GRACE MOORTON BSc (Hons), MSc

THE EXPERIENCE OF LONELINESS IN WOMEN

Section A

Enhancing Understanding of Increased Loneliness in Women With Breast Cancer: An Integrative Review

7900 Words (265)

Section B

"Feeling unconnected when you want to be connected": The Experience of Loneliness in Autistic Women

7962 Words (334)

Overall Word Count: 15,862 Words (599)

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Statement of Context

It is important to note that this study makes a clear distinction between a breast cancer diagnosis, which is a physical disease, and an autism diagnosis, which describes how some individuals experience the world in different ways. Section B of this Major Research Project (MRP) exploring the experiences of loneliness in autistic women, was linked to Section A through the implication that different groups of individuals may experience loneliness differently, which was not a focus of the studies reviewed in Section A but that may be useful to explore in order to enhance an understanding of the construct of loneliness in women, including women with breast cancer. Autistic women are one such group who may experience loneliness in a unique way compared to other individuals and are often underrepresented in research. However, it should be made explicitly clear that this study does not view autism as a disease or deficit and that the sections of this MRP were not linked in this way.

Summary of the MRP

Section A: This section is an integrative review of the literature exploring the factors linked to increased loneliness in women with breast cancer. Eighteen studies were appraised and analysed using thematic synthesis. The findings suggested that loneliness in women with breast cancer is complex, psychologically painful, and disabling. This necessitates a holistic approach from health professionals in order to be able to support women to have a better quality of life.

Section B: This section examined the experiences of loneliness in autistic women. Ten autistic women were interviewed. Interviews were analysed using interpretative phenomenological analysis and six themes were generated, suggesting that autistic women experience loneliness through: *Feeling different; Trying to fit in; Misunderstandings and understandings of autism; A balancing act;* and *Building the bridge alone;* with *Being autistic is "part of who I am"* at the core of this. Seeing beyond the label of autism and taking time to ask autistic women about what autism means for them may help to alleviate feelings of loneliness.

Please note: the topics in this Major Research Project may be triggering for some people. They include breast cancer statistics and detailed accounts of loneliness.

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SECTION A

Enhancing Understanding of Increased Loneliness in Women With Breast Cancer: An Integrative Review

Word Count: 7900 Words (265)

Abstract

Introduction: This integrative review aimed to examine the factors related to increased loneliness in women with breast cancer, in order to understand how to support this population and to improve quality of life. **Methodology:** Eighteen studies were included in this integrative review and a thematic synthesis was used to explore the results. **Results:** Themes for the factors related to increased loneliness in women with breast cancer were: *Relational difficulties*, *physical and mental health difficulties,* and *multiple concomitant difficulties*. These factors suggested that, in women with breast cancer, loneliness is: *complex, psychologically painful,* and *disabling.* To support women with breast cancer who experience loneliness, the findings of this review suggested that healthcare professionals should: *use a holistic approach, offer psychological support* and *increase understanding and awareness of difficulties*. **Discussion:** Increased loneliness in women with breast cancer is related to a range of factors that are complex and often occur simultaneously. A holistic approach may be needed to help tackle loneliness in this population. More research is needed to explore loneliness in women with breast cancer from marginalised groups and to understand what loneliness means to individuals across different cultures and populations.

Keywords: Loneliness, breast cancer, women, review

Introduction

Loneliness and Related Psychological Theories

Loneliness is a common experience that has gained increased attention on an international scale due to the significant associations it has with both physical and mental health difficulties (Surkalim et al., 2022). The factors related to loneliness are extensive and transcend the lifespan. They include depression, anxiety, difficulties with cognitive function, stress, maladaptive health behaviours, impaired cardiovascular function, and even death (Elovainio et al., 2017; Hawkley & Capitanio, 2015; Park et al., 2020).

Loneliness has been defined as "a distressing feeling that accompanies the perception that one's social needs are not being met by the quantity or especially the quality of one's social relationships" (Hawkley & Cacioppo, 2010). The cognitive discrepancy model of loneliness first suggested by Peplau & Perlman (1979) offers an explanation for this definition that encompasses key elements from previously proposed theories of loneliness and has been widely used in empirical research (Perlman & Peplau, 1982). It suggests that individuals evaluate their social relations through a cognitive process. When their perceived social relationships fall short of what they desire from these relationships, then loneliness is experienced. According to this model, this cognitive process and the conclusions made by an individual can also be influenced by their cultural norms and values.

This integrative review focussed on loneliness in women with a diagnosis of breast cancer.

Breast Cancer

Cancer cases are increasing in the United Kingdom (UK), largely due to rising populations and higher life expectancies (Cancer Research UK, 2024). Amongst cancer cases, breast cancer is one of the four most common types of cancer diagnosed in England (Baker & Mansfield, 2023) and the most commonly diagnosed cancer worldwide (World Health

Organization [WHO], 2023). Breast cancer is a disease that begins when abnormal cells grow in the milk ducts of the breast. These cells can spread to other parts of the breast tissue as well as other organs or parts of the body at more advanced stages (World Health Organization [WHO], 2024). There are different types and stages of breast cancer, which can influence the treatment offered to individuals. Treatments can include surgery, radiotherapy, chemotherapy and removal of all or some of the breast (Macmillan Cancer Support, 2023). Physical side effects, as well as psychological difficulties as a response to diagnosis and treatment, can be significant and last for many years after the initial diagnosis (Macmillan Cancer Support, 2023).

Women With Breast Cancer

One of the strongest risk factors for breast cancer is being female, with 99% of cases occurring in women (WHO, 2024). With longer survival rates, women are at risk of experiencing a range of related challenges, often with limited support, such as physical and mental health difficulties, and loneliness (Keane et al., 2023; WHO, 2023). Women play an integral role in societies around the world, for example, as professionals, mothers, community members and leaders. They also continue to experience inequality globally, such as being subjected to less access to work and education, and gender-based violence (UN-Women, 2024). Therefore, the importance of supporting women after a diagnosis of breast cancer and improving their quality of life has huge implications, not only for the women themselves, but for wider society and those working with, looked after, and led by them. Furthermore, research has suggested that improving the quality of life in women with breast cancer can help to reduce related symptoms and aid recovery (Keane et al., 2023; Tan et al., 2023).

The term *women with breast cancer* used in this review describes women at any time in their breast cancer journey from the point of diagnosis to the rest of their lives. It was felt that "breast cancer survivor" did not correctly describe women in the studies who had just

been diagnosed or were undergoing treatment, and that "breast cancer patient" did not account for the women who were in remission from breast cancer. Therefore, the term "women with breast cancer" was used to describe all the participants, particularly as many studies referred to women collectively at different timepoints in their journey without making this distinction. However, it is acknowledged that this language use could also be problematic as not all women were living with cancer when they participated in the studies.

Loneliness in Cancer

Loneliness in people who have had a diagnosis of cancer has been related to an increased risk of mortality, as well as a range of other factors, such as increased blood pressure, alcohol consumption, smoking, and depressive symptoms (Gallagher et al., 2021; Rokach, 2019). Loneliness may be particularly prevalent in people who have been diagnosed with cancer due to a felt sense of being different from people who are healthy and being less able to take part in everyday activities due to feeling unwell (National Cancer Institute, 2019). Although the causal mechanisms behind loneliness are still not fully understood (Perlman & Peplau, 1998), these multiple related factors fit with the biopsychosocial model of illness (Engel 1977), which posits that physical ill health is not just linked to biological processes, but also closely related to psychological, social and behavioural factors.

Previous Reviews

There have been a range of studies exploring the effectiveness of interventions to reduce loneliness in women with breast cancer (Abed et al., 2020; Yu et al., 2023; Montali et al., 2021). However, there has been limited research to explore factors linked to increased loneliness in women with breast cancer. Gaining an enhanced understanding of which factors are linked to increased loneliness in women with breast cancer may help to inform interventions that can be developed and tailored specifically to this population, which could

also improve their quality of life. No previous reviews exploring the factors linked to increased loneliness in women with breast cancer have been identified.

Review Approach

Research into loneliness and breast cancer has come from a range of disciplines and study designs, about a range of communities (Marziliano et al., 2024). An integrative review method would therefore be appropriate for this study as it would accumulate research and findings on a topic from different perspectives, cultures, or communities, different methods or approaches, and across different disciplines (Cronin & George, 2023). In doing so, it would provide an opportunity for the reviewer to understand a topic wholly, with the possibility that new insights would be gained that would otherwise not have been acquired within single research studies (Cronin & George, 2023).

Review Questions

This review therefore aimed to answer the following questions:

1. What factors relate to increased loneliness in women with breast cancer?
2. What can these factors tell us about loneliness in women with breast cancer?
3. What can these findings tell us about how healthcare professionals can support women with breast cancer who experience loneliness?

Methodology

Information Sources and Search Strategy

Arguably one of the key factors that distinguishes an integrative review from other types of review is that it amalgamates data from across disciplines and researchers, rather than from within one particular type of philosophy or practice (Cronin & George, 2023). Therefore, in keeping with this, a wide variety of databases covering different disciplines were searched. Search terms recommended by database search engines, including each database's thesaurus,

were used, in an aim to ensure that all potentially generative or relevant terminology was captured and included in the search (see Table 1 for suggested terms). All terminology was then used in all database searches (see Appendix A for development of search terms and Table 2 for final search terms).

The search was carried out for all databases in April 2024. Papers were included from all time, and up until the search date. All search results were imported into the reference management software package, RefWorks ProQuest, in order for the articles to be screened. Titles and abstracts were screened according to the inclusion and exclusion criteria after duplicate records had been removed. Full articles were then assessed for eligibility following a hand search for articles. Eighteen articles subsequently met the inclusion criteria and were included in the final review. See Figure 1 for a PRISMA diagram of the search process.

Inclusion and Exclusion Criteria

Articles were included for review if participants were women who had received a diagnosis of breast cancer and if the research explored factors linked to increased loneliness. Quantitative studies were included if they used a measure of loneliness, and qualitative studies were included if they explored distressing feelings linked to loneliness. Studies were excluded if they did not meet the inclusion criteria or were carried out on animals. Studies only exploring related constructs, such as "social isolation", without reference to loneliness or distressing feelings as a result of these experiences, or where loneliness could not be distinguished, were also excluded. Studies that did not separate breast cancer from other health conditions were also excluded. See Table 3.

Quality Appraisal

Quality appraisal of studies in an integrative review has been identified as an essential step to ensure rigour and to be aware of any bias within individual studies that may impact on the results of the review (Remington, 2020). The Mixed Methods Appraisal Tool Version

Table 1

Suggested Search Terms From Databases With a Thesaurus

Key word	Suggested term	Research	Database				
			ASSIA	APA PsycINFO (Ovid)	Medline (Ovid)	CINAHL	Cochrane Library
Loneliness	Alienation		X				
	Social isolation	X	X			X	
	Ostracis*					X	
	Social alienation					X	
	Social deprivation					X	
	Social disconnection	X					
Breast cancer	Breast reconstruction		X			X	
	Lumpectomy		X	X	X		
	Mammography		X				
	Mastectomy		X				
	Lobular Carcinoma					X	
	Malignant neoplasm of breast			X	X		X
	Breast carcinoma			X	X		X
	Breast neoplasm					X	X
	Breast examination					X	
	Human mammary neoplasm						X
	Malignant breast tumor						X
	Mammary cancer						X

Table 2

Search Terms

Topic	Search terms
Breast cancer terms	("breast cancer*" OR lumpectomy OR “breast reconstruction” OR mastectomy OR mammogra* OR “lobular carcinoma” OR “human mammary carcinoma*” OR “human mammary neoplasm*” OR “malignant breast tumo*” OR “breast examination” OR “malignant neoplasm of breast” OR “breast carcinoma” OR “breast neoplasm” OR “mammary cancer”)
	AND
Loneliness terms	(lonel* OR "social isolation" OR alienation OR "social disconnection" OR “ostracis*” OR “social alienation” OR “social deprivation”)

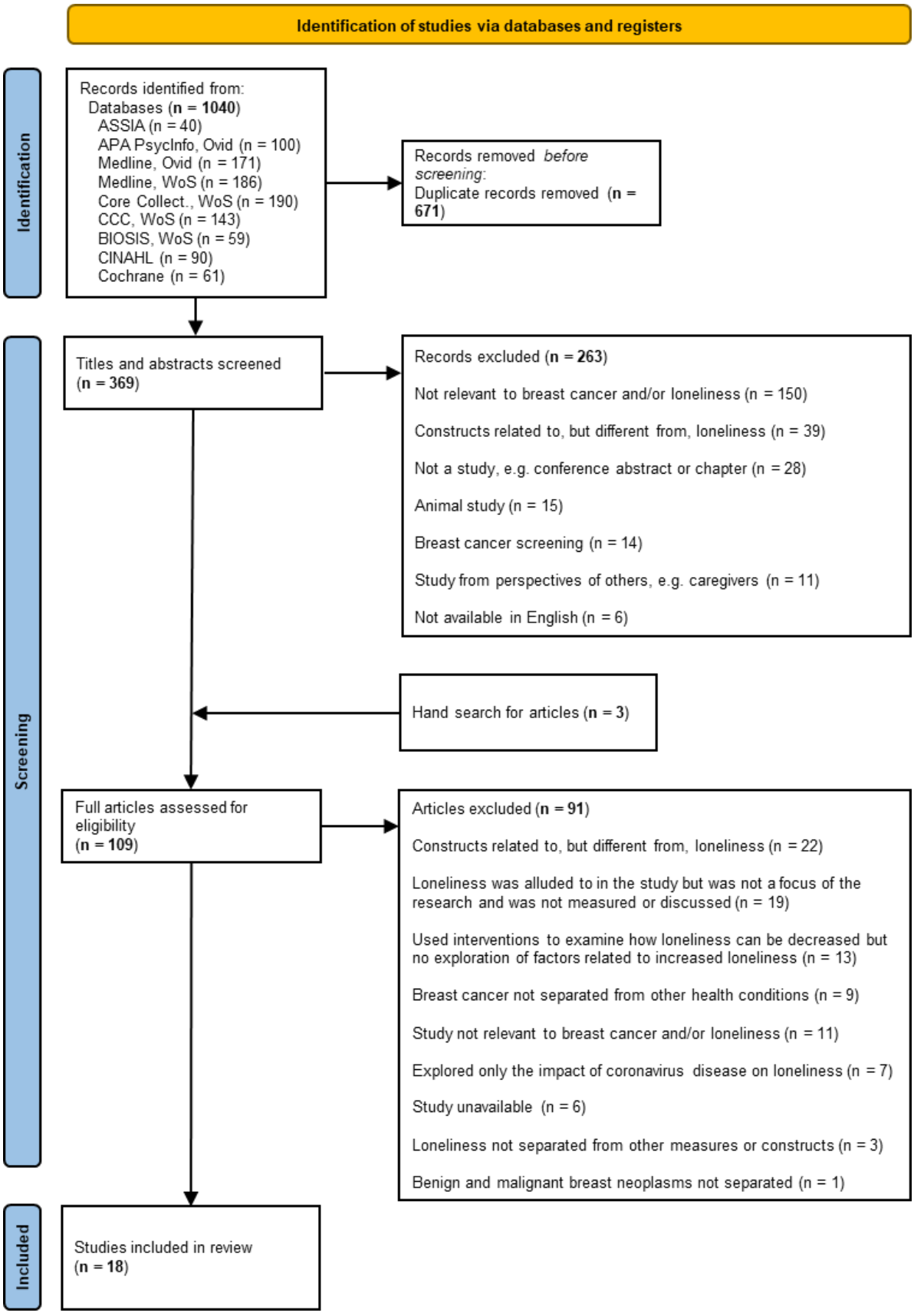
Table 3

Inclusion and Exclusion Criteria

Inclusion	Exclusion
Participants were women with a diagnosis of breast cancer.	Participants were professionals or family carers of women with breast cancer. Breast cancer was not separated from other health conditions or types of cancer. Animal studies.
Studies reporting on increased loneliness in relation to women with breast cancer.	Studies reporting on how loneliness can be decreased in women with breast cancer, e.g. intervention studies. Studies exploring the impact of coronavirus only on loneliness in women with breast cancer.
Quantitative studies including a measure of loneliness.	Loneliness not measured, or measured with tools where it could not be distinguished from other constructs. Similar constructs to loneliness measured, such as "social isolation" with no reference to loneliness or related distressing feelings.
Qualitative studies exploring distressing feelings linked to loneliness.	Qualitative studies not referring to distressing feelings linked to loneliness.
Any type of research exploring increased loneliness in women with breast cancer including unpublished research, such as dissertations.	Studies not in English.

Figure 1

PRISMA Diagram of Selected Studies



2018 (MMAT; Hong et al., 2018) was chosen to assess the quality of the studies used for this review and is a well-used, evidence-based tool. It allows for detailed appraisal of a large range of study designs (Hong et al., 2018), which was felt to be particularly useful for comparing the varied study designs included in this integrative review. The MMAT includes criteria for broadly five study designs. All eighteen studies were appraised for quality using the criteria based on their study design and included within the final results.

