and circumstances.

Importantly, this research extends the existing literature by exploring intersectional identities in relation to age and cultural background in the context of a breast cancer diagnosis rather than exploring these phenomena separately.

GET 1: Hair Journey

The participants in this study discussed the hair loss process which was consistent with the findings of a study by Frith, Harcourt (74). Initially participants considered what it would be like to lose their hair. For many this occurred immediately after they received their diagnosis, they then came to terms with the likelihood of hair loss. They prepared themselves for hair loss, and finally, participants described taking control of their hair loss experiences, through shaving their hair or wearing wigs or hair coverings. Despite having been warned about the possibility of hair loss, many felt surprised and distressed when they started to lose their hair. This is consistent with wider literature (26).

Participants described how they perceived their physical appearance. This was rooted in their social contexts, including cultural influences and their age group. Loss of femininity following hair loss was a common experience. This is in line with the literature which suggests that hair loss directly challenges women's identities and sense of femininity and can impact their emotional wellbeing (6-9). Further, literature suggests that women's experiences of their physical appearance are shaped by societal influences (75).

Social identity theory explores the notion that one's sense of self is influenced by group membership (76). Group membership can contribute to self-esteem and provide individuals with a sense of identity (76). There are many ways in which individuals may be grouped. Research suggests that appearance, facial features and hair allow people to be categorized by gender, health status and age (20). When there are visible changes to people's appearance, this can impact how they behave socially and how others interact with them, directly impacting their social identity.

Appearance is linked to identity, and controlling appearance enables people to direct and influence the perception of others about themselves (77). This was evident in this study, where the participants assumed that, because they had lost their hair, others might perceive them as being unwell; however, this was not the case. Alternative explanations for hair loss were often suggested, including stress induced alopecia. Additionally, a Black participant shared that as it is commonplace for women in the Black community to wear wigs, she was not questioned for wearing a wig when she had lost her hair. None of the participants experienced other people assuming they had a cancer diagnosis, and that hair loss was a result of chemotherapy.

These findings are supported by theories around body image and self-esteem which can both be impacted by hair loss (18, 78-80). Body image describes appearance

satisfaction or dissatisfaction, appearance investment, appearance behaviour and the emotions that are related to appearance (81). Appearance investment involves motivational salience, which refers to how people might manage their appearance to improve their attractiveness, and self-evaluative salience, which refers to the importance placed on physical appearance in relation to self-worth and self-concept (81). Additionally research suggests that hair loss is linked to feelings of humiliation, decreased self-esteem and increased depressive symptoms(82). All the participants in the current study reported changes to their body image in line with the model presented above. They engaged in appearance investment in relation to hair loss, some describing using wigs or head coverings and some using false eyelashes or makeup to recreate eyebrows. They did not report depressive symptoms in relation to their hair loss, but some did share that hair loss had a negative impact on their mood. Moreira, Silva (81) found that higher levels of depression, lower psychological and social quality of life and fear of others' negative responses to cancer patients were predicted by higher levels of self-evaluative salience. Higher levels of motivational salience were protective.

Body image concerns can link to self-esteem. All of the participants in the current study experienced a disruption to their 'norms', and some reported changes to their sense of self as a result of emotional, behavioural and cognitive changes (37) during diagnosis and treatment of breast cancer. Whilst there is a focus in this study on the impact of hair loss on individuals, breast cancer diagnosis must be held in mind especially in relation to women's sense of self. Many of the participants reported narratives around age and breast cancer, many of them believing that they were too young to receive a diagnosis. For some, this was reiterated by their medical teams. The diagnosis may have felt sudden and unexpected for women, potentially challenging their norms (30) and impacting psychological wellbeing and the desire to engage with others (31-33).

GET 2: Support and connection

Changes to self-esteem and self-image, may lead cancer patients to experience feeling a loss of control(83), which in turn may prompt identity re-evaluation(84). Patients may experience distress as a result, but studies report that such distress may be managed by accessing psychosocial support(85), which may improve psychological well-being and illness adjustment(86). Few participants in this study spoke about psychological support accessed during this time, although one participant engaged with MacMillan once in remission. However, participants emphasised the importance of connection and peer support, consistent with research that highlights the benefits of such support on wellbeing for individuals with cancer (87).

Literature reports that peer to peer support in particular is effective in promoting emotional wellbeing, reducing negative symptoms, and improving stress management and quality of life (88, 89). Further, research suggests that peer to peer support can offer additional benefits when individuals are matched according to cultural background as unique cultural perspectives and experiences may be shared (89, 90) and culturally relevant support provided. This was relevant to participants in this study, who emphasised the importance of connection with their communities and peers with similar experiences. They emphasised the importance of the type of support offered, which aligns with research that highlights that the quality of support can have a significant effect on patient wellbeing, rather than the quantity (91).

In relation to hair loss, participants sought tailored support from hairdressers and advice from peers with similar experiences. Additionally, emotional support was sought from faith groups and members of the local community. This is in line with research which suggests that Black and South Asian women draw on support in relation to their

diagnoses from their communities, drawing on religion for both explanations of illness and sources comfort (57, 65) and with Black women, in particular, accessing culturally relevant community support (57, 65). This was evident in the study with women reporting the importance of their faith groups and communities in providing practical and spiritual support, and with Black women in particular naming the importance of hairdressers that knew how to manage their hair texture.

Participants in the study used scalp cooling with varying success. Black women in particular shared that they felt the scalp cooling process was not designed for afro hair and, therefore, were reluctant to use it during chemotherapy. A study published in 2021 (data were collected in 2019) reports that scalp cooling is less effective for women of colour (92). However, there were 14 participants that took part in the study, the trial closed due to lack of efficacy, and it was based in the USA where scalp cooling is relatively new (93). Paxman (93) reports qualitative data from patients who have experience of scalp cooling, and there is existing best practice guidance for using the cold cap with type three or type four hair (94). Services should refer to such guidance when advising patients around cold cap use.

Participants in this study discussed disclosure experiences. Most shared their diagnosis with their family and friends, but others decided not to disclose. Reasons for this included protecting the emotions of other people, avoiding managing the responses of others and wanting to maintain a sense of normality. Barlow and Lloyd-Knight (95) explored how women from Asian and Black women make decisions to disclose a breast cancer diagnosis. Asian women reported feelings associated with shame that influenced their decisions regarding disclosure, and Black women reported wanting to protect family and friends from experiencing difficult emotions regarding the diagnosis.

GET 3: Context

Context was an important theme in this study. Whilst it was expected that age and cultural background would impact cancer experiences, contexts such as treatment setting (NHS or private), the context of COVID-19 and location in the country were important factors to consider.

Some participants had treatment during the pandemic, which shaped their treatment experiences. During this time, cancer patients mostly communicated with their healthcare teams remotely and other support spaces that would have ordinarily been offered in person were not available (96). Not only would this have impacted on relationships between patients and their medical teams, but it also limited the opportunity for patients to interact in treatment spaces as they would have done prior to the pandemic. Feelings of loneliness and isolation within cancer patients are likely to have increased as a result (96).

In line with the research, the participants in this study reported feeling significant differences between their experiences as younger women and the experiences of older women. Despite having had similar treatment trajectories, experiences were dependent on life stage and the age that they are diagnosed (42, 43). For some, connecting with women the same age was more important than making connections with women from the same cultural background.

Strengths and limitations

Strengths

This study explored younger women of colour's experiences of hair loss due to chemotherapy for breast cancer. A key strength is the unique exploration of age and

cultural background in relation to this phenomenon. The research highlights the specific needs of this cohort, and data collected from the nine participants were rich and in depth. A diverse range of women were recruited, across cultures, ages, and areas in the UK.

A further strength is that the lead researcher is a woman of colour who previously lost her hair because of chemotherapy for breast cancer. Some shared characteristics between the researcher and participants may have allowed for a degree of openness and inferred understanding. This is acknowledged in the lead researcher's reflexive statement (page 69) and further reflections on the experience of hearing her participants' accounts can be found in Appendix 11. The experiences of the research team in relation to cancer diagnoses are also acknowledged (page 69) and it is important to consider that this may have shaped the interview and analysis of the data.

Using IPA allowed for a detailed account of participants' experiences of hair loss. It is an approach particularly suited to understanding patients' illness-related experiences (97), privileging individual narratives. The approach also allowed for reflexivity of the researcher and allowed for interpretation of data collected (66).

Limitations

Participant interviews for this study were carried out either online or in person. There were differences observed when interviews were in person compared to when interviews were online. Rapport building was easier in person, and data obtained were richer. This is something that has been observed in the literature (98). Furthermore, it has been suggested that completing online interviews introduces distance between researcher and participant (99). Whilst the online interviews in this study were structured in a way that considered their remote nature, it was not possible to observe participants' body language or to be sure of their environment (100). Additionally

managing emotion was easier when in the same room as the participants. In person interviews took place at Maggie's Centres and not all participants had a Maggie's Centre in their locality, therefore it would not have been possible for all interviews to be completed in person. Additionally, online interviews allowed for additional flexibility and potentially increased accessibility for participants.

This study reported the experiences of women of colour, using an umbrella term to include experiences of women who self-identified as being from minoritized backgrounds. Women from different cultural backgrounds reported different experiences, and it is important to consider the heterogeneity between ethnic groups in the sample.

The sample consisted of nine participants as per the IPA approach, whilst this provided rich data and a thorough narrative of experiences, findings lack generalisability due to the small sample size.

Clinical implications and recommendations

The study findings were shared with a lead MacMillan cancer nurse and the clinical implications and recommendations for clinical practice were discussed and co-developed. This was to ensure that recommendations made were meaningful, realistic and applicable to current practice.

This research highlights gaps in support in relation to hair loss that is culturally informed. Participants felt they were underprepared from healthcare professionals for the realities of hair loss. They received support from their communities when managing the process, including hairdressers and family. It is important that information about the hair loss process, including information about losing body hair, is communicated to patients by healthcare staff clearly and that patients are directed to relevant sources of

community support, such as hairdressers and wig makers. This should be done prior to starting chemotherapy, at the pre-assessment stage.

Participants were reluctant to engage with the scalp cooling process, with some doubting whether it was suitable for all hair types. Patients' expectations of scalp cooling should be managed, and accurate information about outcomes should be provided. Furthermore, NHS services should provide nursing staff with thorough and regular training on the use of the cold cap with different hair types. Patients should be offered informed advice when making decisions about scalp cooling.

The importance of support and connection throughout journeys with breast cancer was highlighted in the study, this is in line with research that reports that peer support and connection have positive effects on mental health and wellbeing. Patients should be informed about relevant support groups, and services may consider implementing buddy systems, connecting patients of similar age groups with similar experiences.

There are existing charities, many of which have an online presence, that women can be directed to. Developing stronger working relationships between such charities and the NHS may provide opportunities for collaborative working between services and increase the likelihood of facilitating connections and relationships between patients. Additionally, all patients should be offered a breast cancer nurse specialist who can offer emotional support around hair loss and changes to identity because of breast cancer. If necessary higher intensity psychological support can be accessed through nurse specialists. MacMillan services are available for both private and NHS patients, and this should be communicated to patients clearly. Patients should be encouraged and supported to access these spaces.