Data Analysis

Data were analysed using thematic synthesis, an approach using a three-step process outlined by Thomas and Harden (2008). Whilst there are no widely used analytic methods developed specifically for integrative reviews (Dwyer, 2020), Thomas and Harden's (2008) thematic synthesis allows for multiple data sources to be organised and explored, and has been commonly used to analyse findings for integrative reviews (Dhollande et al., 2021; Dwyer, 2020). Furthermore, the method proposed by thematic synthesis is in line with the philosophy of an integrative review, which emphasises the importance of abstracting higher order themes from the findings of studies and examining relationships across these themes, in order to build bridges across research disciplines and make sense of the literature as a whole (Cronin & George, 2023).

For question one, each finding from the results sections across all 18 articles related to increased loneliness in women with breast cancer was written as a separate statement (N = 38) and imported into the qualitative analysis software programme, NVivo (version 12) to aid the analysis. This aligned with the aims of "completeness" and "balance" that have been suggested for the integrative review process, whereby all data for every article in the review was considered individually for analysis, across researcher disciplines and philosophical underpinnings, before being grouped to look at the meaning of the studies as a whole (Cronin & George, 2023).

Consistent with the approach used by Thomas and Harden (2008), initial codes were assigned to each research finding as a way to begin to describe and group patterns across the data, using an inductive and data-driven approach. As per Thomas and Harden (2008), descriptive themes were then developed by combining these codes and looking for patterns across them to describe the data. Finally, broader analytical themes were developed to go beyond the data by using the research question as a way to organise the descriptive themes. For example, the finding in Hissa et al., (2020) of feeling unloved linked to increased loneliness was assigned initial codes including, "not given love when needed linked to increased loneliness", and "perceived unmet needs for being loved". These were then grouped with other findings to create descriptive themes, such as, "unmet needs in relationships linked to increased loneliness", which were then grouped within the broader analytical theme of "Relational difficulties".

The same steps suggested by Thomas and Harden (2008) described for question one were used to answer question three, but this time, data was taken from the clinical implications of the results suggested by researchers found in the discussion sections. In order for a review to be fully integrative, Cronin and George (2023) suggest that, as well as developing themes to connect study findings, attention also needs to be paid to the relationships across themes. Therefore, themes were further developed with a broader view for question two, which aimed to link the findings and themes together to make sense of the experience of loneliness in women with breast cancer across studies. As the level of abstraction became broader in this way, the need for interpretation from the researcher increased accordingly. A reflexive research diary was kept by the researcher throughout the review process (Appendix B), in order to address this and to set aside potential biases (Braun & Clarke, 2013; Cronin & George, 2023).

Results

Overview of Studies

Groups of researchers in this review differed across articles, with the majority of first authors and their research team, where known, from clinical health psychology ($N = 6$) or nursing professions ($N = 5$). Four of the studies used a qualitative approach, whilst the rest were quantitative ($N = 14$). In light of the focus of the studies on women, it may be of interest to note that, where known, the majority of first authors also identified as female ($N = 13$).

Studies included in this review were published between 1992 and 2024, with all but one study published since 2006. The total number of participants were 2938 women, with participant numbers ranging from three to 492, across studies. The overall age range of women, where reported, was 24 to 85+, which covers a considerable amount of time across the lifespan. Since, many of the studies included a wide range of ages, with only two that reported focussing on a more specific range (Hissa et al., 2020; Lemij et al., 2023), all age ranges over 18 were included. However, it should be kept in mind that developmental needs and experiences of women differ at various stages of the lifespan, which could impact on experiences of loneliness. More than half of the studies were carried out in the United States of America. Reporting of ethnicity was variable, with some studies not reporting this at all, and some using very broad terms, including the term "other" to describe participants.

Where reported, women participated between zero months and 18 years post treatment for breast cancer, with the majority having a stage one or stage two diagnosis at the time of participating. In 11 of the studies, the term "breast cancer survivors" was used to describe women, and this varied from the time of diagnosis to over 18 years post breast cancer treatment. In two of these studies, this term was used interchangeably with "women with breast cancer". In the remaining studies, the terms "breast cancer patients" and "women

with breast cancer" were used, sometimes interchangeably. This varied from the time of diagnosis to an unspecified time post treatment. See Table 4 for an overview of studies.

Quality Appraisal

The studies in this review fell into three of the five categories of criteria for the MMAT and were appraised accordingly (Tables 5-7 and Appendix C). According to the criteria, all studies appeared to be of a good overall quality.

Quantitative Studies

A key strength of these studies was the justification and use of appropriate measures for the factors being explored. Cause and effect could not be inferred from any of the quantitative studies due to the methods and analysis used. This means that the results of this integrative review were able to highlight the factors associated with increased loneliness, but not the direction of the effects.

Sampling Strategy and Target Population. Care was given within studies to recruit women with breast cancer from a variety of sources. For example, Choi and Henneghan (2022) recruited women from an online community of oncology nurses, a local breast cancer resource centre, and a cancer research charity. However, a key critique across four of the studies was that the target population was neither explicitly stated, nor clearly operationalised, making it difficult to ascertain whether the sampling strategy was appropriate (Ban & Bai, 2024; Choi & Henneghan, 2022; Henneghan et al., 2018; Henneghan et al., 2021).

Furthermore, for many of the studies, even when the target population was described, it covered a very broad group of people. Notably, the timepoint at which women with breast cancer participated since diagnosis spanned a long period within seven of the studies: three studies covered nine and a half years each (Choi & Henneghan, 2022; Henneghan et al., 2018; Henneghan et al., 2021) and four studies two years and 10 months each (Jaremka et al.,

Table 4

Overview of Studies

Study No.	Author (year) and study location	First author discipline	Participants and age range	Stage of breast cancer	Ethnicity	Study design	Loneliness measure	Study aims & Terminology
1	Ban & Bai (2024) China	Unknown	*N* = 492 Age range not reported	At discharge post-surgery Stage 1: 143 Stage 2: 199 Stage 3+ 4: 150	Not reported	Quantitative: Descriptive cross-sectional	3-item UCLA Loneliness Scale (Hughes et al., 2004)	To examine how perceived stress, loneliness, sleep disorders and resilience are related. To examine whether resilience moderated the relationships between perceived stress and loneliness with sleep disorders. *"Breast cancer patients"*
2	Choi & Henneghan., (2022) USA	Nursing	*N* = 90 Age range not reported	Post-treatment (0.5-10 yrs) Stage 1: 19 Stage 2: 51 Stage 3: 19	African American: 6 Asian: 3 Hispanic White: 5 Non-Hispanic White: 75 Other: 1	Quantitative: Cross-sectional descriptive	UCLA Loneliness Scale, Revised (Russell, 1996)	To compare loneliness, perceived stress, depressive symptoms, anxiety, fatigue, and daytime sleepiness between breast cancer survivors younger than 50 years old and breast cancer survivors older than 50 years old. *"Breast cancer survivors"*
3	Fanakidou et al., (2018) Greece	Health psychology, nursing	*N* = 81 38-52 years	Post-surgery (1 year) All stage 2	Not reported	Quantitative: Cross-sectional analytic	Greek version of UCLA Loneliness Scale	To compare loneliness, illness perception, health-related quality of life and mental health between women with breast cancer with and without breast reconstruction. *"Breast cancer patients"*

4	Fox et al., (1992) USA	Unknown	*N* = 72 "Early 30's to upper 70's"	Post-diagnosis (Immediate and any time)	"Approx. 95% Caucasian"	Quantitative: Analytic cross-sectional	UCLA Loneliness Scale (Russell & Cutrona, 1987)	To compare loneliness, emotional repression, poor marital quality, and major life changes between women with and without breast cancer. *"New breast cancer", "previous breast cancer"*
5	Henneghan et al., (2018) USA	Nursing	*N* = 90 24-65 years	Post-diagnosis (0.5-10 yrs) Stage 1: 19 Stage 2: 51 Stage 3: 19	White: 80 African American: 6 Asian: 4	Quantitative: Correlation analyses	UCLA Loneliness Scale, Revised, V3 (Russell, 1996)	To examine the relationship between anxiety, depression, fatigue, perceived stress, perceived loneliness and sleep quality with perceived cognitive function in breast cancer survivors. *"Breast cancer survivors"*
6	Henneghan et al., (2021) USA	Nursing	*N* = 66 27-65 years	Post-treatment (0.5-10 yrs) Stage 1: 12 Stage 2: 41 Stage 3: 13	White: 62 African American: 1 Asian: 3	Quantitative: Cross-sectional descriptive analysis	UCLA Loneliness Scale, Revised, V3 (Russell, 1996)	To examine the relationship between perceived stress, fatigue, loneliness, perceived cognitive impairment, daytime sleepiness, sleep quality, and 13 cytokines in breast cancer survivors. *"Breast cancer survivors"*
7	Heshmati et al., (2024) Iran	Clinical psychology, health psychology	*N* = 133 30-66 years	Post-diagnosis (3 months) Stage 1: 35 Stage 2: 51 Stage 3: 38 Stage 4: 9	Not reported	Quantitative: Cross-sectional descriptive analysis	UCLA Loneliness Scale (Russell et al., 1980)	To examine the relationship between loneliness, parental bonding, ambivalence over emotional expression, and self-discrepancy in breast cancer survivors who experienced childhood maltreatment. *"Women with breast cancer/breast cancer patients"*

8	Hissa et al., (2020) Republic of Ireland	Counselling psychology	*N* = 3 41-50 years	Not reported	All Caucasian Irish	Qualitative: Descriptive and interpretative	Qualitative descriptions	To examine the emotional processes in the experiences of anxiety and depression in breast cancer survivors. *"Breast cancer patients/women with breast cancer"*
9	Ikeuchi et al., (2020) Japan	Unknown	*N* = 249 29-83 years	Post-treatment (6 months+) Stage 0: 14 Stage 1: 112 Stage 2: 96 Stage 3: 27	Not reported	Quantitative: Cross-sectional descriptive	Numeric rating scale (1 item from 0-10)	To investigate the relationship between mindfulness and fatigue of breast cancer survivors, with anxiety, depression, pain, loneliness, and sleep disturbance as mediators in a path analysis. *"Breast cancer survivors"*
10	Jaremka et al., (2013a) USA	Clinical health psychology	*N* = 200 27-76 years	Post-treatment (2 months - 3 yrs) Stage 0: 18 Stage 1: 89 Stage 2: 75 Stage 3: 18	White: 177 Black: 18 Other: 5	Quantitative: Cross-sectional descriptive	UCLA Loneliness Scale (Russell, 1996)	To examine the relationship between loneliness, immune dysregulation (through latent herpesvirus reactivation), pain, depression, and fatigue. *"Breast cancer survivors"*
11	Jaremka et al., (2013b) USA	Clinical health psychology	*N* = 144 28-76 years	Post-treatment (2 months - 3 yrs) Stage 0: 11 Stage 1: 63 Stage 2: 56 Stage 3: 14	White: 124 Black: 15 Other: 5	Quantitative: Before-and-after study	UCLA Loneliness Scale (Russell, 1996)	To examine the relationship between loneliness and elevated inflammation (through stress-related cytokine production) in response to an acute stressor, in breast cancer survivors. *"Breast cancer survivors"*

12	Jaremka et al., (2014) USA	Clinical health psychology	*N* = 385 27-88 years	Post-treatment (2 months - 3 yrs) Stage 0: 51 Stage 1: 174 Stage 2: 120 Stage 3: 38	White: 324 Black: 45 Other: 16	Quantitative: Analytic cross-sectional	UCLA Loneliness Scale; 8-item New York University Loneliness Scale	To examine the relationship between loneliness and cognitive function among breast cancer survivors. *"Breast cancer survivors"*
13	Lemij et al., (2023) The Netherlands	Medicine	*N* = 299 70-85+ years	Post-diagnosis (0-5 yrs) Stage 0: 11 Stage 1: 152 Stage 2: 100 Stage 3: 18 Unknown: 18	Not reported	Quantitative: Longitudinal cohort study	De Jong Gierveld Loneliness Scale (De Jong Gierveld & Van Tilburg, 2010)	To examine the relationship between depressive symptoms, loneliness and apathy in older women with early-stage breast cancer. *"Patients/breast cancer survivors/women with breast cancer"*
14	Madison et al., (2022) USA	Clinical psychology	*N* = 79 Age range not reported	Post-treatment (2 months - 3 yrs) Stage 0-1: 40 Stage 1-2: 31 Stage 3+: 8	White: 67 Black: 10 Asian American: 2	Quantitative: Analytic cross-sectional	UCLA Loneliness Scale (Russell, 1996)	To examine the relationship between loneliness, perceived social support, depressive symptoms and inflammatory reactivity to a social stressor. *"Breast cancer survivors"*
15	Madsen et al., (2007)	Medicine	*N* = 24 38-62	Pre-treatment	Not reported	Qualitative: Grounded theory	Qualitative descriptions	To explore the experiences of women receiving treatment for

	Denmark			post diagnosis				breast cancer, both within a trial and outside of a trial. *"Breast cancer patients"*
16	Marroquín et al., (2016) USA	Clinical psychology	*N* = 297 24-91 years	Post-diagnosis (1 year) Stage 1: 175 Stage 2: 155 Stage 3: 44 Stage 4: 16	White/ European American: 266 Latina: 75 Asian/Asian-American: 19 Native American: 11 Black/African American: 7 Multiracial: 8 Other/ unreported: 4	Quantitative: Cross-sectional descriptive	Implicit Association Task of Loneliness (IAT-L; Nausheen et al., 2007)	To examine the relationships between implicit loneliness, emotion regulation and depressive symptoms among women diagnosed with breast cancer. *"Women with breast cancer/breast cancer survivors"*
17	Mohammadi et al., (2019) Iran	Nursing	*N* = 36 24-64 years	Post-surgery, during treatment, post treatment Stage 1: 8 Stage 2: 14 Stage 3: 7 Stage 4: 7	Not reported	Qualitative: Content analysis	Qualitative descriptions	To explore the experience of pity in Iranian breast cancer survivors. *"Women with breast cancer"*

18	Rosedale, (2009) USA	Psychiatric nursing	*N* = 13 33-74 years	Post-treatment (1-18 yrs) Stage 1: 7 Stage 2: 3 Unknown: 3	African American: 3 Caucasian: 10	Qualitative: Phenomenology	Qualitative descriptions	To explore the experience of loneliness in breast cancer survivors more than a year after treatment. *"Breast cancer survivors"*

Note. No. = number. yrs = years.

Table 5

MMAT for Quantitative Descriptive Studies

First author (year)	4.1. Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?
Ban (2024)	Yes	Yes	Yes	Yes	Yes
Choi (2022)	Yes	Yes	Yes	Can't tell	Yes
Henneghan (2018)	Yes	Yes	Yes	Can't tell	Yes
Henneghan (2021)	Yes	Yes	Yes	Can't tell	Yes
Heshmati (2024)	Yes	Yes	Yes	Can't tell	Yes
Ikeuchi (2020)	Yes	Yes	Yes	Yes	Yes
Jaremka (2013a)	Can't tell	Can't tell	Yes	Can't tell	Yes
Marroquín (2016)	Can't tell	Yes	Yes	Yes	Yes

Table 6

MMAT for Quantitative Non-Randomized Studies

First author (year)	3.1 Are the participants representative of the target population?	3.2 Are measurements appropriate regarding both the outcome and intervention (or exposure)?	3.3. Are there complete outcome data?	3.4. Are the confounders accounted for in the design and analysis?	3.5 During the study period, is the intervention administered (or exposure occurred) as intended?
Fanakidou (2018)	Can't tell	Yes	Can't tell	Can't tell	Yes
Fox (1992)	Yes	Yes	Can’t tell	Yes	Yes
Jaremka (2013b)	Yes	Yes	Yes	Yes	Yes
Jaremka (2014)	Yes	Yes	Can't tell	Yes	Yes
Lemij (2023)	Yes	Yes	Yes	Yes	Can't tell
Madison (2022)	Yes	Yes	Yes	Yes	Yes

Table 7

MMAT for Qualitative Studies

First author (year)	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Hissa (2020)	Yes	Yes	Yes	Yes	Yes
Madsen (2007)	Yes	Yes	Yes	Yes	Yes
Mohammadi (2019)	Yes	Yes	Yes	Yes	Yes
Rosedale (2009)	Yes	Yes	Yes	Yes	Yes

2013a, 2013b and 2014; Madison et al., 2022). Distinctions within these timepoints were not made in the studies. Some acknowledgement of this may have been useful, particularly in relation to the interpretation of the results and generalisability of the study findings.

On the other hand, there were some studies that explored more specific characteristics of women with breast cancer, such as women over the age of 70 (Lemij et al., 2023) or women who had experienced childhood maltreatment (Heshmati et al., 2024). Additionally, out of the six studies appraised using the MMAT for quantitative non-randomised studies, five of these acknowledged and accounted for a range of variables, such as age, cancer treatment, and cancer stage (Fox et al., 1992; Jaremka et al., 2013b; Jaremka et al., 2014; Lemij et al., 2023; and Madison et al., 2022). This may have helped to account for some of the differences within such a vast target population. Despite this, there were still some groups of people who were not mentioned at all, such as women with learning disabilities or autistic women, except for very briefly in exclusion criteria for studies on cognitive functioning (Choi & Henneghan, 2022; Henneghan et al., 2018). Although both groups include a hugely diverse range of women, they may also have unique experiences linked to loneliness that are key to research on loneliness in breast cancer.