It is also important for therapists to be aware of some of the existing contexts for women of colour with a diagnosis of breast cancer, including the context of medical racism and potential difficult experiences with hair loss and changes to identity. Specific training with a focus on working cross culturally may be beneficial. Within the therapeutic space patients should be given permission, time and space to allow for vulnerability and open discussion about their experiences.

Finally, to improve experiences of services for younger women and women of colour with breast cancer, it is important that services obtain feedback from patients and implement this in ongoing service development.

Future research

This study highlighted the multifaceted experiences of younger women of colour who lost their hair as a result of chemotherapy for breast cancer. Future research might consider the experiences of women from specific ethnic groups. Additionally, this study focused on the experiences of women losing their hair, but other breast cancer related experiences within the younger female population should be explored. This includes experiences of disclosure, employment experiences and relational experiences of this group of women. It is important that the context of the UK healthcare environment is considered in future research, addressing both the NHS and private systems.

Conversations with other expert researchers in the field highlighted the significance of researcher's cultural background in recruiting and engaging women from minoritized backgrounds when discussing their experiences from a cultural perspective. Additionally, at the research proposal stage, queries were raised about recruiting women from minoritized groups to talk about cancer. This highlighted the importance of

protected characteristics in research and considerations should be made in relation to the researcher identity in future research with a similar topic area.

5. Conclusions

This research explored the experiences of nine young women of colour in the UK who had lost their hair due to chemotherapy for breast cancer. The themes from interviews highlighted the challenges faced by women during this time, including experiences relating to age and lack culturally informed support around hair loss. It is important for services to provide patients with accurate information about hair loss and ensure that necessary support is offered around the hair loss process.

This research highlighted the need for connection for younger women and the impact of context on the experiences of women. Services should hold this in mind and promote connection for younger patients, liaising with appropriate charities and third sector organisations to support this process. Future research should consider experiences of this population, focussing on wider cancer experiences, rather than focussing on hair loss.

6. References

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Chapter 2: Systematic review*

What are the experiences of families when a diagnosis of female breast cancer is shared? A systematic review and narrative synthesis

*To be submitted to: Psycho-Oncology, Journal of Psychological, Social and Behavioural Dimensions of Cancer (see Appendix 1 for author guidelines). The word count for this journal is 4000, however, when writing this paper, to provide adequate detail for viva examination, this has been extended.

Abstract

Objective: This review aimed to systematically review and integrate findings from qualitative studies exploring how the news of a female breast cancer diagnosis is shared within families in the UK. The review aimed to consider the experiences of adult women sharing a diagnosis with family members, and how family members experience receiving the news, with the view of making recommendations for the UK's National Health Service (NHS) practice.

Methods: Four databases were searched from inception to February 2023. Full text, peer reviewed articles that explored familial sharing of a breast cancer diagnosis for adult women in the UK were considered for inclusion. Thematic analysis was used to synthesise the data.

Results: Nine studies were included in this review. They explored the experiences of adult women communicating their breast cancer diagnosis to family members, and the experiences of family members hearing about the diagnosis and managing its impact. Familial perspectives included the experiences of children and spouses. Five themes emerged: 1) maintaining normality, 2) disclosure experiences, 3) the impact of diagnosis on family functioning, 4) sources of support and 5) emotions and reactions.

Conclusions: The findings demonstrate the ongoing nature of disclosure during the cancer journey and the reasoning behind women's disclosure decisions. Support needs around disclosure were highlighted, and these were discussed within the context of family systems theory. Recommendations for future research are made.

KEYWORDS: *Breast cancer, women, sharing, diagnosis, disclosure, family, support, UK*

1. Introduction

Breast cancer is the most common cancer affecting women worldwide (1) and in the UK (2) with a diagnosis impacting physical functioning (3) and emotional wellbeing (4). Research findings suggest that receiving a diagnosis of breast cancer has an impact on the individual and their wider social system (5-7), and, although those with a diagnosis require support, family members may also benefit from support during this time (8).

Patterns of disclosure

Family and friends are a key source of support for individuals with a cancer diagnosis (9). However, patterns of cancer disclosure vary between groups. One study reported that 7% of women with a diagnosis of breast cancer reported little or no disclosure to anyone apart from their doctor or spouse, and 20-30% of women reported little or no disclosure to a large proportion of their social networks, such as friends and family (4). Not only can this have an impact on available care from friends and family, but studies have also shown that unclear communication of diagnoses can impact loved ones, with open communication being associated with better mental health outcomes for adolescent children whose mothers have breast cancer (10). Research has found that inconsistent communication is associated with negative relational outcomes between couples where mothers have a diagnosis of breast cancer (11). Furthermore, open and constructive communication around cancer is related to higher relationship functioning in romantic couples (12).

It has been reported that the quality of interpersonal relationships in the recovery period for individuals with cancer can predict their emotional adjustment (13, 14). Negative responses from spouses and avoidance of discussions about the diagnosis can

have a negative impact on adjustment for cancer patients (15, 16). In line with this, research suggests that there is a link between disease disclosure and outcomes following a diagnosis of cancer (4), with women's adjustment to breast cancer being positively influenced by emotional support from their husbands (17).

The impact of illness on families

Research highlights that cancer is a phenomenon that is experienced within a familial context, not just by the individual in receipt of a diagnosis (18, 19). Receiving a diagnosis can affect relationships and familial interactions (20, 21). Experiences of illness may be influenced by a family's dominant culture and context. For example, there are variations across cultures (internationally) in breast cancer awareness, which might lead to later diagnosis and poorer outcomes, which may in turn have an impact on cancer narratives within particular cultures (22). This has been reported in Oman (the Middle East), where studies have found that breast cancer patients have poorer outcomes than their Western counterparts (23). Additionally, in the UK similar disparities have been reported between outcomes for Black and Asian women who receive a diagnosis and their White British counterparts (24). Additional pressures such as finances, lack of accessibility to treatment and stigma that may sit within a societal context may have an impact on illness perception within families (20).

Historically, the family has been identified as the main source of support for individuals with breast cancer and there are reported emotional changes experienced by family members following a diagnosis within the family unit (25). It is important to understand family functioning within the context of illness including exploring health-related quality of life within family systems. (21). In line with family systems theory, when a family member is diagnosed with an illness, the wider family system is affected (26).

The response to illness is something that reverberates throughout the system and will often affect other people in the family (21). Therefore, in relation to this systematic review, it was important to consider the wider family when exploring disclosure patterns.

Mehta, Cohen (27) report the importance of caring for the whole family when an individual experiences a life-threatening illness, drawing on family systems theory. Family systems theory is presented as valuable in relation to considering an individual's diagnosis and its impact on daily familial functioning (28). The theory focusses on interactions within the family, and the interaction of the family with other systems (27) and asserts that changes in individuals will impact the wider family (29). The model considers hierarchies within the family, familial subsystems (e.g., parent child dyads, sibling relationships and spousal partnerships), and familial boundaries. It also describes how the family (as a whole), and its subsystems, might interact with wider systems. In the context of oncology, this may be in relation to the healthcare systems involved with the family unit. Familial boundaries are also considered. The theory states that when family boundaries are more relaxed, families are more likely to accept resources, support and have more open communication with systems that are able to offer help (27). Within the model, the family is seen as a whole, with greater resources as a collective group than when divided into individual parts (29). Understanding how each part of the family relates to one another can help others recognise patterns of familial communication and relatability (27). Finally, it is important to hold in mind that changes to one part of the family system may lead to compensatory changes in another part of the system (30).

Rationale for the current review

Existing systematic reviews on the impact of female breast cancer on family members, have mainly focussed on the impact of maternal breast cancer on children,

rather than considering the perspective of the person with the diagnosis (31, 32). There is also a lack of systematic reviews addressing the implications of a breast cancer diagnosis on family life (21). Furthermore, reviews considering disclosure have a wide focus, exploring the experiences of women worldwide (8, 33), however, there has been less explored in relation to specific societal contexts, despite this having an impact on the trajectory of illness. There is also a lack of consideration of familial experiences of the diagnosis in existing reviews.

A recent systematic review focussing on maternal communication of cancer diagnoses to younger children reported that there were a number of factors impacting communication patterns between mothers and children, which included characteristics of the children, family communication patterns and mothers' emotions and needs (33). This review highlighted commonalities between mothers breaking news of the diagnosis to their children but recommended that future reviews consider voices of other family members, namely fathers (33).

Research question

What are the experiences of families when a diagnosis of female breast cancer is shared?

Review aims

The current review focused on the experiences of adult women with breast cancer when communicating their diagnoses with family members, and the experiences of family members learning of the diagnosis. The review focused on a UK population with the aim of reviewing the research within a specific societal and cultural context leading to

recommendations for practice within the NHS, specifically, especially around supporting families to manage these difficult conversations.

There are very few systematic reviews that capture experiences of individuals sharing their breast cancer diagnoses within their families. Whilst a recent review explored disclosure of breast cancer diagnosis, this focussed on the mother-child dyad, particularly on children who are considered 'minors' (children were between the ages of 3 and 20), rather than taking the wider family into consideration (33). It is important to gain further understanding of family members' experiences to understand the nature of support required and to inform recommendations for services supporting women when sharing their breast cancer diagnoses with family and loved ones. This review includes experiences of disclosure of both primary and secondary diagnosis of breast cancer, in order to observe any differences in communication patterns, and to identify any specific support needs for families experiencing each type of diagnosis.

2. Methodology

Search strategy and design

This narrative review used a systematic search strategy and thematic synthesis to search and consolidate the existing qualitative research which focussed on familial communication of female breast cancer diagnoses in the UK. The review followed the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement (34) (see Appendix 12).

Studies of interest

The PICO (population, phenomenon of interest and context) framework (35, 36) was used to develop the focus for this systematic review. This is detailed below (Table 1).

Table 2: The PICO framework

Population	Phenomenon of interest	Context
Families where a female over the age of 18 has been diagnosed with breast cancer. The family and individual with the diagnosis must live and have been diagnosed and treated for breast cancer in the UK	Experiences, thoughts and feelings about how the diagnosis is shared, communicated and discussed between family members, from the perspective of family members as well as the individual with the breast cancer diagnosis.	Community contexts, where individuals with a diagnosis of breast cancer and their families may access treatment and support. This may extend to outpatient facilities at hospital but does not include palliative or inpatient settings.

Search methods and inclusion and exclusion criteria

Preliminary scoping searches were completed in February 2023 using PubMed/Medline and Google Scholar to identify keywords and to explore the current evidence base. This process helped refine and develop the review question. A search was also carried out on PROSPERO (Centre for Reviews and Dissemination's international prospective register of systematic reviews). Whilst there were reviews listed that

explored communication of breast cancer within different relationships (8, 33), none focussed on the context of the UK specifically or considered perspectives of multiple family members in relation to disclosure experiences.

The current review was registered with PROSPERO (Ref: CRD42023403559) and a protocol was developed in March 2023.

A computerised search was performed using PubMed/MEDLINE (via Ovid), Web of Science (Core Collection), CINAHL and PsychINFO (via EBSCO). This was in line with recommendations, but also with similar existing reviews (8, 33). The inclusion and exclusion criteria are displayed in Table 2. This current review focused on experiences of familial communication of diagnosis within a UK population.

Table 3: Inclusion and exclusion criteria

<i>Inclusion criteria and exclusion criteria</i>
Studies were included if:
a. They were qualitative studies.
b. They were full text studies.
c. They were published in a peer-reviewed journal.
d. They were written in English.
e. They focussed on communication of a diagnosis of breast cancer between family members.
i. Focussed on the diagnosis being shared with partners, parents, siblings, or children of women with breast cancer.
ii. From the perspective of women with breast cancer, their partners, siblings, or children.
f. They focussed on disclosing primary or secondary breast cancer diagnosis. In studies where other cancer diagnoses are explored, the dominant diagnosis must be breast cancer.
g. They have a participant sample where a family member is a female over the age of 18 with a diagnosis of breast cancer.
h. They have taken place in the UK.
Studies were excluded if:
a. They were quantitative studies.
b. They were systematic reviews.
c. The focus of familial communication is a type of cancer diagnosis other than breast cancer.
d. Communication was not within the family.
e. The focus was on terminal breast cancer.
f. The participants were in palliative care.
g. They were not published in a peer-reviewed journal.
h. They were not written in English

Search terms

The same search strategy was maintained across all databases for continuity. The search strategy included the terms listed in Table 3.

Table 4: Example search terms.

	Concept 1	Concept 2	Concept 3	Concept 4
	Combined with 'AND'			
Combined with 'OR'	Communicat*	Child*	Breast cancer	Experience
	Disclos*	Spouse	Female breast	Event
	Discuss*	Relative	cancer	Feelings
	Shar*	Family		about
	Talk*	Parent		Qualitative
	Tell*			Narrative
	Inform*			Account
	"Break bad news".			

Data extraction

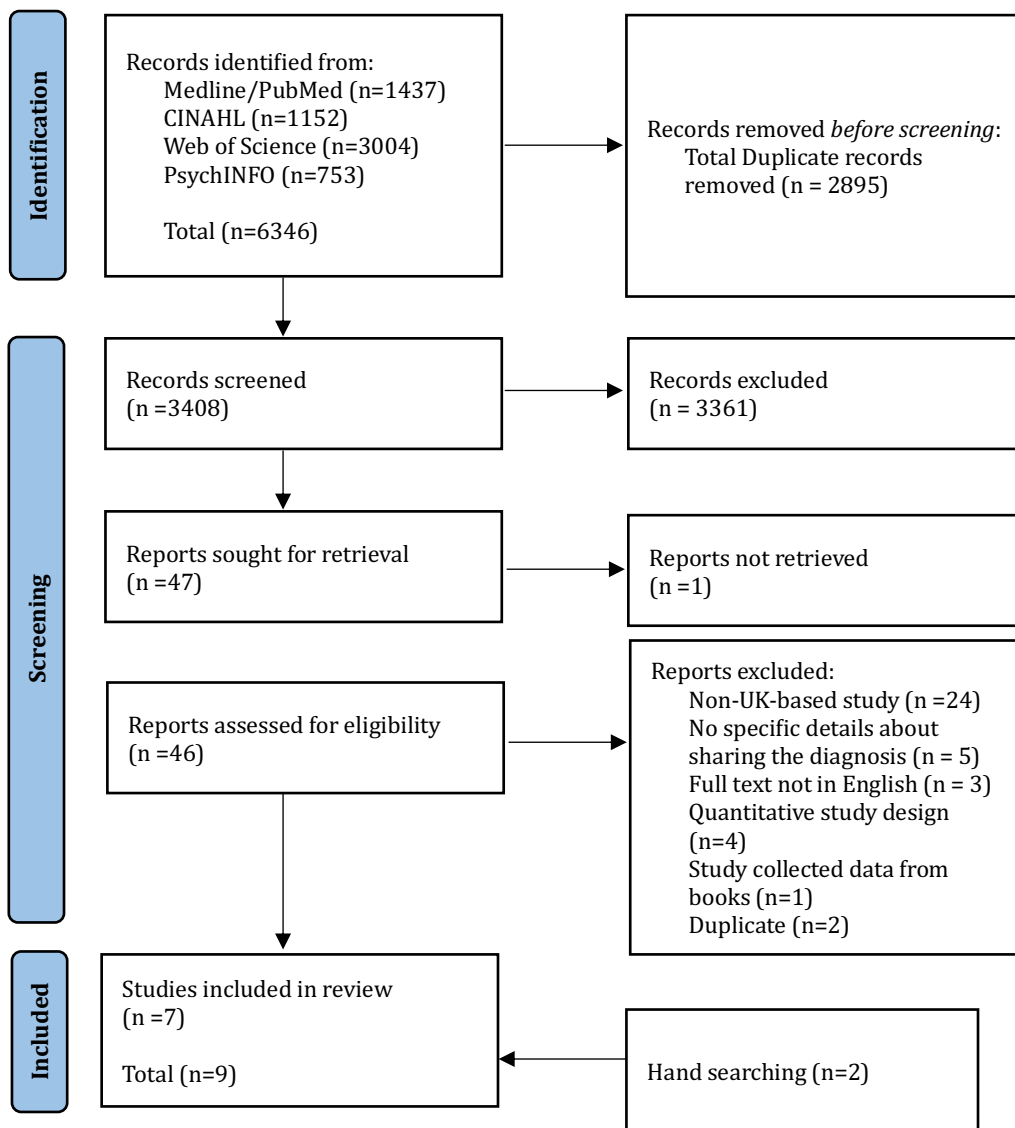
Searches were carried out in accordance with the ENTREQ statement (34). The lead researcher scrutinised all full-text papers. Search results were saved to and screened through Rayyan, an online systematic review management programme. Duplicates were removed, and missing data were requested from study authors. Searches were repeated prior to the completion of the review to ensure that all publications were included.

Thematic synthesis was used to synthesise findings of papers included in the review (37). This involved analysing included texts and identifying recurrent themes observed. A summary table (Table 6) was used to detail the key themes in the literature (38). Subthemes from the texts were identified and were then grouped into wider themes. Wider themes were 1) maintaining normality, 2) disclosure experiences, 3) the impact of diagnosis on family functioning, 4) sources of support and 5) emotions and reactions.

Search outcome

A total of 6346 papers were identified across four databases. After duplicates had been removed, 3408 papers were identified for screening of titles and abstracts. 47 papers were identified, of which 46 full texts were obtained (one full text was unavailable). Full texts were screened against the inclusion and exclusion criteria. 39 papers were excluded, and seven met the inclusion and exclusion criteria. Two additional studies were included following hand searching the reference lists of included papers. Twenty percent of the papers identified for screening were screened by an independent reviewer (MKH). There was full agreement between raters regarding the papers included. Figure 1. outlines the search process and the number of papers identified for inclusion in this review.

Figure 1: Identified papers and PRISMA flow diagram



Quality assessment

The quality of the nine included papers in this review was assessed and evaluated using the 10-item Critical Appraisal Skills Programme (CASP) (39) checklist for qualitative studies, a widely used quality assessment tool for assessing qualitative research (Table 4). There were no concerns about the quality of studies and all studies were included.

The majority of studies met most of the CASP checklist criteria (see Table 4), however, many did not consider the researcher's relationship with the participants. Only three studies explored this.

Table 5: CASP quality assessment tool

	(Ashbury et al., 2014)	(Barnes et al., 2000)	(Corney et al., 2016)	(Finch & Gibson, 2009)	(Forrest et al., 2006)	(Forrest et al., 2009)	(Kenen et al., 2006)	(Lalayianni et al., 2018)	(Sheppard & Markby, 1995)
Screening questions:									
Does the paper report on findings from qualitative research and did that work involve both qualitative methods of data collection and data analysis?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is the research relevant to the synthesis project?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
CASP questions:									
Section A: Are the results valid?									
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is it worth continuing?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Has the relationship between researcher and participants been adequately considered?	No	No	No	Yes	No	No	No	Yes	Yes
Section B: What are the results?									
Have ethical issues been taken into consideration?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Section C: Will the results help locally?									
How valuable is the research?	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable

3. Results

Themes from the literature

The nine studies included in the review explored sharing and receiving news of a female breast cancer diagnosis within families. Three of the reviewed studies explored mothers' experiences of sharing a breast cancer diagnosis with their children. Two of these studies focused on primary breast cancer diagnosis (40, 41), and one explored the experiences of mothers with a diagnosis of secondary breast cancer (42). Three studies explored parental cancer diagnosis from young people's and children's perspectives. Two studies compared children's experiences to parental experiences of maternal breast cancer (6, 43) and one study explored the experiences of young people finding out about parental cancer (44). Two studies explored the experiences of partners of the diagnostic process, one from the perspective of couples with young children, and one from the perspective of men who had lived experience of having a partner with female breast cancer (11, 45). One study explored experiences of women sharing their diagnosis of breast cancer after being told that they also carry the BRCA (BReast CAncer) gene (46). The BRCA describes a particular gene that makes an individual more susceptible to breast and related cancers. Table 5 details studies included in the review, and Table 6 displays study characteristics for studies included in the review.

Table 6: Included papers

Author (year)	Title
Ashbury et al. (2014)	How do I tell the children? Women's Experiences of Sharing Information About a Breast Cancer Diagnosis and Treatment (40)
Barnes et al. (2000)	Qualitative interview study of communication between parents and children about maternal breast cancer (41)
Lalayiannis et al. (2018)	How do women with secondary breast cancer experience telling their adolescent children about their diagnosis? (42)
(Forrest et al., 2006)	Breast cancer in the family—Children's perceptions of their mother's cancer and its initial treatment: Qualitative study (6)
(Forrest et al., 2009)	Breast cancer in young families: A qualitative interview study of fathers and their role and communication with their children following the diagnosis of maternal breast cancer (43)
(Finch & Gibson, 2009)	How do young people find out about their parent's cancer diagnosis: a phenomenological study (44)
(Kenen et al., 2006)	'Social Separation' Among Women Under 40 Years of Age Diagnosed with Breast Cancer and Carrying a BRCA1 or BRCA2 Mutation (46)
(Sheppard & Markby, 1995)	The partner's experience of breast cancer: a phenomenological approach (45)
(Corney et al., 2016)	Couple relationships in families with dependent children after a diagnosis of maternal breast cancer in the United Kingdom: Perspectives from mothers and fathers (11)