Nonresponse Bias. Reviewing nonresponse bias is important because data may be shifted towards results that represent only a particular group of participants, i.e. the participants who chose to, or were able to, respond (Simsek et al., 2020). This was appraised in eight of the studies, with five not providing enough information to be able to establish why some people did not respond (Choi & Henneghan, 2022; Henneghan et al., 2018; Henneghan et al., 2021; Heshmati et al., 2024; and Jaremka et al., 2013a). However, due to the recruitment strategies used for two of these studies, acquiring this information may not have been possible, as participants were recruited in response to flyers (Henneghan et al., 2018) and media sources (Jaremka et al., 2013a).

Measures of Loneliness. Most of the studies used the UCLA Loneliness Scale to measure loneliness (N = 11). The UCLA Loneliness Scale is a widely used measure (Surkalim et al., 2022) with strong test-retest reliability and construct validity (Penning et al., 2014). Since different scales may represent slightly different definitions of loneliness, the use of the same scale across most of the quantitative studies in this review makes the studies easier to compare as it is more likely they were reporting on similar understandings of the sub-constructs of loneliness.

Qualitative Studies

The qualitative studies all fitted the appraisal criteria well, with a particular strength being the appropriateness of the qualitative approach and data collection to answer the research question. More detail in the results sections may have been helpful across the studies. However, it is likely that it was challenging to report results in any more detail due to the publication restrictions of the journals, and qualitative research often requiring a higher word count for the results section (Braun & Clarke, 2014).

Definitions of Loneliness. Definitions of loneliness were not given, rather women spoke about their associated emotions and experiences. In one of the studies, the word "loneliness" was used by the authors to describe experiences expressed by the women (Madsen et al., 2007). In the other three qualitative studies (Hissa et al., 2020; Mohammadi et al., 2019; Rosedale, 2009) the experience of loneliness was covered in more detail; with associated experiences, images, words, and feelings, described.

Thematic Analysis

Themes were developed in relation to the three research questions for this integrative review. The themes for question two were developed from the studies reviewed and the themes in question one. They acted as a central point to link all the research questions and

themes together. This is described in more detail below and illustrated visually in Figure 2 (see Appendices D and E for individual theme diagrams).

Question One: What Factors Relate to Increased Loneliness in Women With Breast Cancer?

Two key themes and one metatheme described the factors related to increased loneliness in women with breast cancer (Table 8).

Theme One: Relational Difficulties. A third of the studies ($N = 6$) described how increased loneliness was associated with the relationships that women had with other people. This theme seemed to be particularly pronounced in the four studies using qualitative research methods, although was also found in two of the quantitative studies (Fox et al., 1992; Heshmati et al., 2024). The point at which women participated since diagnosis covered a large timespan in two of the studies (Mohammadi et al., 2019; Rosedale, 2009). In three of the studies women participated much closer to the time of their diagnosis, up to three months (Fox et al., 1992; Heshmati et al., 2024; Madsen et al., 2007). The studies informing this theme varied across disciplines, research methods, ages of participants, and countries and cultures within which the research took place.

This theme described how women did not simply feel lonely as part of a remote, internal experience. Rather, it was linked to the actions of others, or to women's own actions within relationships. Although no direction of effects can be inferred from the studies, these relational difficulties seemed to explain a cyclical or interrelated process of loneliness whereby the actions of others, and the actions of self, were connected. For example, Mohammadi et al., (2019) found that women experienced pity from others when they shared their experiences of cancer, which made them feel lonely. However, hiding information about their cancer experience from others to avoid pity also made women feel lonely.

Figure 2

Theme Diagram With all Themes Linking the Three Research Questions

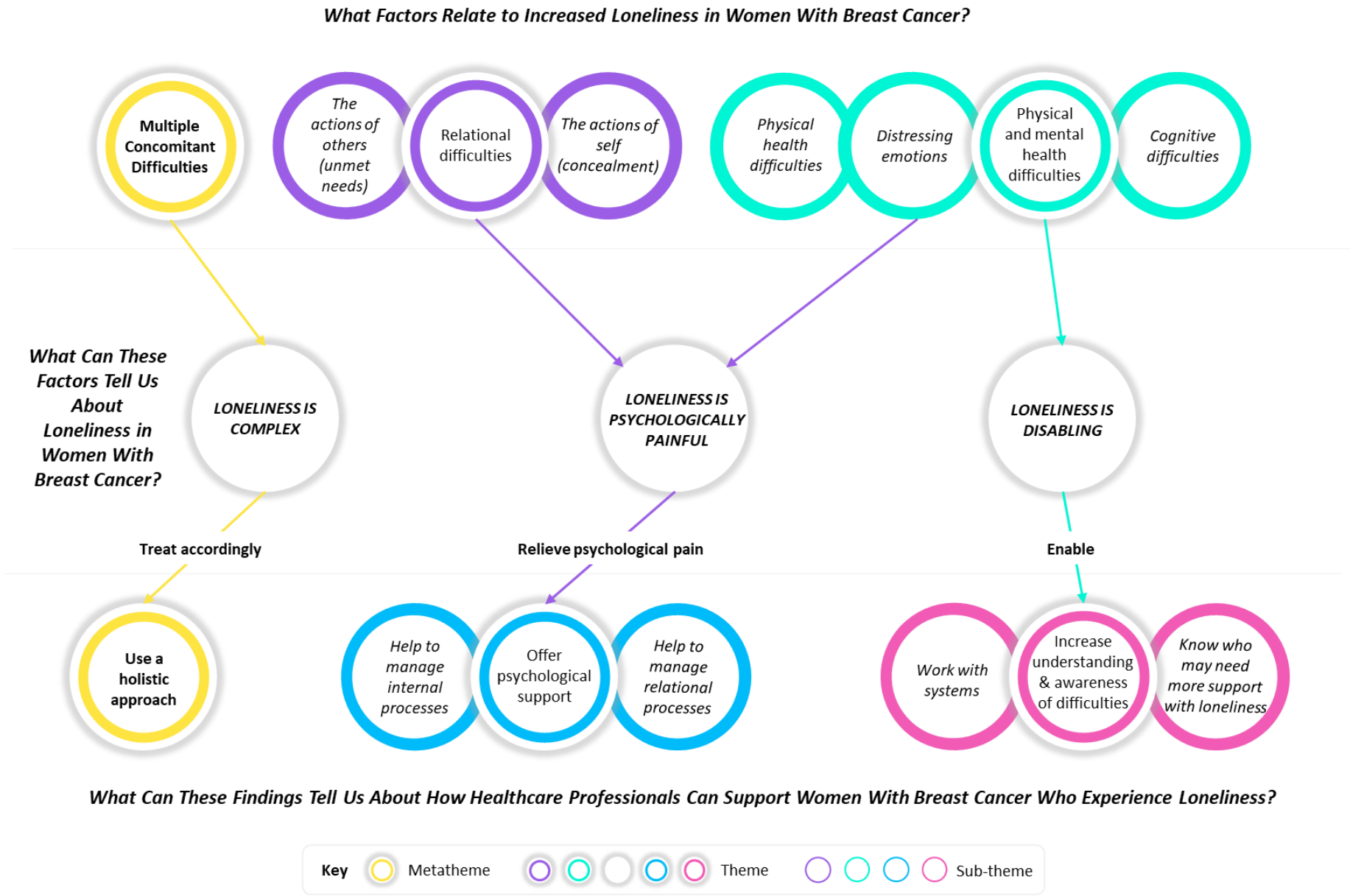


Table 8

What Factors Relate to Increased Loneliness in Women With Breast Cancer?

Themes and subthemes	First author (year)	Factors related to increased loneliness
Relational difficulties		
The actions of others (unmet needs)	Fox (1992)	Low marital quality (newly diagnosed/new cancer group).
	Hissa (2020)	Feeling unloved, uncared for, and abandoned, particularly within intimate relationships. Unmet needs for support, love, acceptance, care, and affection. Past abandonments make these difficulties more painful in the present.
	Heshmati (2024)	In women who had experienced childhood abuse: Lower parental care in childhood; Higher overprotection in childhood.
	Madsen (2007)	A lack of confidence and trust in medical professionals (due to perceived unpreparedness, a lack of support, and incompetence) when needing to make decisions about healthcare.
	Mohammadi (2019)	Pity from others when sharing information about breast cancer experiences.
	Rosedale (2009)	Lack of awareness and understanding from others of breast cancer experiences.
The actions of self (concealment)	Fox (1992)	Repressing emotions, such as anger, worry and unhappiness.
	Heshmati (2024)	In women who had experienced childhood abuse: Emotional ambivalence (linked to lower parental care in childhood); Self-discrepancy (linked to higher overprotection in childhood).
	Mohammadi (2019)	Hiding away from others and hiding illness to avoid pity.
	Rosedale (2009)	Pressure from the reactions of others to change self, conceal negative aspects of breast cancer and act like a hero; Withholding aspects of illness to protect others.
Physical and mental health difficulties		
Physical health difficulties	Choi (2022)	Fatigue, daytime sleepiness. Comorbidities in older BCS.
	Henneghan (2018)	Fatigue.

	Henneghan (2021)	Fatigue, IL-2 inflammatory cytokine.
	Ikeuchi (2020)	Fatigue; Pain linked to fatigue.
	Jaremka (2013a)	Pain, fatigue and higher antibody titers.
	Lemij (2023)	Frailty.
Distressing emotions	Choi (2022)	Perceived stress.
	Fanakidou (2018)	No breast reconstruction following a year after mastectomy linked to anxiety.
	Henneghan (2018)	Anxiety.
	Henneghan (2021)	Stress and depressive symptoms.
	Ikeuchi (2020)	Increased depressive symptoms over time.
	Jaremka (2013a)	Depression.
	Lemij (2023)	Depression linked to frailty.
	Madison (2022)	Depression; Lower mindfulness linked to anxiety.
	Marroquín (2016)	Implicit causal processing linked to depression; Less implicit positive emotion linked to depression.
Cognitive difficulties	Henneghan (2018)	Anxiety and fatigue linked to decreased cognitive function (perceived).
	Henneghan (2021)	Perceived cognitive impairment.
	Jaremka (2014)	Concentration (perceived and actual) and memory (perceived) difficulties.
Multiple Concomitant Difficulties	Ban (2024)	Lower resilience and sleep difficulties.
	Choi (2022)	Perceived stress, daytime sleepiness, fatigue, comorbidities, social factors.
	Fanakidou (2018)	No breast reconstruction following a year after mastectomy, poor health related QOL, anxiety.
	Fox (1992)	Emotional repression, decreased marriage quality.
	Henneghan (2018)	Loneliness indirectly effects cognitive function through anxiety and fatigue.
	Henneghan (2021)	Perceived cognitive impairment, stress, depressive symptoms, and fatigue.
	Heshmati (2024)	Higher emotional ambivalence and higher self-discrepancy with a history of childhood abuse and overprotection and under care.
	Ikeuchi (2020)	Lower mindfulness, sleep disturbance, pain, depression, fatigue, anxiety.
	Jaremka (2013a)	Pain, depression and fatigue, and higher antibody titers.
	Lemij (2023)	Depressive symptoms, frailty, apathy.
	Madison (2022)	Depressive symptoms, elevated inflammatory response to social stressor.

Madsen (2007)	Perceived insufficient knowledge about BC and treatment combined with a lack of support, confidence and trust in medical professionals when needing to make decisions about healthcare.
Marroquín (2016)	Implicit causal processing linked to depression; Less implicit positive emotion linked to depression.

The Actions of Others (Unmet Needs). Increased loneliness linked to the actions of other people included intimate others and professionals. This increased loneliness seemed to be associated with particular relational needs that the women had, which had not been met. Some of these needs were linked to past relationships. For example, a lack of care from parental figures in women who had experienced childhood abuse, as well as past abandonments, were linked to women feeling lonelier during their present cancer experiences (Heshmati et al., 2024; Hissa et al., 2020). Other unmet needs may have been linked to current relationships, with lonelier women who had a diagnosis of breast cancer, reporting the lowest marital quality compared to other groups (Fox et al., 1992).

Women across studies in Ireland, the USA, Denmark and Iran also expressed a need for appropriate responses from others in relation to their breast cancer experiences, with feelings of increased loneliness when this need was not met. For example, some women felt that intimate others did not understand them, shown by the comments they made, as well as unhelpful responses to fears expressed by women related to their illness (Rosedale, 2009). In a different study, women with breast cancer experienced more loneliness when they felt medical professionals were not able to give them the information they needed about their treatment (Madsen et al., 2007). Where reported, this need was expressed by both women who were recently diagnosed (Madsen et al., 2007; Mohammadi et al., 2019; Rosedale, 2009), as well as women who had completed cancer treatment up to 18 years later (Mohammadi et al., 2019; Rosedale, 2009).

The Actions of Self (Concealment). Increased loneliness was also associated with concealing parts of the self from others. In some studies, concealing emotions seemed to be demonstrated through more trait-like behaviours, for example, higher emotional ambivalence and self-discrepancy were linked to increased loneliness in women with breast cancer who

had experienced childhood abuse (Heshmati et al., 2024). In other studies, women appeared to be making purposeful decisions to conceal their breast cancer illness and related emotions to: avoid unwanted reactions from others, such as pity (Mohammadi et al., 2019); protect others from their experiences (Rosedale, 2009); and change aspects of themselves in response to pressure from others to appear in a certain way (Rosedale, 2009). All of these actions of concealment were linked to increased loneliness.

Theme Two: Physical and Mental Health Difficulties. Increased loneliness was linked to a number of physical and mental health difficulties in women with breast cancer across ten of the studies, all of which used quantitative methods. The time at which women took part since diagnosis varied greatly both within and between studies for all themes (zero to 10 years). This implies that physical health difficulties, distressing emotions and cognitive difficulties linked to loneliness in women with breast cancer may occur both at diagnosis, and for many years after.

Physical Health Difficulties. Unsurprisingly with a physical health focus, four out of six of these studies consisted of lead authors from a nursing or medical background (Choi & Henneghan, 2022; Henneghan et al., 2018; Henneghan et al., 2021; Lemij et al., 2023). Fatigue was the most common physical health difficulty linked to increased loneliness in women with breast cancer and was reported in five of the studies (Henneghan et al., 2018; Henneghan et al., 2021; Jaremka et al., 2013a; Ikeuchi et al., 2020; and Choi & Henneghan, 2022). Pain was also linked to fatigue and increased loneliness in two of the studies (Jaremka et al., 2013a; Ikeuchi et al., 2020). Biomarkers for immune system regulation and dysregulation were linked to increased loneliness in two studies (Henneghan et al., 2021; Jaremka et al., 2013a). Finally, frailty and a higher number of comorbidities were linked to increased loneliness in older women with breast cancer aged 70 and over, and 50 and over, respectively (Lemij et al., 2023; Choi & Henneghan, 2022).

Distressing Emotions. Depression or depressive symptoms were the most common mental health difficulty associated with increased loneliness in women with breast cancer, with six of the studies reporting this (Madison et al., 2022; Lemij et al., 2023; Henneghan et al., 2021; Jaremka et al., 2013a; Ikeuchi et al., 2020; Marroquín et al., 2016). In all of these findings, depression and loneliness were both linked to other factors, including physical health difficulties. Perceived stress and anxiety were also linked to increased loneliness in women with breast cancer (Henneghan et al., 2018; Henneghan et al., 2021; Fanakidou et al., 2018; Choi & Henneghan, 2022).

Cognitive Difficulties. Three studies suggested that increased loneliness was connected to perceived cognitive impairment in women with breast cancer (Henneghan et al., 2018; Henneghan et al., 2021; Jaremka et al., 2014), with one study specifying these impairments as concentration and memory difficulties (Jaremka et al., 2014). In addition to this, Jaremka et al., (2014), found that concentration was also impaired in lonelier women when it was measured objectively through standardised neuropsychological tests.

Metatheme One: Multiple Concomitant Difficulties. The factors highlighted within the above themes linked to increased loneliness were associated with multiple factors simultaneously in 13 of the studies. All of the studies included in this theme were quantitative, perhaps because they used objective measures of particular factors related to loneliness. Some of these studies termed them "cluster" symptoms, for example, Jaremka et al., (2013a) found that higher loneliness was linked to pain, depression, fatigue and immune dysregulation.

Question Two: What Can These Factors Tell Us About Increased Loneliness in Women With Breast Cancer?

These themes extended the themes developed from question one and were central to the three research questions for this integrative review.

Theme Three: Loneliness is Complex. This theme describes the multifaceted aspects of loneliness that were prevalent across all of the studies, such as increased loneliness clustering together with multiple physical and psychological symptoms, and its association with both internal psychological processes, as well as wider, systemic factors (see Metatheme One: Multiple Concomitant Difficulties).