Table 7: Study characteristics

Author (Year)	Study Objectives	Sample Characteristics	Ages	Methodology	Results
(Ashbury et al., 2014)	To explore experiences of mothers sharing their diagnosis of breast cancer with their children and to explore reasons for this.	10 women with breast cancer with children living at home. 9 participants (90%) lived with their partners, and 1 (10%) lived alone.	Mothers- Not reported. Children-2-24, mean age-13	Qualitative – semi structured interviews lasting up to 60 minutes Analysis-thematic analysis	<ul style="list-style-type: none"> • Women wanted to protect their children from distress by maintaining normality, managing the amount of information shared about the diagnosis, and managing their emotions. • Children’s wellbeing was the priority. • Children’s personalities influenced how much women shared. • Women both shared and withheld information from children as they deemed appropriate.
(Barnes et al., 2000)	To explore how parents communicate maternal breast cancer diagnosis and initial treatment with their children.	32 women with stage 1 or stage 2 breast cancer children (mean age, 12). 27 (84%) participants were married or in a stable relationship.	Mothers- 31-52, mean age-43 Children- mean age-12	Qualitative – semi structured interviews Analysis-content analysis	<ul style="list-style-type: none"> • Most women spoke to their partners about their diagnosis from the early stages, but few women told their children until a formal diagnosis was given. • There was variability in the information shared with children. • Women both shared and withheld information from children as they deemed appropriate. • Most mothers would have welcomed support from healthcare professionals regarding sharing diagnoses with children.
(Lalayiannis et al, 2018)	How women with secondary breast cancer experience telling their adolescent children about their diagnosis of secondary breast cancer	7 women with secondary breast cancer with at least one child living at home at the time of diagnosis. 3 participants were married, 2 were divorced, 1 was single and 1 was widowed.	Mothers- age not reported. Children-9-19	Qualitative semi structured interviews Analysis-interpretative phenomenological analysis (IPA).	<ul style="list-style-type: none"> • Women found it easier to tell children about the diagnosis the second time having cancer. • The age and maturity of their children helped them when deciding what to say and how to share the diagnosis with children. • The diagnosis had an impact on the wider family
(Finch & Gibson, 2009)	To understand how young people experience learning about their parent’s cancer diagnosis.	7 young people, 4 participants had mothers who had a diagnosis of breast cancer and 3 participants had fathers	14-18	Qualitative-semi structured interviews Analysis-interpretative	<ul style="list-style-type: none"> • When young people first heard about parental cancer diagnosis, they worried about parental death. • Most young people had the diagnosis shared with them following test results confirming the diagnosis.

with a diagnosis of non-Hodgkin's lymphoma and Acute myeloid leukaemia.

phenomenological analysis (IPA).

- Communication of the cancer diagnosis was not a single isolated incident but was an ongoing conversation.
- Young people modified their behaviour to be emotionally strong and to provide support to their family.
- Support was offered to young people following knowledge of the cancer diagnosis, especially from school. Little support offered from hospital.

(Forrest et al., 2006)	To explore children's illness perceptions of their mothers who have been newly diagnosed with breast cancer and their initial treatment, and how these contrast with mothers' perceptions of their children's perspectives.	37 mothers with early breast cancer and 31 of their children. Interviews were carried out separately with mothers and children.	Mothers mean age-46 Children-between 6-18	Qualitative semi structured interviews Separate interviews for mothers and children. Analysis-thematic analysis	<ul style="list-style-type: none"> • Mothers reported not realising how aware of cancer their children were. • Some children found out about diagnosis before being told. • Most children were told about the diagnosis by both parents together. • Children over 10 were normally told that their mother had breast cancer, but children between the age of 6 and 10 were told that their mother was ill, • Children of different ages wanted to know different things about the diagnosis.
(Forrest et al., 2009)	To explore communication between fathers and children following a diagnosis of maternal breast cancer,	28 fathers with female partners who had breast cancer, 26 of whom lived with the family (23 birth fathers and 3 stepfathers).	Father's mean age-46 Children-between 6-18	Qualitative semi structured interviews Separate interviews for fathers and children. Analysis-thematic analysis	<ul style="list-style-type: none"> • Fathers felt that they needed to maintain a family life and normality, so took on the management of practical tasks around the house. • Most fathers said that they believed in an open and honest approach when talking about maternal breast cancer. • Fathers offered support to children following maternal diagnosis; trying to make sure that children understand what is going on, providing opportunities for children to ask questions and to talk things over, to ensure that the children's school is aware of the situation.
(Kenen et al., 2006)	To explore the experiences of women who had been diagnosed with breast cancer under the age	13 women who developed breast cancer under the age of 40 and who were	Women's' age range-49-59	Qualitative semi structured interviews within 3 focus groups.	<ul style="list-style-type: none"> • Women experienced separating themselves from others. • Some family members shared that they did not know what to say, so instead they avoided conversations following diagnosis.

	of 40 and who identified as being carriers of the BRCA 1 or BRCA 2 mutation.	identified as carrying the BRCA+ mutation.		Analysis-not reported	<ul style="list-style-type: none"> • Women avoided talking about the BRCA mutation with family members. • Most women felt an added sense of guilt telling people about their diagnosis of breast cancer, but then also having to explain that they also carry the BRCA gene.
(Sheppard & Markby, 1995)	To describe the immediate lived experience of partners of breast cancer patients.	7 men who had lived experience of their partners being diagnosed with breast cancer	Not reported	Qualitative ‘in depth’ interviews Analysis-interpretative phenomenological analysis (IPA).	<ul style="list-style-type: none"> • Men were fearful about their wives’ futures, and worried about whether they had cancer themselves. • They shared a feeling of helplessness and being in denial about the diagnosis. • Men described having mixed emotions at this time, many of which they struggled to verbalise.
(Corney et al., 2016)	To explore the facilitators and barriers to relationships in families with dependent children after a diagnosis of maternal breast cancer.	23 participants, which consisted of 10 couples and 3 women whose partners declined to take part. All participants were married and in heterosexual relationships.	Women’s age range-31-48, mean age-40 Children’s ages from 8 months-23 years old.	Qualitative-in depth semi structured interviews. Analysis-Thematic analysis	<ul style="list-style-type: none"> • Men reported initially coping well with their partner’s diagnosis, but became stressed, exhausted, and frustrated over time. • Recognition that there is little emotional support offered to partners from healthcare professionals. • Women responded to their illness in different ways; some tried to make light of it and carry on as normal, and others became depressed and detached. • Couples experienced difficulties talking about the illness after diagnosis, some preferred to not talk about it but others wanted to discuss it.

Theme 1: Maintaining normality

Studies included explored the theme of maintaining normality.

I didn't want them to see us, I mean if I was upset, I made sure I did it out of, I got upset at work ... I thought I could let it out there, the kids won't see us here (40), p567.

Four studies focussed on the context of normality within the family unit, (40, 42) three studies reported mothers' wishes to preserve normality for their children and one study reported fathers' perspectives on this (6). Additionally, another study reported children being able to maintain normality by continuing to engage in everyday activities such as continuing to attend school (44).

Asbury, Lalayiannis (40) explored the importance of maintaining normality within the family unit for mothers. Mothers reported this serving as a way to protect their children and household from the effects of the diagnosis, and shared a number of ways in which they did this. Mothers attempted to maintain routines in the family home in the face of roles potentially changing. Additionally, mothers tried to limit their children's exposure to the effects of treatment, such as hair loss and surgical wounds.

Managing parental emotions about the diagnosis when the children were present was significant in maintaining familial stability (40, 42). Mothers reported minimising their own needs and reactions, trying to maintain a positive attitude when they were around their children (40), with mothers reporting to express negative emotions about the diagnosis when they were away from their children. One study explored mothers putting on a façade of strength as a means of protection for their children from worry

(42). Maintaining normality served a dual function and mothers reported a positive impact on their own wellbeing (40).

This was similar in another study, considering fathers' and children's experiences of communication of maternal breast cancer (6). Fathers reported feeling the need to maintain family life and a sense of normality for their children and took on practical tasks around their homes as their partners were no longer able to do this. Although fathers felt it was important to provide normality for their children, they reported struggling to maintain a sense of normality for themselves, finding that taking on more practical tasks at home, and managing at work was sometimes too difficult.

Theme 2: Disclosure experiences

There were varying perspectives regarding disclosure decisions across studies. Six of the included studies explored decisions around disclosure of diagnosis, and the experiences of family members experiencing the diagnosis being shared.

...I didn't tell them when I had found the lump and I didn't tell them when I was having investigations, I kept that, I did tell my husband obviously and me mam and me sister, but I didn't tell the kids, I only told the kids when it was actually confirmed that it was a cancer (40), p568.

Barnes, Kroll (41) explored communication of diagnosis and treatment between mothers with breast cancer and their children. Decisions around disclosure were also explored. Mothers shared that they wanted to withhold information from their children to avoid conversations and questions about cancer and death, to prevent distress, to preserve special family time and also because they did not always feel that their children would be able to understand their illness (41). Ultimately, mothers aimed to protect their

children by withholding information. This was reported in another study in this review (40). By not communicating the diagnosis to children, mothers were also able to protect their own emotions and worries about their mortality (41). Other studies reported reasons for nondisclosure including avoiding difficult conversations and protecting children's emotions. There were variations in relation to what to tell children, when to tell them and how much to tell them, if anything at all (40-42).

One study explored women's experiences of disclosure when they also carried a BRCA gene. Participants shared that they felt a sense of responsibility when communicating the diagnosis and were mindful of the emotional impact of the diagnosis on other people. This caused them to manage what they said to whom (46). Women shared feelings of isolation and fear, and described being careful about who they shared their diagnosis with. Women were often more concerned about sharing their genetic diagnosis rather than their diagnosis of breast cancer.

When exploring reasons why children should be told about maternal diagnosis, mothers felt that it was important to communicate and be open with their children, they wanted to keep their children's trust and they felt that communicating the diagnosis might help alleviate children's distress (42). Mothers reported wanting to share information about their health with their children in a timely and sensitive way (40) wanting to be honest, and sharing information that was categorical, rather than speculative in an attempt to cause minimal concern (40).

One of the studies reported timings of illness disclosure to children by their mothers (41). Women shared information about diagnosis with their partners before a formal diagnosis was given but shared this information with children much later in the process. At the stage of surgery, in this study, 44 children out of 56 knew that their mothers were unwell, but 32 knew specifically of the cancer diagnosis (41). Forrest,

Plumb (43) reported that in general children over the age of 10 were told about the breast cancer diagnosis and subsequent treatment plans.

In the study exploring mothers' experiences of sharing a secondary breast cancer diagnosis with their adolescent children, mothers felt that disclosure was inevitable (42), explaining that this was due to the family's relationship with the diagnosis, and the children's intuition and their previous experiences with the illness.

Additionally, mothers with a secondary diagnosis had older children, many of whom played a supportive role throughout the diagnostic process. At times, choice was taken away as children were present at appointments where a diagnosis was shared, so they inevitably learnt of the diagnosis (42)

Four of the reviewed studies reported variations in relation to how young people found out about parental ill health (6, 42-44). Children reported that they suspected that something was wrong before this was confirmed by parents (6, 43). This was through hearing conversations, picking up on changes to parental mood or seeing information from the hospital (43). Some children suspected that parents were hiding the severity of the diagnosis from them, and reported feeling excluded from discussions.

In younger children it was common for both parents to share the news of the diagnosis with children (43), with fathers being a supportive presence and mothers often sharing the diagnosis (6). A few younger children were informed about maternal diagnosis with only one parent present (43).

One of the themes explored regarding disclosing diagnosis was the information needs of the family, namely children (40-42). Age was an important factor in deciding what information to share with children. Mothers with a diagnosis of secondary breast cancer often had older children and felt that as their children were older and closer to

adulthood, they were able to better understand what was happening (42). Gender was also an important consideration for parents (40).

The amount of information shared with family members varied. Two studies reported that information was held back from children when things seemed uncertain or information was not deemed to be relevant to the child and their wellbeing (40) and to avoid additional questioning from children (41). When mothers with secondary breast cancer communicated their diagnosis, they reported sharing information in a positive way, giving their children a hopeful message (42).

Theme 3: The impact of the diagnosis on family functioning

A number of the reviewed studies reported factors relating to family dynamics and roles influencing how a diagnosis of breast cancer is shared.

The most extreme one was my brother. When I had the diagnosis of cancer, he came over a couple of times but didn't talk to me at all about, you know. I remember we went out for a cup of coffee and I said, "Look, you know about this" and he just didn't want talk about it. I feel very hurt by that and considerably affected (46), p155.

Mothers with secondary breast cancer shared that although they found it easier to share their diagnosis the second time round, their children found it more distressing, and grew concerned about the potential for their mother's health to deteriorate and the possibility that they would need to take on a caring role in the future (42).

Findings included the potential support from the family when sharing a diagnosis with a child. The family structure was important in deciding who was best placed to have conversations with children about the diagnosis, and previous familial approaches to difficult conversations were considered when mothers thought about disclosing their illness to their children (40).

Two studies explored the impact of women's reactions to illness on their relationships with their partner (11, 45). When women were more distressed their partners found it harder to manage (11, 45). One participant described how hard it was seeing his partner frightened (45) and it was reported that fear affected partners' lifestyles, impacting concentration and workplace performance (45).

One of the studies reported that couples that reported issues in their relationships also shared that they struggled to talk about the illness following a diagnosis (11). Often the lack of communication around a diagnosis was with the intention of protecting partners and managing emotions, similarly to other studies included (40-42).

When sharing their diagnosis and BRCA status with family members, women found that their loved ones would retreat and distance themselves from the conversation, experiencing this as very hurtful and upsetting.

Theme 4: Sources of support

Two of the reviewed studies described mothers wanting support from professionals regarding sharing their cancer diagnosis with their children and families.

But if you've got an illness that could take your life, as I said tomorrow next week or whatever, you really do need someone to em, help your kids cope psychologically even if they're older. And I think if you've got younger kids they get more support than if you've got adult children. (42), 1229.

Two of the reviewed studies described mothers wanting support from professionals regarding sharing their cancer diagnosis with their children and families. Suggestions included counselling, helpful books, and consultation from professionals with an understanding of child development (41). Mothers with secondary breast cancer

shared that they did not need support in sharing the diagnosis, but rather wanted support for their children in managing the long-term impact of maternal diagnosis (42).

Additionally, mothers suggested that services link in with community spaces such as their children's schools in order for adequate support to be provided to children. The specialist nature of the support required was highlighted by mothers. They reported that limited support was available for children over the age of 18, and they were keen for this to change. It was felt that more support was available for younger children compared to older, adolescent children (42).

Children had ideas about what cancer was before being told by their parents. Younger children associated cancer with something '*scary*', relating it to '*stress*'. One 10-year-old believed that death was inevitable if someone was diagnosed with cancer (43).

One of the reviewed studies reported that older children took on responsibility for their parents and did not want to discuss the cancer diagnosis with them fearing that it would upset their parents, preferring, instead, to share their concerns with people outside the family home, including worries about parental death (44). This finding was mirrored by fathers, who reported not wanting to discuss the diagnosis with their children to avoid upsetting them (6).

Two studies described the importance of being able to connect with individuals who had been in the same situation as them. Fathers reported that they would have found it helpful to be able to access support from other fathers that had previously been in their position (6). Young people reported finding their friends and other young people in the same position as them helpful in relation to support and understanding (44). Other sources of support for young people included school and the hospital, although support from school was limited. For example, one young person expressed her wish for school to offer more support (44). For some, school was the opportunity to connect with normality,

but others wanted more practical support, such as flexibility with homework deadlines, and support regarding information about cancer (44).

Parents in the reviewed studies reported that they would like support from healthcare professionals in communicating the diagnosis to their children or preparing them for what to say (6, 43). Views from children in relation to this were mixed. Some children wanted more involvement with their mother and hospital team (43) but others preferred to seek support away from the hospital environment (44).

Couples with more available support outside of the immediate family felt under less pressure than people who did not have access to such sources of support. This helped partners better manage negative emotions displayed by their partners with the diagnosis. This highlighted the need for support throughout the overall cancer process, not just when sharing or discussing the diagnosis (11).

Theme 5: Emotive responses to diagnosis

The reviewed studies explicitly explored emotional reactions following sharing a diagnosis with family members, considering both the views of the individual with the diagnosis, and those hearing the diagnosis. This differs from themes 3 and 4 as there is a focus on responses on an individual level.

'I was a bit upset because I thought we were going to lose her, because cancer to me is a killing thing, you know' (45), p137.

One study exploring women's experiences of sharing a secondary breast cancer diagnosis with their children, described mothers experiencing feelings of guilt and devastation that their children would have to worry about them having a secondary diagnosis (42).

One study explored the responses of men to their partner's diagnosis of breast cancer (11). Men reported that they initially managed well with their partner's breast cancer diagnosis, but with time became frustrated, which had an impact on their relationships (11). Partners reported feeling emotionally exhausted and described a lack of support available for them (11), similarly to the findings of Forrest, Plumb (6), and named a lack of 'family focus' from healthcare professionals. Similarly, another study explored partners' emotions in response to hearing about their partners' diagnosis. They reported experiencing fear and anticipation of fate, with many men in the study sharing that they worried that their partners would die from the disease (45). Participants in this study also questioned their own health and became concerned that they might have cancer as well, justifying their concerns by naming physical symptoms. These concerns and worries impacted participants' mood, their concentration, work performance and their thoughts about the future. All participants taking part in the study described feelings of helplessness and denial. There was the desire to help and respond to the diagnosis, but they did not always know what would be helpful. Additionally, some participants pretended that the experience was not happening in order to protect themselves from reality (45).

Sharing diagnoses had an impact on romantic and wider familial relationships (11, 46). Women reported experiencing feelings of awkwardness and uncertainty when sharing a diagnosis, feeling as if they were breaking bad news. These women also had to manage sharing their genetic information with family members, which put a strain on interactions and relationships with family members (46). Two women described their brothers not talking to them about the diagnoses at all, and another woman described her mother telling her that she did not know what to say to her regarding the diagnosis.

Couples also reported feelings of resentment and frustration following discussing breast cancer diagnosis (11).

4. Discussion

This narrative review aimed to explore the experiences of family members when a female family member disclosed a breast cancer diagnosis. Thematic analysis of the nine reviewed studies' results found five themes: These were 1) maintaining normality, 2) disclosure experiences, 3) the impact of diagnosis on family functioning, 4) sources of support and 5) emotions and reactions. The review aimed to capture experiences of family members both sharing and receiving news of a diagnosis.

Although the reviewed studies described distinct instances where women with breast cancer shared their diagnosis with family members, in most of the studies, ongoing conversations about breast cancer were described. Throughout the process of cancer diagnosis and treatment, there were several opportunities for sharing information. The sharing process extended beyond just diagnosis, but also throughout treatment, and after treatment had ended, for example, follow up testing. The findings also showed that some people avoided sharing their diagnosis with loved ones and chose not to disclose.

Research suggests that conversations about cancer can be emotionally driven or informational, both serving different functions, with differing impacts (47). Findings of the review suggest that, within families, both emotional and informational conversations around cancer took place, with women wanting to have more factual conversations with their children, but perhaps being more expressive in terms of their emotions with adult family members, for example, partners.

This review considered other factors that might be shared during this process; being a carrier of the BRCA gene and a secondary breast cancer diagnosis. The findings

demonstrate the potential legacy that breast cancer can have on a family, and the ongoing conversations that may occur depending on the familial experience. The findings of the reviewed studies suggest that families would benefit from support throughout the treatment process, rather than just around disease disclosure.

A recent review exploring experiences of mothers sharing their diagnosis with minor children reported that there were differences in disclosure patterns between Western and Asian cultures (33). The review reported that women in Western countries were willing to be more open about their diagnosis than their Asian counterparts (33). This differs from the findings of the present review, which found that there were a number of factors that influenced disclosure decisions. Yu, Huang (33) reported findings from Western countries which included America, the UK and Australia and it is possible that these findings cannot be generalised to the UK population. There were two studies that focussed on the UK population, whereas the present systematic review focusses specifically on the UK population.

Family systems theory provides a framework for working with families where there is a diagnosis present, but little research exists exploring the implementation of the framework (27) within the oncology space. Research has, to date, focussed more on frameworks of couples' dyadic coping in relation to cancer (48, 49). The family systems theory fits with the findings of the present review, in relation to how the family unit interacts as a system, but also considering how subsystems within the family might interact. The studies included in the review explored the parental subsystem making decisions around sharing diagnoses with children, offering support to each other around this and sharing difficult emotions and experiences around diagnosis together. The studies also explored the change in family dynamics and roles when there is a diagnosis of breast cancer within the family. In line with existing research, this review highlights the

potential for turbulent family emotions at this time (28) with family members experiencing similar emotions to the patient in relation to the diagnosis and ongoing treatment (50). Gritti (51) describes negative changes to family relationships as a result of cancer within the family system. This may consist of difficulties in relation to communication, increased isolation or changes to roles. Across the studies included in this review, these processes were evident.

The focus in literature is on experiences of sharing diagnoses with partners and children and there is little consideration on how the diagnosis might be shared by women with their parents and siblings. This means that the perspectives of women with breast cancer who might be single and yet to have children, perhaps younger women, are precluded from the current research base. Literature suggests that young adults with cancer diagnoses experience similar difficulties outlined in the review when sharing their diagnosis with family and friends (7), and it is important that their experiences are captured in UK specific research. Additionally, the studies in this review that named the ethnicity of participants included white women, and experiences of women from minoritized communities were not considered. It is likely that the inclusion and exclusion criteria used in this review, and the focus on experiences of sharing cancer diagnosis with the immediate family, may have excluded studies that focus on the minority experience. The literature suggests that women from South Asian backgrounds living in the UK are more likely to share their experiences with the wider family and also community (24). Conversely, research suggests that within the Black community in the UK, it is more difficult to have conversations about diagnosis, even within the immediate family (24).

Strengths and limitations

Strengths

The current review utilised a thorough search strategy, in line with the ENTREQ statement (34). The search strategy was developed over time and was informed by relevant literature and common search terms used. An independent reviewer screened a proportion of papers and did not find any discrepancies. Additionally, the CASP tool (39) was used to assess the quality of included papers. Whilst the checklist does not provide a score for quality, it is widely used for qualitative health-related research. The review was also able to explore numerous perspectives in relation to female breast cancer diagnoses within families, and experiences were synthesised in a narrative summary.

Limitations

There were some limitations of this review. The nine reviewed studies were heterogeneous in relation to perspectives about cancer diagnosis, but also in relation to breast cancer diagnosis. The reviewed studies explored experiences of both primary and secondary breast cancer, and one of the studies explored the impact of carrying the BRCA gene alongside having a breast cancer diagnosis. Different familial perspectives were included to consider what support is required for families as systems, rather than considering support for individuals within the family, but again this adds to the heterogeneity of the data and limits the conclusions.