Theme Four: Loneliness is Psychologically Painful. A key finding across all the studies in this review was that women experienced difficulties far beyond the physical symptoms directly related to breast cancer and treatment. Women struggled with difficult emotions in connection to, and including, increased loneliness. This theme was related to the distressing emotions that women experienced linked to increased loneliness, such as depression and anxiety (see Theme Two: Physical and Mental Health Difficulties, subtheme: Distressing Emotions). It was also linked to the relational difficulties that women experienced as part of their breast cancer journey (see Theme One: Relational Difficulties).

Theme Five: Loneliness is Disabling. The term *disabling* refers to an injury or illness that affects someone to the extent that "it restricts the way that they can live their life" (Collins, n.d.). This theme describes the physical and mental health difficulties that women experienced associated with increased loneliness, such as depression, anxiety, stress, cognitive difficulties, and fatigue. It is not possible to infer from the studies whether it was loneliness that led to these difficulties, or any other direction of effects, due to the correlational analyses used. However, the associations between increased loneliness and these factors implied that lonelier women with breast cancer were more likely to experience difficulties that would impact on the way they were able to live their lives.

Question Three: What Can These Findings Tell Us About How Healthcare Professionals Can Support Women With Breast Cancer Who Experience Loneliness?

Two key themes and one metatheme described how healthcare professionals can support women diagnosed with breast cancer who experience loneliness (Table 9). These themes were developed from the implications of the results described by the studies.

Theme Six: Offer Psychological Support. This theme leads on from Theme Four: Loneliness is Psychologically Painful and describes ways that this psychological pain could be relieved. Difficult emotions were linked to women's own struggles with their breast cancer journey, as well as the actions of people they had relationships with.

Help to Manage Internal Processes. One study suggested that offering psychological support to women with a breast cancer diagnosis could help them when making important decisions related to their treatment, such as whether to accept breast reconstruction (Fanakidou et al., 2018). This, in turn, may have helped to decrease feelings of loneliness.

The findings also suggested that psychological support or skills training to bring internal processes linked to loneliness into consciousness, as well as to understand the origins of their difficult feelings, may have helped women to manage current emotional difficulties (Fox et al., 1992; Marroquín et al., 2016; Heshmati et al., 2024; Hissa et al., 2020). Where known, the first author of all of these studies was a psychologist, which may have influenced the suggestions made and clinical implications of the study findings, especially in relation to the emphasis on help to manage internal processes.

Help to Manage Relational Processes. Women with breast cancer experienced unhelpful responses from others in relation to their illness, as outlined in Theme One: Relational Difficulties. For example, displays of pity and unmet needs of love and acceptance (Mohammadi et al., 2019; Hissa et al., 2020; Rosedale, 2009). In order to manage the feelings of loneliness linked to these actions, study findings in four studies implied that psychological

Table 9

What Can These Findings Tell Us About How Healthcare Professionals Can Support Women Diagnosed With Breast Cancer Who Experience Loneliness?

Themes and subthemes	First author (year)	How healthcare professionals can support women with breast cancer experiencing loneliness
Offer psychological support		
Help to manage internal processes	Fanakidou (2018)	More psychological support needs to be offered to BCS, particularly when needing to make important decisions, such as with regards to breast reconstruction.
	Fox (1992)	Supporting women to manage their emotions through skills training and exercise.
	Heshmati (2024)	Psychological assessment and interventions should be integrated with medical care for BCS, and psychological therapy offered. A focus on care and overprotection in childhood is important in tackling loneliness, AEE and self-discrepancy.
	Hissa (2020)	Helping BCS to be aware that past abandonments may influence current difficult emotions, including feelings of loneliness, in order to be able to situate and manage these difficult emotions.
	Marroquín (2016)	Teaching BCS skills to help them recognise their own emotions may help bring some internal processes linked to loneliness into consciousness, so that they can be treated.
Help to manage relational processes	Hissa (2020)	Supporting BCS to cope and manage the responses they receive from others.
	Jaremka (2013b)	BCS may need specialist support with help to reduce responses to social stressors.
	Mohammadi (2019)	Strategies to help women cope with unhelpful responses from others, and own emotions in relation to this.
	Rosedale (2009)	Learning how to manage own feelings and behaviours in response to the reactions of others.
Increase understanding and awareness of difficulties		

Work with systems	Fox (1992)	Marriage counselling, support for families, normalising difficulties in marriage following a breast cancer diagnosis.
	Hissa (2020)	Support with intimate relationships and normalising difficulties following cancer diagnosis.
	Lemij (2023)	Patients, caregivers and physicians to be made aware of the potential impact of cancer and its treatment on mental health outcomes.
	Madsen (2007)	Professionals need to treat BCS as "whole person". Importance of BCS feeling listened to, and taken seriously, in order to feel less lonely in decisions.
	Mohammadi (2019)	Work with families to increase understanding and helpful ways to respond to BCS.
	Rosedale (2009)	Working with families to increase understanding of breast cancer journey.
Know who may need more support with loneliness	Ban (2024)	A greater focus on information and coping strategies (in relation to perceived stress, loneliness and sleep disorders) may be needed when supporting BCS with lower resilience.
	Choi (2022)	Being aware of all factors that may be linked to increased loneliness and who may be more at risk.
	Jaremka (2014)	Loneliness should be assessed and support given in BCS where cognitive difficulties are found, and vice versa.
	Lemij (2023)	Awareness of groups within BCS who may be more likely to experience loneliness, e.g. frail adults.
Use a holistic approach	Choi (2022)	Interventions targeting multiple psychosocial symptoms simultaneously.
	Henneghan (2018)	Treating symptoms as a cluster may be an efficient way to intervene to decrease symptom burden and improve quality of life.
	Henneghan (2021)	Factors are clustered together so need to be treated as so in BCS.
	Ikeuchi (2020)	Interventions aimed at increasing mindfulness, or decreasing anxiety, may simultaneously help to reduce loneliness, depression, pain, sleep disturbance and fatigue.
	Jaremka (2013a)	Understanding that symptoms cluster together to explain links between loneliness, physical and mental health difficulties in BCS. Implications for how BCS are understood and supported.
	Madison (2022)	Support with helping to reduce stress, depressive symptoms, and loneliness, as a cluster.
	Rosedale (2009)	Important for healthcare professionals to listen to BCS, show understanding and empathy for unique experiences. Attunement to BCS individual experiences.

Note. BCS = breast cancer survivors.

support may be helpful for developing strategies to cope with this.

Theme Seven: Increase Understanding and Awareness of Difficulties. This theme leads on from Theme Five: Loneliness is Disabling, and describes ways that women could feel enabled, rather than disabled, through an increased understanding and awareness of their difficulties from others.

Work With Systems. Systems included intimate others, friends, families and professionals. The findings of two studies implied that an increased understanding from friends and relatives about the breast cancer journey, may have helped women to manage the feelings of loneliness they experienced as a result of inappropriate actions or comments (Hissa et al., 2020; Mohammadi et al., 2019). Another study suggested that professionals need to have an increased awareness of the impact of breast cancer treatment on the mental health of women (Lemij et al., 2024). One study proposed that this could be shown through validation and empathy based on the knowledge that women may feel misunderstood (Rosedale, 2009). These suggestions came from studies where women participated from no time since diagnosis to 18 years later, and with first authors from a range of disciplines. This suggests that working with systems is important for different professionals when supporting women at all timepoints in their breast cancer journey.

Know Who May Need More Support With Loneliness. Four studies highlighted the importance of an increased awareness from healthcare professionals, such as nurses and physicians, about who may be more at risk of experiencing loneliness, in order to be able to support them effectively (Choi & Henneghan, 2022; Lemij et al., 2023). These findings suggested that certain groups of women may be at more risk of experiencing loneliness, including, women who are frail (Lemij et al., 2023), women with lower resilience (Ban & Bai, 2024), and women with cognitive difficulties (Jaremka et al., 2014).

Metatheme Two: Use A Holistic Approach. This theme leads on from Theme Three: Loneliness is Complex. Seven of the studies commented on the need to treat loneliness with a holistic approach in accordance with its complexity. Five recommended treating multiple factors linked to increased loneliness, as well as loneliness itself, at the same time, in order to address symptoms that cluster together (Choi & Henneghan, 2022; Henneghan et al., 2018; Henneghan et al., 2021; Jaremka et al., 2013a; Madison et al., 2022). One study suggested that treating factors related to loneliness, such as increasing mindfulness or decreasing anxiety, may simultaneously help to reduce loneliness and its related factors (Ikeuchi et al., 2020).

Comparing Women With Breast Cancer to the General Population

Only three studies compared women with breast cancer directly to women who did not have a breast cancer diagnosis (Fox et al., 1992; Jaremka et al., 2013b; Jaremka et al., 2014). The first study found that women who had recently been diagnosed were significantly more lonely than other groups of women, including women who had a previous diagnosis of breast cancer (Fox et al., 1992). On the other hand, the latter studies found that women with breast cancer did not differ from those who did not have breast cancer, on loneliness and related factors (Jaremka et al., 2013b; Jaremka et al., 2014). Some other studies recruiting only women with breast cancer compared their results with findings in the general population. For example, older adults with breast cancer in one study did not differ in prevalence of loneliness when compared to the general population (Lemij et al., 2023).

Discussion

Summary of Results

This integrative review aimed to examine the factors related to increased loneliness in women with breast cancer. Themes from 18 studies were developed using thematic synthesis

and organised according to the three research questions. The first part of the discussion of results will link the findings together through the central themes developed for the second research question.

Loneliness is Psychologically Painful

This central theme was developed from the themes, Relational Difficulties, and Distressing Emotions. It led to the theme, Offer Psychological Support, as a way to relieve this psychological pain. In line with key theories of loneliness used within the literature, women across the studies experienced loneliness as a negative and "distressing feeling" (Hawkley & Cacioppo, 2010).

The Actions of Others (Unmet Needs)

The relational difficulties linked to distressing feelings described by women in the studies, are at the core of key definitions for loneliness where "one's social needs are not being met" (Hawkley & Cacioppo, 2010). In line with the cognitive discrepancy model of loneliness, women in the studies had evaluated their social relationships and perceived them to be falling short of what they desired or felt they needed. Some of these unmet needs were unique to the breast cancer experience of women and involved a lack of understanding and appropriate responses from others, across countries and cultures. This is supported by recent evidence, which suggests that women with breast cancer can experience alienation from society and feelings of stigmatisation across cultures due to a lack of understanding about their illness from others (Heena et al., 2019; Wang et al., 2017; Wu et al., 2023). If women with breast cancer have specific needs that they feel are not understood by others, then in line with the cognitive discrepancy model of loneliness, they may be more likely to perceive a discrepancy in their social relations and feel lonely. This is supported by Rosedale (2007) who suggested a specific loneliness related to being a breast cancer survivor.

The Actions of Self (Concealment)

Closely linked to this was the act of concealment, where women felt they needed to hide their illness or related feelings, from others. Interestingly, a recent review of stigmatisation in women with breast cancer suggested that women experiencing a lack of understanding about their illness, were more likely to hide aspects of it from others (Wu et al., 2023). Although cause and effect could not be inferred from any of the studies, this concealment often seemed to be in response to actions, or the fear of potential actions from others, which, in turn, perpetuated feelings of loneliness.

Distressing Emotions

In addition to loneliness feeling distressing on its own, mental health difficulties were closely linked with loneliness throughout the studies, particularly depression, depressive symptoms, and anxiety. These findings are reflected in research on loneliness in the general population in both young and old people (Achterbergh et al., 2020; van Tilburg et al., 2021). Further research has also suggested that women with breast cancer are more likely to experience depression and anxiety than the general population (Carreira et al., 2018). This may be due to a number of factors, including the distress of receiving a breast cancer diagnosis, physical health difficulties, and unwanted treatment side effects, such as infertility (Breast Cancer Now, 2022). All of these factors may significantly and negatively impact on the quality of life for women with breast cancer (Carreira et al., 2018).

Clinical Implications

Given the strong links found in this review between loneliness and mental health difficulties, and the impact this can have on quality of life, treating psychological pain, rather than just the cancer itself, may be key to supporting women with breast cancer. Research has indicated a range of interventions targeting the reduction of mental health difficulties in women with breast cancer (Jassim et al., 2023) and reducing loneliness in women with breast

cancer (McElfresh et al., 2021). Some of these studies measured or targeted both loneliness and mental health difficulties together (Abed et al., 2020; Yu et al., 2023). This seems appropriate considering the findings of this review, where mental health difficulties were found to be closely related to loneliness across many of the studies.

Loneliness is Disabling

This central theme was developed from the themes, Physical and Mental Health Difficulties. It led to the theme, Increase Understanding and Awareness of Difficulties, as a way to enable women with breast cancer experiencing loneliness.

Physical and Mental Health Difficulties

Fatigue, pain, immune system dysregulation, and frailty, were the key factors linked to physical health difficulties in women with breast cancer in this review. All of these factors have been explored within the breast cancer literature, and each could be discussed in great detail (for example, Ruiz-Casado et al., 2021; Wang et al., 2018; Liu et al., 2022; Wang et al., 2022). However, of note, is that all these difficulties can be extremely disabling, impacting on both an individual's quality of life and recovery from illness (Ruiz-Casado et al., 2021; Wang et al., 2018; Liu et al., 2022; Wang et al., 2022). They also have key psychological components, particularly fatigue and pain (Abd-Elfattah et al., 2015; McCracken et al., 2022).

Mental health difficulties discussed in the previous section, and cognitive difficulties, were also linked closely to loneliness in the studies reviewed, both of which can significantly negatively impact daily functioning for individuals (Rethink Mental Illness, 2017).

Clinical Implications

The findings of this review inferred that increasing awareness and understanding in the systems around women with breast cancer about the challenges they experience and knowing who may be more at risk of loneliness, may help to decrease feelings of loneliness

and the disabling factors related to this. This would allow for appropriate support to be put in place and would help to enable women to live in a way that increased their quality of life.

Loneliness is Complex

This central theme was developed from the theme Multiple Concomitant Difficulties. It led to the theme, Use a Holistic Approach, as a way to be able to appropriately support women with breast cancer experiencing loneliness.

Clinical Implications

The complexity of loneliness in women with breast cancer was evident across all of the studies and themes in this integrative review, indicated by the multiple factors related to loneliness. Although this may seem bleak at first glance, some of the studies in the review highlighted how this could also mean that treating difficulties related to one symptom may simultaneously reduce other difficulties, due to the strong links between factors.

Study findings implied that women should be treated using holistic and individual approaches, and that women are more than just their breast cancer diagnosis. This is supported by evidence in the literature, which argues that the experience of breast cancer diagnosis and treatment has a substantial impact on women in all areas of their life and this should be acknowledged by healthcare professionals who are in a position to support them (Smit et al., 2019). This also fits with the biopsychosocial model of illness and the suggestions made by Engel (1977) about how healthcare providers need to understand and respond to physical health through recognising the close relationship it has with psychological, social and behavioural factors, and to treat it accordingly. By doing so, treatment may be more effective and the quality of life of individuals with physical health problems may be improved (Wade et al., 2017).

Strengths, Limitations and Future Directions

A key strength of this study was bringing together the literature on loneliness in women with breast cancer from across different disciplines. Doing so has provided insight into the factors related to increased loneliness, what this tells us about loneliness in women with breast cancer, and the implications this has for supporting women with breast cancer who experience loneliness.

The Timing of the Experience of Loneliness

Common themes related to loneliness and developed from the study findings in this review transcended multiple timepoints in the breast cancer journey of women. This was often within studies themselves, with some covering a span of zero to 10 years or more since diagnosis. However, no distinctions between these timepoints were made in any of the studies even though there may be many stages to the breast cancer journey, contributing to unique experiences (Ciria-Suarez et al., 2021). For example, the experience of loneliness at the point of diagnosis may differ from the experience of loneliness during treatment, shortly after treatment, and then at different timepoints thereafter. Future research may be needed to focus on specific timepoints of women in their breast cancer journey and to understand how related experiences may differ.

Underrepresented Groups

There were some groups of women who were underrepresented in the studies or noticeably absent from the discussion of the study findings. For example, there were much fewer female participants from racially minoritised groups compared to White women. Additionally, some women were automatically excluded if they could not read and write due to study designs or if they were unable to tolerate the study methods used. There was no discussion of groups of women who may experience loneliness and breast cancer in unique ways, such as autistic women or women with learning disabilities. These groups also

encompass a huge range of diversity within them. These underrepresented groups within the studies may have contributed to distinct results and are essential for gaining a meaningful understanding of the experience of loneliness in women with breast cancer. Therefore, more research is needed to explore the factors related to increased loneliness in women from marginalised groups who have a diagnosis of breast cancer.

Cultural Differences

Connected to this, the themes developed from the studies in this review seemed to transcend research carried out in different countries and cultures. No obvious cultural differences were highlighted or discussed, nor did there seem to be any obvious distinctions or differences within methodologies, which were varied across studies. Nonetheless, it is important to note that loneliness may be understood differently across cultures both within and between different countries. Linking back to key theories of loneliness introduced at the beginning of this review, if individuals use cultural norms and social comparisons to examine their social needs and whether they have been met, then understanding of loneliness is going to inevitably differ across cultures where norms are different.