The CASP tool was used to assess quality in the data. Whilst all the studies included were deemed to be of value, the tool does not provide a measure of quality, but assesses studies alongside a check list. Therefore, the quality of studies may vary. Forrest, Plumb (43) and Forrest, Plumb (6) used the same dataset to report on perspectives of mothers, fathers, and children. One study reported from the perspective of mothers and children (43) and another reported on perspectives of fathers and children (6). Whilst the studies'

authors are transparent about this, they direct the reader to refer to the earlier paper for a detailed methodology and do not report a clear recruitment strategy in the later paper with a paternal focus. Additionally, Barnes, Kroll (41) report on the qualitative findings and provide quantitative results in a separate study at a later date (5).

Experiences of minoritized groups have not been captured in this review. This is partly due to the lack of existing research exploring the experiences of minoritized groups in the UK when sharing a cancer diagnosis. This review's search strategy focussed on sharing a diagnosis within a nuclear family, whereas in minoritized groups literature suggests that the wider family may be involved in such discussions. Hence, the search strategy may have excluded such experiences.

Clinical implications and recommendations

The study findings were shared with a lead MacMillan cancer nurse and the clinical implications and recommendations for clinical practice were discussed and co-developed. This was to ensure that recommendations made were meaningful, suitable, and applicable to current practice.

This review suggests that individuals across the family are impacted by a breast cancer diagnosis, and a range of emotions and difficulties are experienced when a diagnosis is shared. These emotions ebb and flow throughout treatment, and disclosures relating to a diagnosis may be ongoing throughout the cancer journey.

Patients in the reviewed studies generally requested support around sharing their diagnosis with loved ones, namely children, and once a diagnosis was shared, families reported that ongoing support would be helpful. Using a family approach, families may be able to be supported by services throughout their journeys with breast cancer. Gritti (28) presents some guidelines for doing this, encouraging clinicians to meet with relevant

family members, share information about the disease, explore how the family unit is coping with the disease and to explore familial dynamics. This is in line with the family systems theory, which suggests that the cancer diagnosis should be seen in relation to the system rather than on an individual level. It is recommended that services move towards a more systemic approach, viewing the family as a unit and as holding the diagnosis together (27).

Other recommendations for services include clear communication with patients that family members can join appointments with consent from patients (perhaps highlighting this on appointment letters), and clear information being provided to families regarding supportive spaces available for family members (for example, support groups). Additionally, all patients should have a cancer nurse specialist who should share information about support available for family members (for example, MacMillan's offer to support families).

Recommendations for ongoing research

This review highlights the lack of research when considering breast cancer disclosure experiences of family members in general. There is an emphasis in research on disclosure experiences in relation to children, but perspectives of other family members, such as sibling and parental perspectives, should be considered in future research. Whilst the family systems theory seems to be appropriate when considering familial disclosure, little research has explored the practical application of the theory when working with families sharing diagnoses. This should be explored in future research.

When considering familial perspectives, there is a lack of diversity in the literature. Non-nuclear families are not represented in the research, and there is a focus on heterosexual rather than same sex partner relationships. Future research should consider

same sex relationships, but also individuals who are not in relationships. Finally, there is a lack of research exploring disclosure within racially minoritized groups. Disclosure patterns may extend beyond the nuclear family, and future research should explore disclosure experiences with a specific focus on the experiences of ethnic minority groups living in the UK.

5. Conclusion

Qualitative literature included in this review identifies the experiences of families when a breast cancer diagnosis is shared. It considers factors that influence women's decisions to share their diagnosis, but also some of the implications for families when diagnoses are shared; worries about the patient, but also worries about themselves and the family unit. It is important to consider communication about the illness throughout the diagnostic and treatment process, and to ensure families are offered adequate support during this difficult time.

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Appendices

Appendix 1. Author guidelines, Psycho-oncology

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Psycho-Oncology publishes a number of different article types including:

• Original Paper

Original research papers should contain reports of new research findings that make a significant contribution to knowledge. Original papers should not exceed 4,000 words (including no more than four figures and/or tables) plus up to 40 references.

Research articles should not exceed 4000 words, covering all text including abstract, main manuscript, tables, figures and table/figure legends but excluding title page, references, acknowledgements, funding source information, data availability statement and supplemental appendices.

• Reviews

Reviews should be critical reviews of the literature, including systematic reviews and meta-analyses and should not exceed 6,000 words, excluding references.

• Invited Editorials and Commentaries

Please approach the Editorial Office (Psycho-Oncology@wiley.com) for details.

• Clinical Correspondence

The requirements for Clinical Correspondence are as follows:

1. Up to 5 keypoints - no abstract
2. 1500 word limit (excluding references)
3. No more than 2 figures/tables combined
4. Up to 10 references.

• Obituaries

• Registered Reports

Psycho-Oncology is offering authors a new article type designed to increase the transparency and reproducibility of hypothesis-driven science, the Registered Report. Registered Reports differ from conventional research article as part of the review process is conducted *before* authors collect and analyse data. The cornerstone of the Registered Reports format is that a significant part of the manuscript will be assessed prior to data collection, with the highest quality submissions accepted in advance. Please view the full Registered Reports author guidelines [here](#) to help prepare your submission.

Qualitative manuscript submissions should usually be based on a minimum of 20 respondents. Authors may contact the Editor (maggie.watson@live.co.uk) if they require further details.

For cross sectional studies, we require authors to adhere to the **STROBE** reporting standards for observational research. Please upload your **STROBE** checklist alongside your submission.

4. PREPARING YOUR SUBMISSION

Manuscripts must be submitted as a Word or rtf file and should be written in English. The manuscript should be submitted in separate files: main text file; figures.

Main Text file

Manuscripts can be uploaded either as a single document (containing the main text, tables and figures), or with figures and tables provided as separate files. Should your manuscript reach revision stage, figures and tables must be provided as separate files. The main manuscript file can be submitted in Microsoft Word (.doc or .docx) format.

Your main document file should include:

Title

The title should be a short informative title that contains the major key words. The title should not contain abbreviations (see Wiley's [best practice SEO tips](#))

Authorship

Please refer to the journal's authorship policy the Editorial Policies and Ethical Considerations section for details on eligibility for author listing.

Acknowledgements

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement

You will be asked to disclose conflicts of interest during the submission process. See the section 'Conflict of Interest' in the Editorial Policies and Ethical Considerations section for details on what to include in this section. Please ensure that you liaise with all co-authors to confirm agreement with the final statement. The Conflict of Interest statement should be included within the main text file of your submission.

Abstract

Please provide an abstract of no more than 250 words. Abstracts should be structured according to the following headings: objective, methods, results, conclusions.

Keywords

Please provide up to 10 keywords and list them in alphabetical order. Please ensure that the keywords, cancer and oncology, are used for indexing purposes. Keywords should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list at <https://www.nlm.nih.gov/mesh/>.

Main text

Where possible, the text should be divided into the following sections: Background, Methods (including statistical methods), Results and Discussion. All papers must include within the Discussion section a paragraph explaining the study limitations (with subtitle "study limitations") and a paragraph explaining the clinical implications of the study (with subtitle "clinical implications") and a paragraph covering the Conclusions.

A statement explicitly describing the ethical background to this study and any institutional or national ethical committee approval (including approval number) must be included within the manuscript.

For clinical trial reports, the clinical trial registration number must be included within the manuscript.

Appendices

Appendices will be published after the references. For submission they should be supplied as separate files but referred to in the text. Supporting Information

Supporting Information

Supporting information is information that is not essential to the article but that provides greater depth and background. It is hosted online, and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc. [Click here](#) for Wiley's FAQs on supporting information.

Note, if data, scripts or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

The following links provide general advice on formatting and style.

- Abbreviations: In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.
- Units of measurement: Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website at <http://www.bipm.fr> for more information about SI units.
- Trade Names: Chemical substances should be referred to by the generic name only. Trade names should not be used. Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name, and the name and location of the manufacturer, in parentheses.

References

All references should be numbered consecutively in order of appearance and should be as complete as possible. In text citations should be superscript numbers. Journal titles are abbreviated; abbreviations may be found in the following: [MEDLINE](#), [Index Medicus](#), or [CalTech Library](#).

Submissions are not required to reflect the precise reference formatting of the journal (use of italics, bold etc.), however it is important that all key elements of each reference are included. Please see below for examples of reference content requirements.

For more information, please see the [Vancouver Reference Style Guide](#)

Sample references follow:

Journal Article

1. Wood WG, Eckert GP, Igbavboa U, Muller WE. Statins and neuroprotection: a prescription to move the field forward. *Ann N Y Acad Sci* 2010; 1199:69-76.

Book

2. Hoppert, M. *Microscopic techniques in biotechnology*. Weinheim: Wiley-VCH; 2003.

Electronic Material

3. Cancer-Pain.org [homepage on the internet]. New York: Association of Cancer Online Resources, Inc.; c2000–01 [Cited 2015 May 11]. Available from: <http://www.cancer-pain.org/>.

Tables

Tables should be self-contained and complement, but not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figure Legends

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Appendix 2. Data extraction tool

Author
Year
Title of paper
Research aims & objectives
Any further research questions addressed
Setting / context/who's perspective is it from
Study date and duration
Links to services / organisations
Sample
Sampling / recruitment procedures
Age range
Cancer diagnosis
Living context
Ethnicity
Design & methodology
Method of data collection (and by who)
Number of times interviewed Length of interview
Theory referred to or concepts
Findings
Themes listed
Relevant quotes to evidence themes
Ideas mentioned but not as themes
Conclusions
Implications for research
Implications for clinical practice

Appendix 3. Central university ethics approval



Central University Research Ethics Committee A

6 May 2022

Dear Dr Golding

I am pleased to inform you that your application for research ethics approval has been approved. Application details and conditions of approval can be found below. Appendix A contains a list of documents approved by the Committee.

Application Details

Reference: 10652
Project Title: How do young women of colour experience hair loss as a result of chemotherapy for breast cancer?
Principal Investigator/Supervisor: Dr Laura Golding
Co-Investigator(s): Miss Eloise Wynter
Lead Student Investigator: -
Department: Primary Care & Mental Health
Approval Date: 06/05/2022
Approval Expiry Date: Five years from the approval date listed above

The application was APPROVED subject to the following conditions:

Conditions of approval

Please note: Any research ethics approval granted will be subject to the University's Policies on research during the pandemic.

Please ensure you are familiar with the latest guidance on conducting research during the pandemic. The guidance is available on the [research ethics webpages](#).

- All serious adverse events must be reported to the Committee (ethics@liverpool.ac.uk) in accordance with the procedure for reporting adverse events.
- If you wish to extend the duration of the study beyond the research ethics approval expiry date listed above, a new application should be submitted.
- If you wish to make an amendment to the study, please create and submit an amendment form using the research ethics system.
- If the named Principal Investigator or Supervisor changes, or leaves the employment of the University during the course of this approval, the approval will lapse. Therefore it will be necessary to create and submit an amendment form within the research ethics system.
- It is the responsibility of the Principal Investigator/Supervisor to inform all the investigators of the terms of the approval.