Furthermore, and linked closely to this, are the differences in how women are viewed and the role that they play in society, across cultures and countries. This may have impacted on how women with breast cancer made sense of their experiences of loneliness in the studies reviewed. Further studies may need to be carried out that focus on the cultural experiences of women, in order to fully understand the nuances and difference in how loneliness is understood.

Measuring Loneliness

Although most of the loneliness measures included in the reviewed studies have been widely tested and used in research in this area, using them makes the assumption that the specific theories and definitions of loneliness they are based on are the correct or only way of

defining this experience. The experience of loneliness may differ across cultures and contexts and may be influenced by wider systemic factors and individual differences (Arnoso et al., 2022; Maes et al., 2016; Maes et al., 2022). Therefore, more research may be needed to qualitatively explore the experiences of loneliness in different groups of women, in order to be able to fully understand the factors related to increased loneliness in women with breast cancer.

Data Analysis

Thomas and Harden's (2008) thematic synthesis was chosen as the method of data analysis due to its close alignment with the philosophical underpinnings of integrative reviews (Cronin & George, 2023; Dwyer, 2020). However, it is important to note that this method was originally developed to analyse qualitative studies and not specifically for integrative reviews (Thomas & Harden, 2008). Detailed discussions have been written to guide researchers on the considerations that need to be taken into account in order to address the qualities specific to integrative reviews (Cronin & George, 2023; Dwyer, 2020; Torraco, 2016). However, the qualities that make an integrative review valuable, particularly the focus on drawing on research from different methods and disciplines, can also make it challenging. A universally applied specific approach to data analysis in integrative reviews would help to ensure rigour and overcome some of these challenges.

Cronin and George (2023) discuss the need for "balance" in integrative reviews, which includes an emphasis on the goal of the researcher in trying to ensure that the analysis of the results are not biased towards their own research discipline. This is particularly important considering the role of subjectivity in interpretation of higher level themes, which bring together different research. For the current study, it is acknowledged that the researcher had a clinical psychology background, which may have meant that some of the themes were influenced by this perspective. It would have been useful to address this by working with

consultants from medical and nursing backgrounds to ensure representation of the disciplines of the included studies and a "balance" in the interpretation of findings.

Conclusion

The findings of this integrative review suggested that increased loneliness in women with breast cancer is related to a range of factors that are complex and often occur at the same time. These include relational difficulties, physical and mental health difficulties. Loneliness in women with breast cancer is therefore complex and can be both psychologically painful and disabling. Although similar findings have been suggested in loneliness research in the general population, the distinct challenges faced by women with a breast cancer diagnosis mean that these results may need to be interpreted within this unique context. Psychological and holistic support, as well as an increased awareness and understanding of the needs of women with breast cancer may therefore be key to tackling loneliness in this population. This, in turn, may help to improve the quality of life in women with breast cancer who experience loneliness.

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SECTION B

"Feeling unconnected when you want to be connected":

The Experience of Loneliness in Autistic Women

Word Count: 7962 Words (334)

Abstract

Background and Aims: Autistic women are underrepresented in the scientific literature. They may be at high risk of experiencing loneliness, which can have a detrimental impact on mental health. This study aimed to understand how autistic women experience loneliness using a phenomenological approach to enable their voices to take precedent within the research. **Methodology:** Ten autistic women were interviewed about their experiences of loneliness. Interviews were transcribed verbatim and analysed using interpretative phenomenological analysis. A consultant expert by experience advised on the development of interview questions and themes. **Results:** Six group experiential themes suggested that participants experienced loneliness through: *Feeling Different; Trying to Fit in; Misunderstandings and Understandings of Autism; A Balancing Act;* and *Building the Bridge Alone;* with *Being Autistic is "part of who I am"* at the core of this. Eight related subthemes were also examined. **Implications:** Changing societal attitudes and the way that autistic women are understood would help to alleviate feelings of difference and loneliness in this population. A better focus is needed from healthcare professionals to see beyond the label of autism and to take the time to ask autistic women what autism means for them.

Key words: Autistic women, autism, loneliness, qualitative

Introduction

Autistic women may be at greater risk of experiencing loneliness, which can negatively impact their mental health and quality of life. This may be due to misconceptions about how autistic women experience the world, and research to suggest that autistic women may be more likely to try and change aspects of themselves, or "mask", in order to fit into societal norms. In order to be able to support autistic women experiencing loneliness, it is first important to understand how they make sense of these experiences. However, autistic women are underrepresented in the scientific literature and there is a lack of research exploring how loneliness is experienced in this population.

Loneliness: Theories and Definitions

Loneliness is a common experience for many people and can have a detrimental impact on physical health and mental wellbeing when experienced for a sustained period of time (Hawkley & Capitanio, 2015; Park et al., 2020).

Many of the theories related to loneliness can be understood through a discrepancy model (Perlman and Peplau, 1981). Central to this model is the idea that loneliness is an unpleasant and subjective response occurring when an individual perceives there to be a shortcoming in their social relationships. This describes a discrepancy between where a person feels a relationship is and where it ought to be. It is linked to the social needs approach, which posits that individuals desire relationships to fulfil needs, such as attachment, support, and reassurance of worth. Loneliness is experienced when relationships are not available to fulfil these needs (Rokach, 2019). It has been suggested that a desire to fulfil these needs can also be driven by feeling lonely, which acts as an adaptive survival response encouraging individuals to seek out social connections with others, in order to alleviate these feelings (Hawkley & Cacioppo, 2010).

Autism

The definition of autism is linked to much debate and controversy (Bottema-Beutel et al., 2021; Keating et al., 2022). Research suggests that just over one percent of adults in the United Kingdom have an autism diagnosis (National Collaborating Centre for Mental Health, 2023), with many who remain undiagnosed (O'Nions et al., 2023). To be diagnosed, individuals must have experienced certain characteristics throughout their life, which include communication and social interaction differences that can make interacting with neurotypical individuals challenging, and behaviours that include self-regulating and self-soothing (Seers & Hogg, 2023). However, individual differences vary hugely within this and it has been argued that the diagnostic process, as well as language use around this, can focus on autism as a deficit (Monk et al., 2022; Wilson et al., 2023).

Language

This study uses identity-first language, i.e. *autistic person,* in line with both the preferences articulated by the participants in this study, and current recommendations (Keating et al., 2022; Monk et al., 2022). Similarly, non-autistic people are referred to as *neurotypical*.

Autism and Loneliness

Unfortunately, the experience of stigma in autistic people is common and often due to a lack of understanding about autism from neurotypical people, as well as a perception that autistic individuals do not fit with societal norms due to deficits they hold (Turnock et al., 2022). The *double empathy problem* proposes a counter view, suggesting that difficulties in interactions between autistic and neurotypical individuals are dynamically interpersonal rather than located in one person (Milton, 2012; Milton et al., 2022). Nonetheless, the difficulties that autistic people may experience in interactions with others can increase loneliness and put autistic people at higher risk of experiencing loneliness compared to

neurotypical people (Schiltz et al., 2021). Higher levels of loneliness have been linked to greater mental health difficulties in autistic people (Hedley et al., 2018; Mazurek, 2014).

Loneliness in Autistic Women

Autistic women specifically, may be at greater risk of experiencing loneliness and associated mental health difficulties. One reason for this may be a less well articulated understanding about how autism is experienced in women due to wider understandings of autism being based on male stereotypes, also leading to experiences of stigmatisation (Seers & Hogg, 2023). Another key theory suggests that autistic women are more successful at masking the difficulties they experience compared to men (Hull et al., 2020). Masking is linked to feelings of needing to change aspects of oneself to fit in with societal norms and this can further heighten experiences of loneliness in relation to the self and others (Kanfiszer et al., 2017). Related to these factors, women are also less likely to be diagnosed with autism, with a male to female ratio of about 3:1 (Loomes et al., 2017) and are often diagnosed later in life compared to men (Seers & Hogg, 2023).

Previous Research

Previous research exploring loneliness in autistic women is scarce (Moseley et al., 2021). There has been some research exploring the experiences of relationships in autistic women (Gosling et al., 2023), and late diagnosis (Milner et al., 2021; Yau et al., 2023), which have referenced loneliness, but loneliness has not been the focus of the studies. There has also been research exploring loneliness in both autistic men and women (Elmose, 2020; Grace et al., 2022) but, to the author's knowledge, no research specifically focused on women. Furthermore, measures of loneliness have largely been based on neurotypical experiences and theories of loneliness that do not account for how autistic people may experience the world (Grace et al., 2022; Grace et al., 2024).

Study Rationale and Research Aims

Given the potential for autistic women to be at increased risk of experiencing loneliness, the detrimental impact that this can have on their mental health, and the lack of research on this topic, the current study aimed to address this by exploring the experiences of loneliness in autistic women. In order to ensure that the experiences of women were at the core of the research, an interpretative phenomenological approach was used, which gives precedence to how individuals make sense of their experiences. The current study aimed to explore the following:

- How do autistic women experience loneliness?
- Do participants make sense of these experiences in relation to being an autistic woman, and if so, how?

Methods

Design

Interpretative Phenomenological Analysis

This study used interpretative phenomenological analysis (IPA), which is a qualitative research approach grounded in three philosophical positions: phenomenology, hermeneutics, and idiography. Phenomenology refers to an emphasis on examining the lived experiences of participants in their own right rather than trying to fit experiences into predefined categories or ideas. In the current study this was reinforced through carefully designing interview questions that were open and exploratory, and keeping the words of the participants at the focus of the analysis, without using established theories or research to inform this. Hermeneutics refers to the sense-making or interpretation of lived experience from the perspective of both the participant and the researcher. This includes the idea of a double hermeneutic, whereby the researcher plays a key role in interpreting the participant's interpretation of their lived experience.

In order to acknowledge potential bias in the interpretative role of the researcher (hermeneutics) and to keep the experiences of the participants at the centre of the study (phenomenology), *bracketing* was used. This helps researchers to reflect on their own biases and perspectives throughout the research process and to separate these from the data (Howitt, 2019). This also increases rigour in the study (Thomas & Sohn, 2023). This was facilitated through a bracketing interview held before the interviews commenced (Appendix F) and a research diary completed throughout the study (Appendix G). Most importantly, a consultant expert by experience (EBE) was recruited to advise on the interview questions and theme development.

Finally, idiography refers to a focus on the unique experiences of individuals first, before exploring similarities and differences across multiple individuals. This was reflected in the analytic methods proposed by IPA and used in this study, which focussed first on interviewing and analysing data for individual participants, before looking at relationships across themes.

Quality of the Study

The current study used guidelines suggested by Ahmed (2024) to assess and monitor quality. These guidelines align well with the IPA approach and its theoretical underpinnings. Most notably, these guidelines suggest four components with recommended strategies for "ensuring trustworthiness" in qualitative research: credibility, transferability, dependability, and confirmability. Examples of the strategies include providing detailed descriptions of the method and data analysis, to allow for other researchers to assess the applicability of the findings to their settings. Additionally, seeking feedback from experts to validate interpretations and counteract bias, which was accomplished through consulting with an expert by experience. All of these strategies combined helped to support the transferability and rigour of the study.

Participants

Sample

Ten autistic women who had experienced loneliness took part in this study. This is in line with a suggested sample size of 10 participants for IPA research in professional doctorates (Smith et al., 2022). A homogenous sample was sought by recruiting individuals over the age of 18 who identified as female, autistic, and having experience of loneliness, and thus for whom the research questions would be meaningful. This is consistent with the theoretical positioning of IPA, which aims to focus on a detailed account of how individuals make sense of their lived experiences and is an important criterion to enhance the validity of an IPA study (Levitt et al., 2018; Smith et al., 2022).

Inclusion and Exclusion Criteria

Participants were not excluded if they had experience of mental health difficulties, given the strong links with loneliness (Leigh-Hunt et al., 2017), and the prevalence of mental health difficulties in autistic adults (Lai et al., 2019). However, if participants reported recent or current mental health difficulties impacting on their ability to cope, they were excluded from the research to avoid further distress. No further exclusion criteria were applied to allow for a realistic recruitment process in a population that is underrepresented in research, and to ensure that the study embodied the diversity of autistic women.

Demographic Information

Demographic information for participants is outlined in Table 1. In order to ensure anonymity of the participants, all were given pseudonyms and some of the demographic information will be described in more general terms. The ages of participants ranged from 19 to 55. All participants had a diagnosis of autism: two participants had received a diagnosis in their "late teens"; four in their twenties; three in their forties; and one in her fifties. Three women identified as bisexual, one woman as pansexual, and the other women as

Table 1

Participant Demographics

Pseudonym	Ethnicity	Marital Status	Highest Education	Employment	Living Situation
Emily	White British	Single	University degree	Student, Part-time work	Living alone, some external support
Rebecca	White British	Married	Masters level university degree	Full-time employment	Living at home, husband is carer
Jane	White British	Single	Doctoral level university degree	Part-time employment	Living with no external support
Lauren	Caribbean	Married	College	Student	Living with some external support
Sarah	White and Asian	Single	Secondary school	Self-employed	Living with no support at home
Jessica	White British	Living with partner	University undergraduate degree	Full-time employed	Living with no external support
Megan	White British	Single	Secondary school	Training	Living with support at home
Hannah	White British	Living with partner	Doctoral level university degree	Student	Living with no support at home
Claire	White British	Married	Secondary school	Unemployed/ not looking for work	Living with no support at home
Nicola	White British	Divorced	Masters level university degree	Full-time employment	Living with no external support

heterosexual. Seven of the women reported having experience of mental health difficulties, three had been diagnosed with a chronic physical health condition, and one woman had a diagnosed learning disability.

Semi-Structured Interviews

Consistent with the IPA approach, individual semi-structured interviews were conducted in order to facilitate in-depth accounts from participants about their unique experiences of loneliness (Smith et al., 2022). Interview questions were developed to support this approach (Appendix H). Crucially, to ensure that these questions were appropriate and to alleviate bias from neurotypical views from the researcher, a consultant EBE who identified as an autistic woman examined a draft of the questions. The researcher then met with the consultant to receive feedback, and questions were adapted accordingly (Appendix I). The feedback was highly valued and had a notable positive impact on the interview questions.

Procedures

Recruitment

Participants were recruited using purposive sampling, which is a technique that focuses on the selection of a specific group of individuals to offer insight into a particular phenomenon and aligns with the theoretical positioning of IPA (Smith et al., 2022). Participants were recruited in two distinct ways: Through an online study advert (Appendix J) posted electronically on Twitter (now known as X) and Facebook; and through a clinical psychologist working at a private practice. Women identified through the clinical psychologist were emailed the study poster and asked to contact the researcher directly if they were interested in taking part, in order to retain anonymity.

Setting up and Interviewing

Participants who showed interest in the study were emailed an information sheet explaining the background and procedures (Appendix K). If they wanted to participate, they were sent an email with a consent form (Appendix L), a link to an online demographic form (Appendix M), and an online meeting link for an agreed date and time to participate in a semi-structured interview using the Microsoft Teams application. Completed interview times

ranged from 42 to 112 minutes, with an average time of 75.5 minutes. Once the interview had been completed, participants were sent a £10 voucher for Amazon or a VEX Gift Card to thank them for taking part. They were also sent an information sheet with links to further support (Appendix N). Interviews were audio-recorded and transcribed verbatim by the researcher.

Data Analysis

Data were analysed in line with the underlying principles of IPA and the suggested steps for this approach (Smith et al., 2022). There was dynamic movement between these steps, and analysis did not always follow a linear route. Analysis began for each individual with their transcript being read thoroughly multiple times, followed by exploratory notes, marking anything of interest to the researcher. Experiential statements were then constructed, which aimed to synthesise and summarise the experiences shared by the participants (Appendix O). Experiential statements were then transferred to the qualitative analysis software programme, NVivo (version 12) and were grouped into personal experiential themes (PETs) based on connections between them (Appendices P & Q). Finally, group experiential themes (GETs) were created for all participants by searching for connections and differences across all PETs (Appendix R).

Ethical Considerations

Psychological safety of participants was a priority throughout the entire study process, particularly considering the emotive content of the topic. The choice of the participant to leave the study at any point during the data analysis phase, was emphasised in the information sheet and verbally at the beginning of each interview. Furthermore, throughout the interviews, the researcher held a compassionate and supportive stance. Following advice from the consultant EBE, a signal was agreed with women at the beginning of the interview to let the researcher know if they needed a break. The approach and procedures of this study

closely aligned with the values outlined by the National Health Service Constitution (Department of Health & Social Care, 2023), particularly, *respect and dignity*, and *compassion*. This study was approved by the Salomons Ethics Panel in February 2022 (Appendix S).

Researcher Standpoint: Validity

In line with the IPA approach, I aimed to focus on the experiences of participants in the interpretation of the data, whilst also being aware of my own biases. Of most relevance to this study, it has been important for me to be aware that I am neurotypical and so am not able to understand being autistic from lived experience of this. As discussed previously, I used bracketing techniques to address this. Furthermore, themes and associated transcript excerpts were checked by a consultant EBE who gave me feedback in an online meeting. This highly valuable feedback was used to validate the themes and interpretations I had created and to help highlight key messages that related to core aspects of being autistic.

Results

"I just want people that have autism to know that they're not alone" (Megan).

Results are discussed through six themes and eight sub-themes (Figure 1).

The double hermeneutic in IPA and the role of the researcher in interpreting the findings is particularly pertinent to this section. This was addressed through continued reflection supported by a research diary throughout analysis and write-up and the advice of a consultant EBE. However, it is important to consider when reading these results that the researcher was neurotypical, which may have influenced interpretations. Furthermore, whilst findings were grouped into common themes, in line with the idiographic approach in IPA, there were differences in the experiences of participants within these themes, which are illustrated through qualitative descriptions and quotes specific to individual experiences.

Figure 1

Group Experiential Themes and Sub-Themes

Theme One: Feeling Different (Experiencing Loneliness Through Feeling Different)

Participants described distinct ways in which feeling different from others led them to feel lonely.

Feeling Different due to Being Left Out

Seven of the women described an awareness of being left out through comparing themselves to what they observed others to be doing. Being left out highlighted to them that

they were different from others, and this led to feelings of loneliness. For example, Lauren said:

> *I try and stay off social media as well because then you see like you know, people having fun and I know it is just a glass and it's not all real life, but it does make you feel oh look they're doing that today and I'm by myself and I don't really feel like I can reach out to people like that.*

Here, Lauren describes the powerful role of social media and how, even though she was aware that it does not always reflect reality, it still led her to make comparisons. This made her feel lonely for not being able to have relationships in the same way as others, which she related to being autistic. Hannah described a similar experience:

> *I'd still be on things like social media erm so then I was actively aware that they were kind of like leaving me out of certain things […] I do think that was like making me feel lonelier was through that comparison through social media.*

Looking back, she related these experiences to being autistic, although she did not have a diagnosis at the time. Emily described similar experiences outside of social media in which her felt difference to others was highlighted by being left out:

> *So I sort of notice myself feeling a bit sort of off the side and a bit lonely sometimes in those larger group settings, and like the rest of the people I was with were like very sociable people, so it's a lot, I think I noticed it's a lot easier for them to be in a big group.*

Emily's loneliness in these situations seemed to be heightened by comparing herself to others who not only interacted differently but interacted more easily. She linked this to her *"fear of messing up that's the result of autism because I don't read social cues as well as other people"*.

Feeling Different Within the Autistic Community

Some women described a feeling of difference within the autistic community, which led to loneliness. Although not explicitly stated, it seemed that, for some, this loneliness was fed by a disappointment in an unmet expectation of solidarity with other autistic people. Lauren spoke of this in relation to being diagnosed as autistic later in life:

> *So it's more like feeling lonely in the discovery as well cause a lot of erm other autistic women that I've met and know would have known that they have autism in childhood and have been able to process that and reflect on that […] I feel like I'm dealing with it myself and I don't know anyone else who has had that similar experience to me.*

Here, Lauren implies a need to connect with women diagnosed later in life.

For Sarah, this feeling of difference from others went beyond autistic women to *"exclusively straight white guys of middle-class backgrounds who know that they're autistic and have been afforded more grace by the rest of society."* For her, the loneliness came from a breakdown in *"autistic solidarity as an antidote to neurotypical alienation"* as a result of these encounters. This feeling of difference crossed into issues of oppression and intersectionality for Sarah, who identified as a bisexual, White and Asian woman.

Theme Two: Trying to Fit in (Experiencing Loneliness Through Trying to Fit in)

Feeling different led women to want to be able to fit in so that they could make connections with others and alleviate loneliness. This theme describes how the process of doing this was related to feeling lonely.

Fitting in Feels Difficult but it is Needed

A core aspect of the experience of loneliness described by women was a pull between wanting and needing to fit in with others in order to have meaningful connections but finding this hard and effortful. Jane summarised a sentiment shared by many of the women when she

said, *"I don't know what percentage of autistic [people] I'm talking for but we want connection even if it's difficult "*. She spoke of the reasons why trying to fit in felt effortful: *"I guess I'm always worried about what I'm saying and saying the right thing and er being appropriate […] which is why it's quite tiring, people, being with people."*

Here, Jane alludes to the feelings of worry that she experiences alongside trying to fit in and behave in a way that is socially acceptable. Similarly, Megan also described feelings of anxiety about trying to fit in:

> *I'd like to be able to engage with people but it's difficult with my anxiety, so my anxiety stops me and then I've got my loneliness coming through so it's like a full circle in my opinion.*

Megan describes poignantly the barrier that anxiety creates to trying to fit in and connect with others, and how this can further perpetuate feelings of loneliness, which she linked to being autistic. Nicola contextualised these experiences by describing how society is set up in such a way that often compels individuals to try and fit in, in order to make connections:

> *Actually, that is how you meet people and that is how you make friends and that is how you get to the next level that's how society works […] I risk missing opportunities to find that connection, because I'm less willing to do that uncomfortable bit.*

She described how the difficulty of trying to fit in meant lost opportunities for connection, which led to loneliness.

Fitting in is Conditional on Behaviours That do not Feel Authentic

Many of the women spoke about changing their behaviours in order to be able to fit in with others and make connections. Sarah described this as her *"protective camouflage"* and explained how it enabled others to have a good opinion of her, which reduced *"the sense of being alone, isolated, different, alien, not right".* However, she also described this as being a *"mental effort"*, which created a barrier for people being able to get to know the real her.

Emily echoed this when describing how she would often concentrate on many aspects of how she was presenting in interactions. She described her motivation for this when she said, *"it makes me look normal, like I know autism isn't you know weird or abnormal, it's natural, but it makes me look normal to other people".* Despite the effort, changing her behaviour in social interactions helped Emily to fit in. Jessica expressed a difference in her view of this: *"I did want to have friends I did want to feel like I fit in, but then I kind of didn't want to have to change who I was to do that".* This posed more of a dilemma for Jessica, as she did not want to change part of who she was.

Some felt that changing part of who they were to be able to fit in and to connect with others had costly consequences that eventually led back to feeling lonely. Hannah stressed the powerful and influential role of television and movies for autistic women and how this led her to change who she was and accept behaviours from others that were *"abusive"* because *"I'd see that as what was normal".* In the interview, Hannah spoke of how this is often not understood by neurotypical people and highlighted how this is something she felt would be important for people to be aware of. As a neurotypical researcher, it therefore felt of particular importance for me to pay attention to this experience and prioritise the inclusion of it in the write-up.

Theme Three: Misunderstandings and Understandings of Autism (Experiencing Loneliness Through Understandings of Autism)

Women described how a lack of understanding about autism from others increased feelings of loneliness, compared to increased understanding about autism from the self and others, which alleviated loneliness.

A Lack of Understanding about Autism from Others Leads to Loneliness

Women in this study commonly experienced unhelpful reactions from others when communicating their autism diagnosis. For example, Claire said: *"Anyone I've said, they've*

gone, what?! Are you sure? How, you don't, you know? And I said, well, it's because it's not what people think it is." Through this statement Claire implies that being autistic is something that is widely misunderstood. Similarly to Claire, Hannah made sense of these reactions being due to a lack of understanding that does not go beyond autistic stereotypes: *"but there's always going to be people who discredit the diagnosis 'cause I don't present in the typical Rain Man male kind of form."* Here, she suggests a lack of understanding from others specifically related to being an autistic woman.

Both Sarah and Rebecca felt that this lack of understanding came from what Sarah described as *"mostly media misinformation and stereotypes"*. Rebecca noticed this through invalidating responses when she was first diagnosed:

> *That was kind of tough at the time, especially as you're going through what is incredibly life-altering, yeah not being able to at least at the start go through it and be like, hey this is a thing that's happening, and people would be like yeah but is it really, because they didn't have the information.*

Experiencing these reactions from others led to feelings of loneliness and a distance from others. Sarah described this with a close friend who had questioned her diagnosis: *"we used to have quite a lot of closeness and I just felt that kind of evaporate you know she felt really kind of further away"*. Not being able to understand Sarah's diagnosis as an autistic woman created a rupture in the relationship with her friend. Similarly, Rebecca described loneliness as *"not being with people that get you"* as this led to a lack of community and support.

Increased Understanding of the Self Through an Autism Lens Alleviates Loneliness

Women spoke of how an autism diagnosis validated their current and past experiences, as well as offering an explanation for why they felt different. This helped them to feel connected to others and less lonely. For example, Jessica said:

> *It's not just I'm odd, that's just it, you know, there's sort of a reason that I'm different […] but sort of understanding and sort of normalising how I am because there are other people who are like it and there is a reason there's a whole group of people that are the same, well not, obviously not exactly like me.*

Jessica's diagnosis helped her to feel connected to other autistic people. Like Jessica, Hannah's diagnosis also helped her to have a better understanding of herself, which alleviated feelings of loneliness:

> *I don't feel lonely erm and I don't know as well if it's because I understand my diagnosis and stuff that I know how I am so I don't, I suppose, feel lonely in my own kind of experiences of the world.*

This understanding helped Hannah to hold a more compassionate view of herself, which was illustrated when she said, *"so the position I'm at now if something doesn't kind of like serve me or I suppose I'm just kinder to myself because I understand why I'm the way I am and […] I just won't do it".* It also gave her permission to withdraw from situations that were uncomfortable for her.

For some women it took time to be able to understand and identify with their diagnosis, such as Lauren, who explained that *"it was only when I read up on women with autism and I was like ok it makes sense".* Lauren needed to read about autistic women specifically and their experiences in order to understand her diagnosis. With a better understanding of themselves in relation to being autistic, many women described being able to advocate for themselves with others. For example, Nicola said:

> *I guess that feels less lonely because I feel like people get me now, so the diagnosis has maybe made me feel less lonely in that I feel more able to say to people that's gonna be hard for me I don't like that, and people would be less inclined as well to put me in a situation that was going to be tricky.*

There is a sense of empowerment for Nicola who, through her own understanding of her diagnosis, is able to help others to understand her. Rebecca shared this sentiment and described the diagnosis as a *"toolkit"* or *"label"* to help others to understand her: *"whereas now at least I have a toolkit even though the explaining is hard now I have the label I can tell people the label and they might have even heard of it"*. Here, there is an idea of a shared language or a way for others to recognise autism. Megan reiterated the importance for her of gaining understanding from others about autism when she said: *"I personally want people to understand people with autism better and to be able to listen to our voices in particular about how we have to cope with things like this [loneliness]"*. This summarises beautifully a view shared by many of the women in the study about the importance of others listening to autistic women and their needs, in order to be able to understand them.

Theme Four: A Balancing Act (Experiencing Loneliness as Part of a Balancing Act)

There was a sense from the women in this study that alleviating loneliness was a fine balancing act because making connections was needed but this often felt hard.

Being Alone is not Always Lonely

Many of the women emphasised how being alone sometimes felt positive and was not always lonely. For example, Claire said: *"I've always, for years since I can remember, I've always craved solitude, not the whole time but I definitely need it occasionally".* Here, Claire describes being alone as a need, which she related to being autistic. Similarly to Claire, Emily felt that being alone was needed at times:

> *I spend quite a lot of time on my own and I'm very happy on my own, I sort of need that time every day, like I'd say like five to six hours, I'll call it my down time, I need that time on my own just to feel, to recharge.*

This need for essential time alone in order to *"recharge"* was shared by many of the women, including Nicola, who said:

> *For me, being autistic means that sometimes being on my own is a good thing because it lets me recharge and it lets me process and it lets me not feel like I've got to worry about if I'm doing the right thing, and I'm okay with that.*

Here, Nicola expresses the need to be alone as a direct comparison to finding interactions hard, in relation to being autistic. Note the use of the word *"sometimes"* by Nicola in relation to being alone, with similar implications in the quotes from Emily and Claire. Nicola clarified this further when she said *"I think it [loneliness] means feeling unconnected when you want to be connected […] because sometimes feeling unconnected is fine. Sometimes feeling unconnected is good".* This view was shared by many of the women in the study and some reported ways of finding connections when alone, in order to avoid the difficulties associated with connecting through social interactions. For example, Nicola said:

> *"A really comfortable situation for me would be like sitting at a cafe where I'm on my own, but there are other people there and I can see them […] so I am part of a connection, but I'm not having to engage with that."*

This ability to be alone and not lonely, was described by Claire as a strength directly related to being autistic, *"actually, it's quite because you can always just be in your own company and then if that's a nice place for you to be, then that's a gift really".* Claire perceived this as a *"gift"* when being alone felt nice or positive.

Balancing Connecting with Being Unconnected

A need for connection combined with finding social interactions hard, meant that alleviating loneliness and maintaining wellbeing was a fine balance. When this balance was off, this resulted in further feelings of loneliness. Jane described a desperation in being alone, which led her to seek social interactions:

> *I was quite desperate at the weekends being on my own erm but I think the contrast between, so I'm trying to be sociable and I'm making connections, but then as soon as I was on my own, I just felt really awful erm yeah, that's the crushing one [loneliness].*

For Jane, being by herself directly after engaging in social interactions amplified feelings of being alone and left her with a *"crushing loneliness"*. However, she also described a desperation in needing to be alone after connecting with others:

> *I desperately want to spend time on my own and then I get in my flat, which is my safe space and sit down with a sigh of relief and then erm and then it can rapidly switch into loneliness.*

Lauren described this need to connect with others, balanced with recovery from connection, as a *"cycle"* or a *"pattern"* when she said:

> *I wish I could just go out more I wish I could do it you know, every other weekend not every month but then when I do, do it more often, then I feel overwhelmed. So it's like a cycle of feeling lonely, wanting to do things, doing things, feeling burnt out, retrieving back into myself, feeling lonely, so it's a real pattern."*

Similarly, Emily found this a hard balance to strike but had developed strategies to try and manage this:

> *So yeah when I'm on my own […] and I notice I'm not lonely it's usually because like I feel like my alone time has made me feel rested and recovered […] I don't see people every day necessarily, usually have like a day or so in between to myself where I'm just on my own, so it's like having that certainty that I will see people next week but I'll also I'll have a good balance to my week.*

Both time on her own, and time connecting with others, felt manageable when there was a balance, and this helped to alleviate loneliness for her.

Theme Five: Building the Bridge Alone (Making Connections is Everyone's Responsibility)

In her interview, Sarah described the process of connecting with others as building a bridge. In an ideal and meaningful connection, this bridge would be built by each party on their respective side, and both would meet in the middle. Sarah described this process as *"instinctive"* for neurotypical people, but for her as an autistic woman, she saw this as a conscious and effortful process, in which she had to build bridges *"brick by brick"*:

> *I and people like me are the ones pretty much doing all the work to [bridge] that barrier and now feeling lonely and isolated and because of erm feeling well cross about that and yeah, a bit jolly put out [laughs] by the fact that erm we're the ones doing all the work.*

She felt that, as an autistic woman, she was working hard to build bridges to make connections with others, but that neurotypical people were often unaware, or unwilling to do the same. This made her feel lonely and cross, as she felt that building bridges was everyone's responsibility. Hearing Sarah speak about this was a key moment for me as a researcher. I had often questioned whether I should be doing this research as a neurotypical person due to my lack of experience of being autistic and the biases that may come with this. However, this changed my understanding and helped me to see the importance of the effort and role of neurotypical researchers in trying to build bridges. Jessica described a different experience to Sarah:

> *It was very much my boyfriend in the last few years who sort of put it to me that he wanted to help, so therefore we had come up with a way to allow him to do that […] and we sort of came up with a better way of dealing with it.*

Here, Jessica explains how her boyfriend supported her when she felt lonely. Jessica was unable to communicate how she was feeling when she was most lonely, so, with Jessica's

help, her boyfriend learnt ways to reach out to her at these times. He took responsibility for building his part of the bridge by asking her how he could help. The importance of this in alleviating loneliness was echoed by Rebecca when she said "i*f you just go ok, you're autistic what does that mean for you what yeah what is that for you how can I help you."* Rebecca described how experiences like this had helped her to feel valued and less lonely. She took responsibility for communicating her diagnosis of autism and what this meant for her, and others took responsibility by acknowledging her needs.

Theme Six: Being Autistic is "part of who I am"

Many of the women saw being autistic as part of who they were. This meant that when they made sense of their experiences related to loneliness, they were not always able to detach being autistic from other parts of their identity. When Emily was asked if she linked being autistic to her experiences of loneliness, she replied that *"it is just you know part of who I am"*. Emily described her autism diagnosis as *"a label to explain you know why I behave the way I do 'cause I've always been like this".* Here, Emily implies how autism is integral to her identity.

Claire struggled to make sense of the extent to which her experiences of loneliness were related to being autistic and how much were part of the other different identities she held: *"is that general parenting, autism, or worried about just the general state of world. And is that complicated by autism? Who knows"*. For Claire, these identities were all part of her. Lauren shared similar reflections about her different identities as a parent, student, and patient. She said that this made it *"hard to find women who relate to where I'm at in terms of life, so I find that quite lonely because I can't relate to them in that way"*. She expressed a need for finding people to relate to on all levels of her identity but stated *"I just feel like I'm just too many people".*

These different parts of their identities made Claire and Lauren unique individuals: A point that was emphasised by many of the women. For example, Megan expressed passionately that *"people should understand that there are different erm traits with autism and that they should erm try to […] erm yeah, see you as an individual"*. This view was echoed by Rebecca, who said *"everybody's individual right we all experience autism in a very different and separate way"*. Like many of the women, Rebecca's autism diagnosis helped her to make sense of her experiences related to loneliness, but this was a label for just one part of her identity. Rebecca summarised this sentiment shared by many of the women when she said: *"I'm still a human being"*.