Kind regards,

Central University Research Ethics Committee A

ethics@liverpool.ac.uk

CUREC-A

Appendix - Approved Documents

(Relevant only to amendments involving changes to the study documentation)

The final document set reviewed and approved by the committee is listed below:

Document Type	File Name	Date	Version
Evidence Of Peer Review	Eloise Wynter - Formal approval from RRC 21.09.2021	21/09/2021	1
Study Proposal/Protocol	Research Proposal FINAL (no line numbers)	19/11/2021	2
Interview Schedule	Interview schedule	17/12/2021	1
Debriefing Material	Debrief form	28/01/2022	1
Advertisement	Study Poster 3	18/02/2022	3
Interview Schedule	Screening questionnaire	14/04/2022	1
Participant Information Sheet	Information sheet V5	14/04/2022	5
Participant Consent Form	consent form V3	14/04/2022	3

Appendix 4. Study poster



How do young women of colour experience hair loss as a result of chemotherapy for breast cancer?



ARE YOU A WOMAN OF COLOUR BETWEEN THE AGES OF 21 AND 45?

DID YOU EXPERIENCE HAIR LOSS AS A RESULT OF CHEMOTHERAPY FOR BREAST CANCER BETWEEN THE AGES OF 21 AND 35?

If **YES**, you might be interested in this research

What is this research about?

This study aims to understand the experiences of younger women of colour who have lost their hair as a result of chemotherapy for breast cancer. It aims to understand the psychological impact of hair loss, and the specific support services and systems available throughout this journey for this group of women.

What will happen?

You will be invited to have an interview to talk about your experiences. The interview will last between 60 and 90 minutes.

Your personal data will be kept confidential and will not be identifiable to you. You can choose not to talk about anything that you find uncomfortable, and you can stop the interview at any point without explanation.

Who is it for?

You may take part if:

- You identify as a woman of colour/as coming from an minority ethnic background.
- You had chemotherapy for breast cancer between the ages of 21 and 35.
- You are currently between the ages of 21 and 45.
- You have been diagnosed and treated within the last 10 years.
- You have experienced hair loss as a result of chemotherapy for breast cancer.
- You are not undergoing chemotherapy, radiotherapy or awaiting surgery.
- You do not have an active cancer diagnosis.
- You are not in end of life care.

If you would like to take part, or want more information please contact:
Eloise Wynter (Trainee Clinical Psychologist)
Email: eloise.wynter@liverpool.ac.uk

Appendix 5. Participant information sheet

Version 3 29/07/2022



Participant Information Sheet

Title of Study: How do young women of colour experience hair loss as a result of chemotherapy for breast cancer?

You are being invited to participate in a research study. Before you decide whether to take part or not, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. You are under no obligation to accept this invitation and should only take part if you want to. If you do decide to take part and you change your mind, you will be free to withdraw at any time without explanation.

What is the purpose of the study?

Having breast cancer is a significant life event for women and their families, and hair loss is something that impacts many women who undergo chemotherapy to treat their breast cancer. Research suggests that there are differences in experiences of cancer related hair loss according to age, with different age groups experiencing hair loss differently. The purpose of this study is to understand what it is like for younger women of colour to experience hair loss due to chemotherapy, and how this affects their self-perception and how they believe they are viewed by others. We are also interested in the psychological impact of hair loss in this group of women, as well as support available to them. Until now, most research has focused on the experiences of older Caucasian women and there has been very little research that considers the perspectives of younger women or women of colour who have been diagnosed and treated for breast cancer.

We are interested in hearing about your experiences. If we have a better understanding of how hair loss affects women's lives, we may be able to improve the care and support for other younger ethnic minority women.

Why have I been chosen to take part?

We are inviting women who self-identify as women of colour and received a diagnosis of, and treatment for breast cancer between the ages of 21 and 35. Participants must have experienced diagnosis and treatment within the last 10 years and currently be between the ages of 21 and 45 to participate in the study. Women must not be undergoing chemotherapy, radiotherapy or be awaiting surgery. We would like to invite women who experienced a significant amount of hair loss as a result of chemotherapy to take part in the study.

Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You will be free to withdraw at any time without explanation.

What will happen if I take part?

If you choose to take part in the research you will be interviewed by a researcher, Eloise Wynter, at a Maggie's centre that is convenient for you to get to. Any support that you might receive from your local centre will not be affected by your participation in this study. The interview will be informal and relaxed, and the researcher will ask you questions about your experiences of hair loss as a result of chemotherapy for breast cancer. Should you not be able

to come into a Maggie's Centre interviews can be conducted over Zoom using a similar process.

There are no right or wrong answers and you do not have to respond to any questions that you do not feel comfortable answering. The interview will last between 60 to 90 minutes; however, you are free to talk as much or as little as you would like to. With your permission, we would like to tape record the interview. Online interviews will be recorded using Zoom's recording facility.

How will my data be used?

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Principal Investigator acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Laura Golding.

Further information on how your data will be used can be found in the table below.

How will my data be collected?	Interviews will be recorded using a Dictaphone and transcribed. The data will then be analysed.
How will my data be stored?	Data will be stored on the University of Liverpool's M Drive.
How long will my data be stored for?	The University requires that research data necessary to support or validate a research project's observations, findings or outputs must be retained in an appropriate format and storage facility for at least 10 years, hence the data will be stored for 10 years following publication. At the end of this retention period, the data custodian will ensure that the data is destroyed.
What measures are in place to protect the security and confidentiality of my data?	Data will be anonymised and stored on the University of Liverpool's secure drives. Personal data that identifies participants, for example, consent forms, will be stored separately from the actual data. Hard copies of the consent forms will be stored securely in the DCLin admin office.
Will my data be anonymised?	Yes
How will my data be used?	Data will be analysed and written up in a paper which will form part thesis submitted in partial fulfilment of the University of Liverpool's Doctorate in Clinical Psychology., with the possibility of publication in a relevant academic journal.

Who will have access to my data?	The research team will have access to both the audio recordings and transcripts. During the viva voce examiners may request to examine anonymised raw data.
Will my data be archived for use in other research projects in the future?	No
How will my data be destroyed?	Transcripts will be submitted for secure destruction by the University Records Management Service. Audio recordings (from both online and face to face interviews) will be submitted to the DClin admin team and then will be deleted following successful completion of the viva voce.

Expenses and / or payments

Participants will be provided with a £20 voucher for their participation and their travel costs will be reimbursed.

Are there any risks in taking part?

We realise that talking about previous experiences of hair loss and breast cancer may be a very personal and distressing experience which you may find difficult to share. If you do decide to take part in this study, you can ask to stop the interview at any time or choose not to answer questions you feel are too personal to talk about.

Are there any benefits in taking part?

This is your chance to talk about your experiences. The information you give will help us understand your experiences better and it may play a part in shaping services for younger women of colour.

What will happen to the results of the study?

The results of this study will be shared with health professionals and other cancer related organisations, such as Maggie's Cancer Charity. You will not be named or identified in any publications that come from the research.

What will happen if I want to stop taking part?

If you decide that you no longer want to take part in the study, you can get in touch with the researcher, Eloise Wynter (email: eloise.wynter@liverpool.ac.uk) and quote your participation number.

You will have the right to withdraw from the study at any point before and up to two weeks after your participation without disadvantage to yourself and you do not have to explain why you would like to withdraw from the study.

What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Dr Laura Golding (goldlau@liverpool.ac.uk) and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and



Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

Who has reviewed this study?

This study has been reviewed and approved by the University of Liverpool Ethics Committee to make sure that it is being carried out in an appropriate manner.

What do I do now?

If you are interested in taking part or would like any further information, you can contact the researcher, Eloise Wynter at eloise.wynter@liverpool.ac.uk.

If you have any concerns about breast cancer, you can contact the following breast cancer organisations for further support: Breast Cancer Care Helpline on 0808 800 6000, NHS Direct on 0845 4647 or alternatively contact your GP.

Should you need emotional support at this time, please see some helpful resources below. Should you need support beyond this point, please contact your GP.

- Black Women Rising (<https://www.blackwomenrisinguk.org>) provides support for women of colour who have experience of cancer. Through the website you can access support groups and be signposted to helpful resources.
- Maggie's Cancer Charity: <https://www.maggies.org/cancer-support/> There are a number of resources that support with stress and anxiety management on the Maggie's website.
- The Macmillan Cancer Support website (<https://www.macmillan.org.uk>) provides various resources to support people to manage their cancer experience, including an online community, but information about accessing further support.

Should you have any concerns or queries following taking part in the study please can in touch with the researcher, Eloise Wynter; ewynter@liverpool.ac.uk.

Thank you for taking the time to read this information and for thinking about taking part in this research.

Eloise Wynter, Trainee Clinical Psychologist

Supervised by Dr Laura Golding and Dr Jane Hutton
Email: goldlau@liverpool.ac.uk, jane.tomashevskii@liverpool.ac.uk

Appendix 6. Debrief form

Version 1.20/01/2022



Debrief form

Title of Study: How do young women of colour experience hair loss as a result of chemotherapy for breast cancer?

Thank you for taking time to participate in this study. By completing this study, we hope to understand what it is like for younger women of colour to experience hair loss due to chemotherapy, and how this affects their self-perception and how they believe they are viewed by others. We also hope to learn more about the psychological impact of hair loss in this group of women, as well as support available to them.

As explained in the information sheet that you were given when you agreed to participate, findings will be reported anonymously, and if you no longer wish to take part in the study, please let us know.

If you would like information about the results of the study, please let us know by contacting Eloise using the details below.

We understand that we talked about some difficult topics during the interview and have included some resources that might be helpful should you feel distressed. Should you need support beyond this, please contact your GP.

- Black Women Rising (<https://www.blackwomenrisinguk.org>) provides support for women of colour who have experience of cancer. Through the website you can access support groups and be signposted to helpful resources.
- Maggie's Cancer Charity: <https://www.maggies.org/cancer-support/> There are a number of resources that support with stress and anxiety management on the Maggie's website.
- The Macmillan Cancer Support website (<https://www.macmillan.org.uk>) provides various resources to support people to manage their cancer experience, including an online community, but information about accessing further support.

Should you have any concerns or queries following taking part in the study please can in touch with the researcher, Eloise Wynter; ewynter@liverpool.ac.uk .

Appendix 7. Consent form

Version 2. 28/01/2022



Participant consent form

Title of Study: How do young women of colour experience hair loss as a result of chemotherapy for breast cancer?

Name of researchers: Eloise Wynter, Dr Laura Golding, Dr Jane Hutton

Please initial

I confirm that I have read and have understood the information sheet dated 07/01/2022 for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that taking part in the study involves taking part in an audio recorded interview.	
I understand that I must not take part if I am in active treatment for cancer.	
I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study up until 2 weeks after my interview, without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any <u>particular question</u> or questions.	
I understand that even once I have given this consent, I have the right to withdraw from the study at any point before and up to two weeks after my participation without disadvantage to myself and without needing to give any reason. I have been made aware that two weeks after my interview, it will not be possible to withdraw my participation as analysis will have begun.	
The information you have submitted will be published as a report; please indicate whether you would like to receive a copy.	
I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my fully anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	
I understand that confidentiality and anonymity will be <u>maintained</u> and it will not be possible to identify me in any publications.	
I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool until it is fully anonymised and then deposited in the archive. Data will not be shared or used by other authorised researchers to support future research.	
I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool and the Data Protection Act.	
I give permission for my direct quotations to be used in the thesis and any publications/reports produced.	
I agree to take part in the above study.	