Discussion

Summary of Results

This study aimed to explore the experience of loneliness in autistic women. The results portrayed a description of loneliness that was related to a strong sense of felt difference in participants compared to others. This was accompanied by a deep need to be able to fit in and make connections, some of the time at least. Loneliness was experienced through the challenges faced by participants in trying to make these connections. These challenges included a lack of understanding and responsibility from others to facilitate connections, which made social interactions harder. Participants expressed a need to have the right balance between "being unconnected" and being "connected", in order to "recharge" and alleviate feelings of loneliness. Many of the participants related their experiences of loneliness to being autistic but being autistic was an integral part of their identity that they could not always set apart. Overall, the participants described loneliness as an experience that was related to their unique identity, with being autistic one part of this.

Relevance to Previous Theory and Literature

This description of loneliness and "feeling unconnected when you want to be connected" is reflected in Perlman and Peplau's (1981) discrepancy model of loneliness. As previously discussed, this model suggests that loneliness is experienced as an unpleasant emotion that occurs when there is a perceived gap between what an individual feels they need from social relationships, and what they are receiving. The study findings also share similarities with the idea that loneliness can motivate individuals to seek connections in order to alleviate it (Hawkley & Cacioppo, 2010). However, the effortful process of trying to make connections and the idea that this could alleviate feelings of loneliness, is where previous models may not have fully captured the experience of loneliness, or the dilemma, described by participants in this study.

What seemed to be a key difference in the descriptions of loneliness in this study was that it could not be alleviated easily through social interactions because of the challenges faced by participants, which meant that finding a balance was a predicament. These challenges could be said to accentuate the gap between actual and desired outcomes of social relationships described in the discrepancy model of loneliness. There was a felt lack of understanding from others about both autism and being an autistic woman. This is supported by evidence in the literature, which suggests that stereotypes and wider understandings of autism often fail to acknowledge the experiences of women, which can lead to further misunderstanding, discrimination and difficulties getting diagnosed at a timely point (Brickhill et al., 2022; Harmens et al., 2022). As expressed by many women in the study, a late diagnosis can make it harder to understand personal experiences, which can further perpetuate feelings of loneliness (Seers & Hogg, 2021; Wilson et al., 2022).

This stigmatisation and discrimination linked to being an autistic woman is also likely to differ across cultures and contexts where autism and women are viewed differently (Obeid

et al., 2015). Further issues of intersectionality expressed by women in this study are also important to consider here, such as differences in ethnicity, sexuality, and physical abilities, with discrimination against minoritised groups within the autistic community creating additional feelings of difference and loneliness (Mallipeddi et al., 2022; Slade, 2014).

Linked to this feeling of difference, participants in this study described the effort it took to change their behaviours or "mask" their authenticity to try and fit in. Research suggests that masking behaviours are common in autistic women and highly related to feelings of difference and stigmatisation (Alaghband-rad et al., 2023; Turnock et al., 2022), with some more recent studies suggesting that masking can perpetuate feelings of loneliness by creating a distance from the self (Elmose, 2020; Pearson & Rose, 2021; Grace et al., 2022). Related to all of this, some of the participants spoke about the need for others to take on responsibility for building connections, which is supported by the philosophy of the double empathy problem and the emphasis on mutual effort in interactions (Milton, 2012).

Strengths and Challenges

Through the experiences expressed by participants in this study, new insight was gained into how loneliness can be understood in autistic women, and how this may enhance current definitions of loneliness. The study contained a rich dataset and many of the issues raised spoke to highly relevant and multifaceted issues related to being an autistic woman.

Finding a homogenous sample is recommended as part of IPA research due to its role in helping to ensure that the research question is meaningful to participants and can be explored in-depth (Smith, 2022). Whilst homogeneity in this study was sought through recruiting autistic women who had experienced loneliness, it was also challenging to create an inclusion criteria that was both homogenous, as well as inclusive with the ability to generate a realistic response rate. This meant that the sample consisted of a wide range of individual differences, such as a large age range, which have implications for how loneliness

may be experienced. This may have taken away from the idiographic focus sought in IPA with less time to explore how these individual identities were specifically related to different experiences of loneliness. Whilst the data analysis suggested that many of the themes transcended these individual differences, further research with more homogenous samples may be needed to thoroughly explore the variation within this. Caution should also be taken when generalising these findings to other groups of autistic women who may experience loneliness in distinct ways.

Linked to this, the recruitment methods used for this research may have influenced who responded to the study adverts, which could have further shaped the findings. For example, the study was advertised on Facebook and X but there are many more social media platforms, with research suggesting that they attract different demographics (Farsi, 2021). Furthermore, half of the women were recruited through a private clinical psychology practice. People able to access this practice may differ in their experiences compared to those who do not have access to private services, which may have further implications for their life experiences and related feelings of loneliness. Many of the women who participated were highly educated, which may have influenced how they made sense of their experiences of loneliness.

Finally, findings could have also been influenced by online interviews. Whilst being online may have made the interviews more accessible to the women who participated, there was a need for participants to have a minimum level of familiarity with technology in order to be able to take part, which may have influenced who responded to the study adverts. Furthermore, online interviews can make it harder for researchers to detect subtle signs of distress or changes in emotion (Lobe et al., 2022), which may have influenced the follow-up questions chosen and the interpretation of the results.

Finally, all of the participants in this study identified as women and some of the findings alluded to experiences that participants related specifically to their gender identity. The discussions surrounding gender identity in autism are beyond the scope of this study, but it is important to hold in mind that gender encompasses numerous perceptions in different cultures and communities (Moore et al., 2022). Thus, what it means to be a woman, may hold different meanings for different individuals.

Clinical Implications

Previous interventions to mitigate loneliness have suggested approaches to help individuals to cope with, and close, the perceived gap between their desired and actual social relationships, based on Perlman and Peplau's (1981) discrepancy model. Most commonly these include cognitive behavioural therapy approaches, which focus on challenging distorted negative interpretations of social events, and increasing social connectedness (Ellard et al., 2023; Hickin et al., 2021; Sullivan & Bendell, 2023). However, the results of the current study imply that negative cognitions experienced by autistic women related to social events, such as feeling left out, may be entirely valid, given the lack of understanding of their experiences from others. Trying to challenge these thoughts could invalidate the difficulties and discrimination experienced by autistic women. Furthermore, these approaches do not consider the effortful processes relayed by women in this study about trying to engage with others and closing this gap.

Based on the findings of this study, in practice, these approaches could be adapted by clinical psychologists to work collaboratively with autistic women to find ways in which they can mitigate loneliness and connect with others as part of a "balancing act", where respite from the effort of social interactions is also considered. Methods such as "energy accounting" (Toudal & Attwood, 2024) have been developed for this purpose and help individuals to plan out tasks based on the energy costs involved. Having an awareness of the wider contexts that

autistic women may find themselves in, such as a lack of understanding from others about being an autistic woman, and the effort needed when trying to fit in, may help psychologists to develop an empathy and understanding through the therapeutic relationship that could help to mitigate loneliness in this population. Raising awareness of these adaptations through formulation, with neurotypical clinical psychologists also taking on this responsibility, and supporting multidisciplinary teams to see autistic women as individual "human beings" beyond their diagnostic label, could further facilitate this (Bealey et al., 2021; Bonin, 2018).

Theoretical and Research Implications

Experiences described by participants in this study highlighted a gap in the current scientific literature and further research is needed to continue to develop an understanding of how autistic women experience loneliness. In order to broaden knowledge in this area, it may be helpful to examine loneliness with different populations of autistic women or focus more explicitly on a particular component of loneliness, such as the cognitive processes involved in the perception of loneliness. Finally, using a different methodology to build on this research, such as grounded theory, may help to develop a unique theory of loneliness for autistic women. This could further inform the development of loneliness measures for autistic women or individuals, which are currently still in their infancy (Grace et al., 2024).

Conclusion

This study is the first study, to the researcher's knowledge, that has directly explored the experiences of loneliness in autistic women. The study findings revealed a description of loneliness that went beyond current general theories of loneliness. Further research is needed to continue to enhance this understanding and to close the gap in the literature on this extremely important topic.

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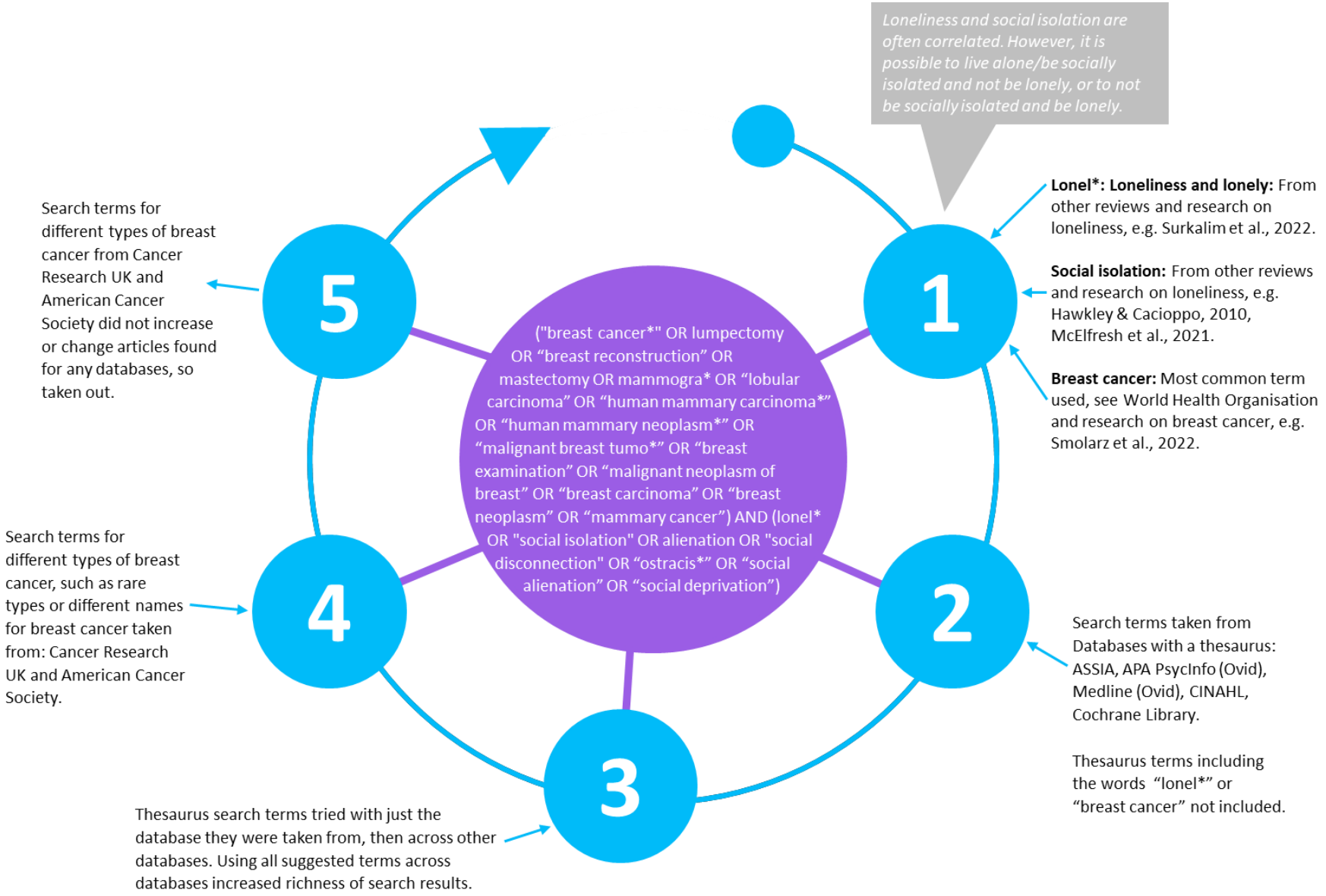
SECTION C

Appendix of Supporting Material

Appendix A: Development of Search Terms, Section A



Appendix B: Abridged Research Diary, Section A

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Appendix C: Detailed Notes for Quality Appraisal, Section A

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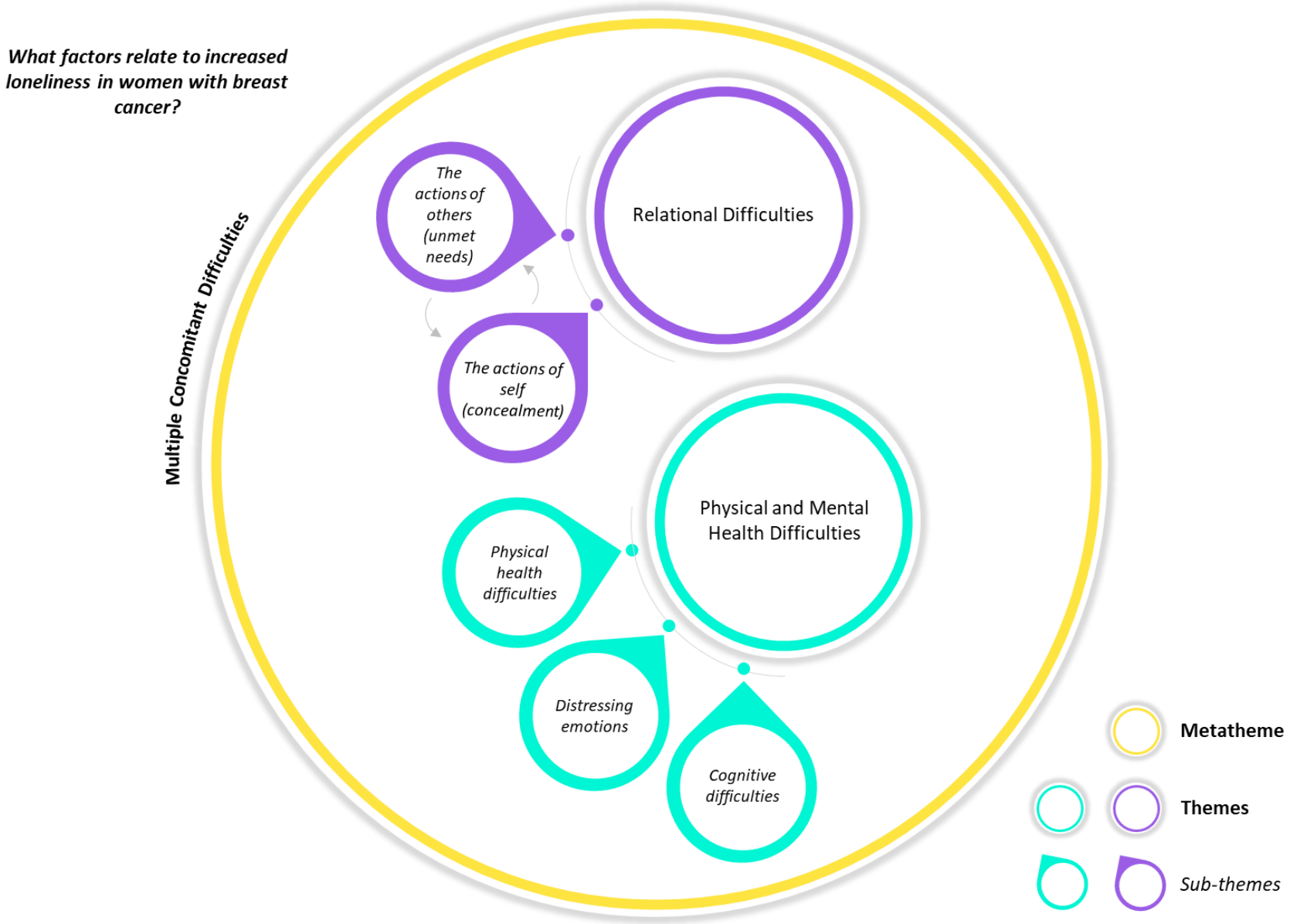
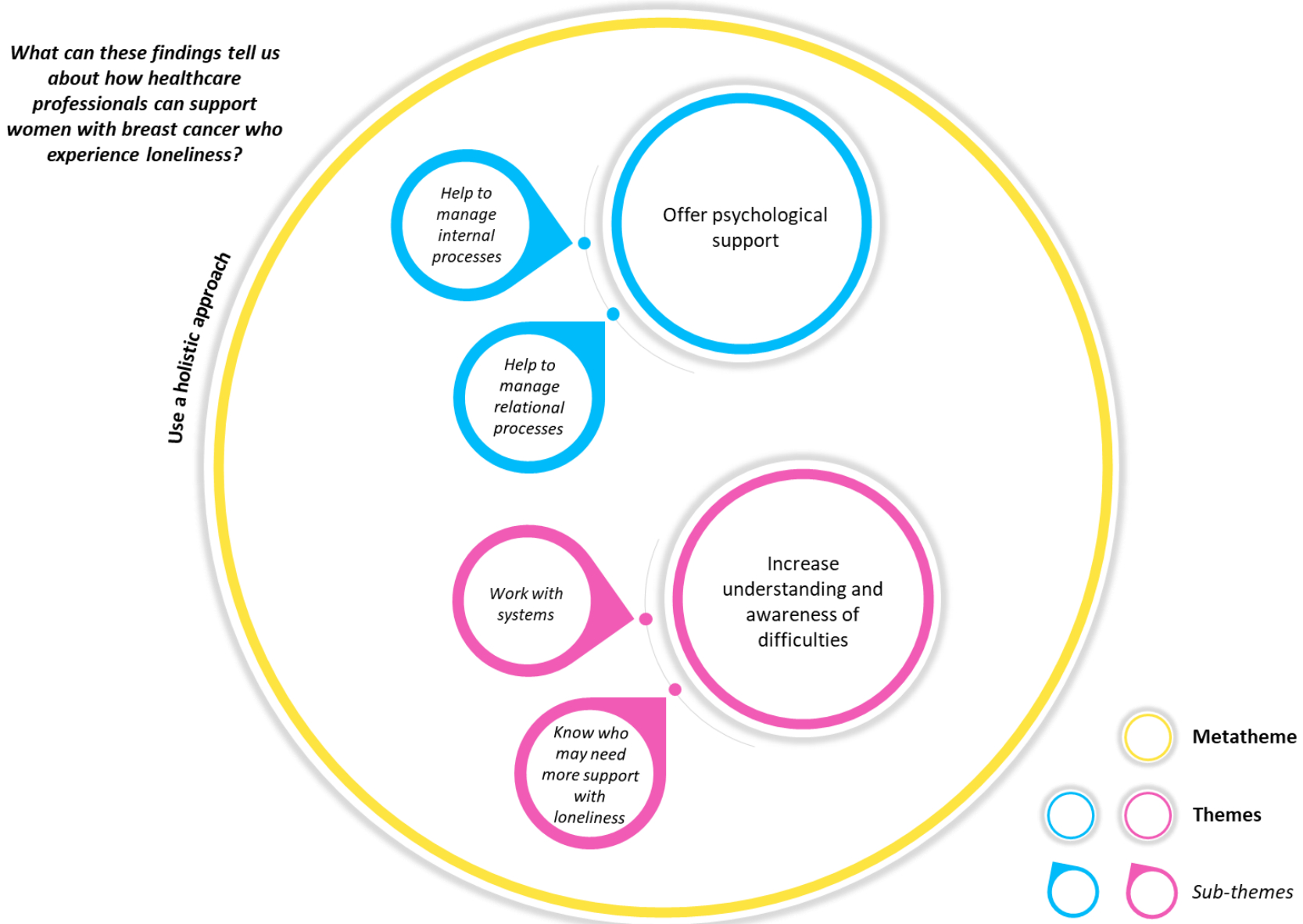
Appendix D: Theme Diagram for Question One, Section A