Participant name

Date

Signature

Name of person taking consent

Date

Signature

Principal Investigator
Dr Laura Golding
goldlau@liverpool.ac.uk

Student Investigator
Eloise Wynter
eloise.wynter@liverpool.ac.uk

Appendix 8. Interview schedule

Interview question: Tell me about your experiences of losing your hair as a younger woman of colour who was treated for breast cancer.

Prompts:

Questions about hair loss

- Tell me about your hair loss journey during treatment.
- What were your initial thoughts and fears about hair loss when you were first diagnosed?
 - What information were you given about hair loss?
 - What was your perception when you heard that you were going to lose your hair?
 - How did services prepare you for hair loss?
 - What did you do to prepare yourself for losing your hair?
- How did losing your hair get in the way of you doing what you normally do?
- How do you feel losing your hair effected your psychological wellbeing and mental health?
 - Where did you seek support for this?
 - What was helpful? What wasn't helpful/what else could have been?
- What other parts of the body did you lose hair from and how did you cope with this?
 - How did this change how you perceived yourself?
 - How do you feel this changed others' perception of you?
- Looking back, what did you notice about yourself in terms of how you were dealing with hair loss at that time?
 - What has helped you get through the experience?
 - What changes if any, have remained?
 - What aspect of losing your hair was particularly difficult?

Questions regarding ethnicity

- How does your culture (or people in your community) deal with illnesses such as breast cancer?
 - Is it openly talked about?
- As a young woman of colour, what did you notice about other people's perceptions of you following losing your hair?
 - Did it vary from people from your community and people outside of this?
 - How did this impact on your behaviour?
 - How did this impact on how you perceived yourself?
- How did the support you receive take your cultural background into consideration?

Experiences of breast cancer in relation to age

- How did you deal with having breast cancer being a young woman?
- How did you manage hair loss as a young woman?
- How do you think that losing your hair as a younger woman impacted your sense of self?
- What age/life stage appropriate services did you access?

- Were there spaces for you to seek support where your life stage felt held in mind?

Preventative measures for hair loss

- What did you use to help prevent hair loss?
- How did you feel this helped?
- What information were you given about how you might be able to manage your hair loss?
- Was information tailored based on your background?
- Once you lost your hair did you do anything to change your appearance?
 - If yes, what did you do?
- If you wore a wig or a head covering where did you source these things from?
 - What support did you need to access these things?
 - Can you tell me about the process?

Regrowth of hair

- Tell me about how you experienced your hair growing back?
- How did this impact how you felt about yourself?
 - How was your psychological wellbeing affected?
- How has your relationship with your hair changed as a result?

Appendix 9. Example of annotated transcript with experiential statements and exploratory notes

Experiential statements		Transcript	Exploratory notes Descriptive; <i>Linguistic</i> ; <u>Conceptual</u>
	S1	Okay, so I'm gonna start with a big overarching question, erm...which is...tell me about your experiences of losing your hair as a younger woman of colour who was treated for breast cancer.	
<p>Distress at hair loss</p> <p>Other people's understanding of how it feels</p> <p>Hair and identity</p> <p>Treatment of hair before and after cancer.</p>	S2	<p><i>Honestly, honestly, that was tormenting I feel, I even felt like the pain I felt from the cancer did not erm, erm, was not up to the pain I felt losing my hair. I'm a Black woman, my hair is like my crown, I love it so much, I have taken time to grow it, to nurture it, and then it's fallen off, every day. I have to wear wigs. I, I had to cut my hair; my partner also had to join me in solidarity. That was, I, I didn't know, when I tell people this, they feel like I'm being petty, or I'm erm...I'm being frivolous, but me losing my hair was horrible.</i></p>	<p>-Repetition of 'honestly'</p> <p>-'Tormenting', idea of experiencing torment from hair loss. Evokes distress, feelings of agony.</p> <p>-Hair loss felt more painful than receiving a diagnosis of breast cancer.</p> <p>-Naming that she is a Black woman, explaining her unique experience/relationship with her hair. Is she implying that because she is Black her relationship with her hair is different?</p> <p>-Hair being her crown and glory, stressing how much her hair means to her- 'my hair is like my crown'. Images of Royalty, what does hair do for her sense of self? Her identity?</p> <p>-Investing time and care in her hair before having cancer made it even more traumatic when she lost her hair. The investment in her hair was wasted as it fell out. Ideas around 'nurture' and 'growth'.</p>

Social support			<ul style="list-style-type: none">-Distressing and traumatic experience. The final statement is very resolute and clear-Support from her partner, 'solidarity'-Other people don't understand, feeling like others think it's 'petty', but it felt very important to her.
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Appendix 10. Example of quotes used to form a subtheme

Subthemes	Quotes
<p>Identity</p>	<p>Changes to identity Yeah, so my self-image, I think that suffered a lot, just my identity, like erm...maybe a lot of my identity came from how I looked, or do you know what I mean, like my, my image and things-p14, Gina</p> <p>I think a lot of our identity is within our hair and how we look, and how we look, so I can understand them wanting to erm pursue it and try it at least-p18, Gina</p> <p>Not recognising themselves Because obviously my hair was gone, I had no eyelashes, from the steroids as well, your face goes really puffy and round, so and that's when it really hit me. I was like, I looked in the mirror and I was like who is this person?-Gina</p> <p>you just don't recognise yourself, like I didn't recognise myself-Gina</p> <p>just whenever you look in the mirror regardless of how good people say you might look, erm, you, you haven't got what you had before you had cancer, so you don't feel great about it. - Monica</p> <p>But I've never, ever rocked my hair natural and short like this. Never in my life. So, I would say for me, having that and going through the baldness, it just changed how I saw myself.- Kamille</p> <p>I just thought, you know what? You are absolutely beautiful with bald hair.- Kamille</p> <p>Rock it girl, you look banging with short, short hair...short, natural hair. Rock it, literally. So, for me, it was just almost like a change in - how did you say it? You know what I'm trying to say, right?- Kamille</p> <p>I was like oh it looks really manly-Luna</p> <p>I was, it's a weird thing when you think oh, you know, I'm not at my prettiest, I'm really unattractive and stuff like that-Anna</p> <p>but the eyelashes, oh my gosh, I feel like you look really unwell when you don't have facial hair, like you really look ill. Like I remember I'd look at myself and I would just be like gosh you look, you look unwell-Anna</p> <p>So, you've lost your hair but you still for a while, you'll maintain your eyebrows and you're like, I still look like me.-Monica</p> <p>that little transfer period of a week or two when I really started losing my eyebrows especially, but my eyelashes too, that was when I found it the hardest to look in the mirror and be like, "Who is that person?"-Tara</p> <p>And I just liked having that big messy look to my hair and I think that's what people associated with me.- Monica</p> <p>just with the self-image, erm...I think I found out, I think I'm more vain than I realised-Gina</p> <p>you just don't recognise yourself, like I didn't recognise myself- Gina</p>

	<p>Yeah, so my self-image, I think that suffered a lot, just my identity, like erm...maybe a lot of my identity came from how I looked, or do you know what I mean, like my, my image and things- Gina</p> <p>it's just an identity thing. It was very...it was a very strange journey to go on as an Indian woman who is Hindu to then realise that after I started wearing you know, a head wrap, I potentially was being confused for a Muslim woman.-Tara</p> <p>I think a lot of our identity is within our hair and how we look, and how we look, so I can understand them wanting to erm pursue it and try it at least- Gina</p> <p>I actually knew that I looked weird with my bald head-Florence</p> <p>. Erm...and obviously that's a huge part of it because that's one most closely linked to your identity I guess, and as it was for me and I know it is for a lot of women, It's kind of the biggest sign to the outside world that you're sick, erm, you know, if you can keep your hair or maintain that kind of look then it's, it's a little easier to get away with especially with make-up and good days, et cetera.-Tara</p> <p>And so, for me, that way, I don't hold on to like the old school traditional vibes of what my crowning glory is. Like to me, hair is to be played with, experimented with, to be seen in many different ways, and I think maybe that's why it was easier on me. And I was like, well, this is just yet another expression of what my hair is going to do, and in a little way, you know, once the trauma had kind of passed through, in a little way I was kind of excited that I'd get to try hairstyles that I would never...like to actually chop it off, I would never have done that, I would never, I'm too much of a wuss. But now I do get to have a pixie cut because it's just going to go that way.-Tara</p> <p>it's your hair is almost like this separate identity that you have and you hold like you do, you use it to express yourself, you use it to kind of just project whatever you want into the universe-Esther</p>
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Appendix 11. Reflections

As a woman of colour who previously lost my hair as a result of chemotherapy for breast cancer, this research felt very close at times, and I related to the narratives shared by the women that took part in the study. Often when talking to other Black women especially, I noticed that during interviews women often used words or phrases such as ‘obviously’ or ‘you understand’. I wondered if this was due to my ethnicity or perhaps my age, and participants feeling like we had some shared characteristics and that I had an understanding of their perspectives. Additionally, when I started interviews, I didn’t disclose my previous experiences of breast cancer with the women taking part, but after completing two interviews, I decided to share this information once the interview had come to an end. Whilst this sparked additional conversation, these were not included in the data.

Interviews were a mixture of online and in person. I experienced the interviews completed in person feeling different to those completed online. Mainly, there was a stronger sense of connection, and emotions were more tangible. Additionally, in person interviews were longer.

One of the participants was aware of my cancer experience prior to the interview. This shaped the direction of the interview, as she asked about my experiences compared to hers, considering similarities and differences. The dynamic of this interview felt different; more conversational and there was a lot more assumed knowledge. I had to ask for clarification a number of times to make sure that the correct information was obtained for the interview.

Appendix 12: The ENTREQ statement

No	Item	Guide and description
1	Aim	State the research question the synthesis addresses.
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. <i>meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis</i>).
3	Approach to searching	Indicate whether the search was pre-planned (<i>comprehensive search strategies to seek all available studies</i>) or iterative (<i>to seek all available concepts until they theoretical saturation is achieved</i>).
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. <i>in terms of population, language, year limits, type of publication, study type</i>).
5	Data sources	Describe the information sources used (e.g. <i>electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists</i>) and when the searches conducted; provide the rationale for using the data sources.
6	Electronic Search strategy	Describe the literature search (e.g. <i>provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits</i>).
7	Study screening methods	Describe the process of study screening and sifting (e.g. <i>title, abstract and full text review, number of independent reviewers who screened studies</i>).
8	Study characteristics	Present the characteristics of the included studies (e.g. <i>year of publication, country, population, number of participants, data collection, methodology, analysis, research questions</i>).
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g. <i>for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development</i>).

No	Item	Guide and description
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. <i>assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings</i>).
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. <i>Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting</i>).
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. <i>all text under the headings "results /conclusions" were extracted electronically and entered into a computer software</i>).
15	Software	State the computer software used, if any.
16	Number of reviewers	Identify who was involved in coding and analysis.
17	Coding	Describe the process for coding of data (e.g. <i>line by line coding to search for concepts</i>).
18	Study comparison	Describe how were comparisons made within and across studies (e.g. <i>subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary</i>).
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations or the author's interpretation.
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. <i>new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct</i>).