Appendix E: Theme Diagram for Question Three, Section A



Appendix F: Bracketing Interview Notes, Section B

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Appendix G: Abridged Research Diary, Section B

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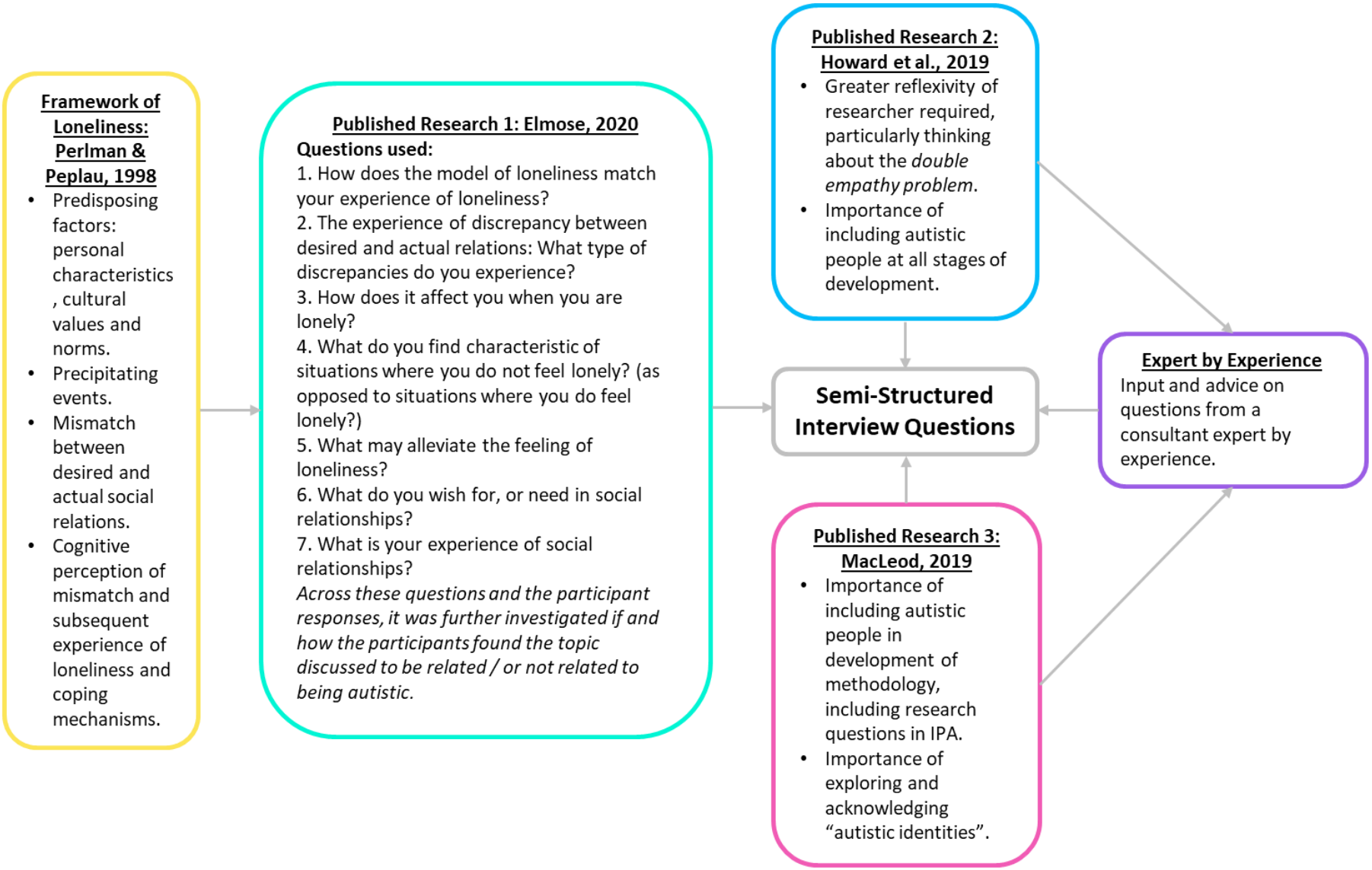
Appendix H: Development of Interview Questions, Section B



References: Elmose, M. (2020). Understanding loneliness and social relationships in autism: The reflections of autistic adults. *Nordic Psychology, 72*(1), 3-22. https://doi.org/10.1080/19012276.2019.1625068 I Howard, K., Katsos, N., & Gibson, J. (2019). Using interpretative phenomenological analysis in autism research. *Autism, 23*(7), 1871-1876. https://doi.org/10.1177/1362361318823902 I MacLeod, A. (2019). Interpretative phenomenological analysis (IPA) as a tool for participatory research within critical autism studies: A systematic review. *Research in Autism Spectrum Disorders, 64*, 49-62. https://doi.org/10.1016/j.rasd.2019.04.005 I Perlman, D., & Peplau, L. A. (1998). Loneliness. In H. S. Friedman (Ed.), *Encyclopedia of mental health* (vol. 2, pp. 571-581). Academic Press.

Appendix I: Interview Questions with Notes Following Feedback From Consultant, Section B

Area of Discussion 1: Confirmation of Consent and Ice Breaking

- Firstly, thank you for taking part in this study and for spending the time to talk to me today. I just wanted to assure you that your information will remain completely confidential and no records of this interview will be kept with your name on them. The only time I would need to break this confidentiality is if I have any concerns for your safety or the safety of others. If I do have any concerns, I will discuss this with you first wherever possible.

- Can I just confirm that you are happy for me to audio record our conversation? Do you have any questions about this?

- How much time do you have today?

- Before we begin, do you have any questions about this project or the discussion we will be having today? Don't worry if you can't think of anything now, I will also ask for questions at the end of the interview and you are welcome to ask me any questions you have throughout the interview.

- I understand that the topic we will be discussing today is a sensitive topic so please let me know if you need to take a break or are finding the questions difficult to answer. You do not have to answer any questions you do not want to and you can leave this discussion at any point.
- How will you let me know if you would like a break, are feeling uncomfortable, etc? Would it be helpful for us to agree a non-verbal cue? For example, you could use the "raise hand" tool?
- Are you happy to have your camera on? Do you have a preference for whether I have my camera on or off? Is there anything else I can do that will help you to feel comfortable during the interview?

- There are no right or wrong answers. I am really interested in hearing about **your** individual experiences. I'm here to learn more. It might sometimes feel like I am asking the same question in again in different ways. Please excuse me for this - this might help me to understand your answers in different ways.
- I have a list of questions and prompts that I will be using to guide me so I might look down sometimes when we are talking to check them.
- I also might nod or give you some non-verbal cues of listening but you don't have to respond to these.
- It is absolutely fine to interrupt me - I want to be led by you and your answers.

- For this first question, it might be helpful for you to think of, or imagine, different situations where you may or may not feel lonely (examples: when alone, on a crowded bus, at a party…). Some people may like to be alone and feel lonely when there are more people around, or some people may be different.
- I was wondering if you could start by telling me what the word *loneliness* means to **you**?
- *Prompts: How would you define loneliness? What do you think loneliness means? I am interested in hearing how you define loneliness, rather than what it is described as. How does this relate, if at all, to being autistic?*

Area of Discussion 2: Experiences of Loneliness

- Can you tell me about **your** experiences of loneliness?
  Prompts: How does it affect you when you are lonely? What is it like to experience loneliness? ***Can you tell me about a time you felt lonely recently? (Examples: do you feel lonely when you are doing something you enjoy by yourself? With a colleague at work? In the office…)*** *How do you feel when you do things that you enjoy? What do you think about, if anything, when you are lonely? What feelings do you have, if any, when you are lonely? What do you do or how do you behave when you are lonely? What do you do when you are not lonely? How does this relate, if at all, to being autistic?*
- *To answer this question, it may be helpful to think about your experiences when you are not lonely (examples: with family, friends, by yourself, reading, playing video games, at work…).*

- What may help you, if anything, to feel less lonely or to alleviate feelings of loneliness?
  Prompts: Can you think of an example - when you felt lonely, was there anything you did that helped you feel less lonely? (Examples: put music on, called a friend, went for a walk, spent time alone) How did doing that activity help you (explore the function of it)? How does this relate, if at all, to being autistic?

- What do you find **characteristic** of situations, if any, where you do not **feel** lonely? (as opposed to situations where you do feel lonely?)
  Prompts: Can you think of a time when you were not lonely? How did you feel in that situation? What did you do? What do you do or how do you behave when you are not lonely? (Examples: Are you happy, pre-occupied with a task, listening to music…) What do you think about, if anything, when you are not lonely? Why don't you feel lonely in these situations? What do you experience in those moments as an autistic person? How does this relate, if at all, to being autistic?

- Is there anything you would like to add about your experiences of loneliness?
  Prompts: What would be something you wish non-autistic people knew about your experience of loneliness?

Area of Discussion 3: Social Relationships

- What do you wish for, or need in social relationships?
  Prompts: What is important to you in social relationships? What do you look for in social interactions? What kind of support, if any, do you need (for example, practical, informational, emotional)? What might you want to get out of different relationships? (Examples: talking about emotions with friends…) Do your relationships/interactions differ depending on the person? (Examples: Authority, friend, boyfriend/girlfriend, family member, bus driver, in different settings…) What motivates you, if anything, to have social relationships? How does this relate, if at all, to being autistic? Why do you think people have social relationships and social interactions? What do social relationships mean for you?

- What is your experience of social relationships?
  Prompts: How many relationships, if any, do you have? What are these relationships like for you? What is positive about these relationships? What is challenging, if anything, about these relationships? How do you overcome these challenges? How do you think about yourself in these relationships? As an autistic person, how do you experience social relationships and interactions? (e.g. do you mask, make eye contact, do you feel listened to…) How does this relate, if at all, to being autistic?

- Is there anything you would like to add about your social relationships?
  Prompts: What would you like neurotypical people to know? What would you like the world to know about your experiences? How have experiences been with peers, teachers, bullying, difference, close friendships, etc.

Area of Discussion 4: Closing the Interview

- I think that's all the questions I wanted to ask you today, is there anything else that you would like to add? Do you have any questions for me? Anything I need to clarify? How was it doing the interview? How did you find the process? How have the questions been? Anything I missed? Any feedback to improve it? Anything that was good?

- Thank you very much for helping me with my research and for giving up your time to answer my questions. I will now turn off the recording.

- As a thank you, I wanted to give you a £10 voucher. This comes from a budget I have from the university finance department. They issue Amazon vouchers or a VexMultipay voucher that can be used for lots of different stores online. I was wondering if you had a preference? Would you be happy for me to pass on your email to the university finance department so that they can send you one?

- *Maybe explain that you are neurotypical and you may experience loneliness differently to them – you are not looking for a neurotypical explanation of loneliness but rather how the participants experience loneliness?*
- *If they struggle to think – you may have to create some scenarios – e.g. in the playground at school when you were younger, with your siblings and cousins, at work with colleagues, interacting with members of the public in shops and on public transport*

- *Create scenarios together and call on some memories - how did you feel, in your chest, family experience, strangers experience. Interplay between external stimulus and how people feeling in internal environment. Many social interactions to think of. Did you feel lonely here? Or in this case? Or this? Brainstorming help people to think of experiences and build that up.*

- *Really helpful to know what thinking.*
- *Inclusive and considerate for autistic people.*
- *You might find this question tricky, I might try some words things to help.*

- *Really letting people lead the dialogue. Every autistic person will have different ideas and self-awareness. Ok to interrupt me. Mostly led by you and your answers.*

Appendix J: Recruitment Poster, Section B

Participants Needed for Online Study!

We would like to find out more about how autistic women experience loneliness

We are looking for people who identify as female and have a diagnosis of autism*

You would be interviewed by a trainee clinical psychologist on Zoom for 60-90 minutes

You would be asked about your understanding and experiences of loneliness

You would receive a £10 online voucher to say thank you for taking part

**Depending on your diagnosis or how you identify, this might be called something else, such as, autism spectrum disorder or Asperger syndrome*

Canterbury Christ Church University

For more information about this study, or if you would like to take part, contact Grace at …

Appendix K: Information Sheet, Section B

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Information About the Research Project
Version 2, 13/01/2022

Lead Researcher: Grace Moorton (Trainee Clinical Psychologist, Salomons)
Principal Supervisor: Dr Jerry Burgess
Supporting Supervisor: Dr Elizabeth Kilbey

Name of the research project: Loneliness: Experiences of Women on the Autism Spectrum.

Why is this project being done?
There has been lots of recent research examining the links between loneliness and mental health difficulties in autistic people. This research has suggested that autistic people who feel lonely are more likely to experience difficulties with their mental health. This research is important to psychologists because it helps them to have a better understanding of what might help autistic people to feel less lonely and what might help to improve their mental health. However, most of the theories, definitions and measures of loneliness used in this research are based on the experiences of neurotypical people. Neurotypical people can sometimes make sense of the world differently when compared to autistic people. There has also been research to suggest that autistic women may make sense of the world differently compared to autistic men. However, there is significantly less research carried out with autistic women. To fully understand the links between loneliness and mental health difficulties in autistic women, it is first important to understand how autistic women experience loneliness and what this means to them.

Who is the researcher doing this project?
My name is Grace Moorton. I am a trainee clinical psychologist at The Salomons Institute for Applied Psychology (this is part of Canterbury Christ Church University). This project is part of the main research project I am doing for my training and it is called a major research project.

What will you be asked to do if you take part in this project?
If you wanted to take part in this project, I would email you a consent form to sign. I would also email you a link to a short questionnaire that would include questions about your age, level of education, ethnic group, and national identity. I would then arrange a time and a day to meet with you online. You would meet with me online for 1-2 hours and you would be asked some questions about how you experience and

understand loneliness. The online conversation would be audio-recorded (no video recording would be made).

What will you receive for taking part in this project?
To say thank you for taking part I would email you an online voucher for £10. You would be asked to choose what shop or organisation you would like this voucher to be for.

What will happen with the information you give?
Consent form
The consent form will be saved as a password protected document on a password protected computer. It will not be stored with your answers from the interview and will not be linked to this. It will be deleted after the results of the study have been written up.

Questionnaire answers
The answers to the questionnaire will be saved as a password protected document on a password protected computer. They will not be linked to your name, the consent form, or your answers from the interview. The answers to the questionnaire will be included when the project is written up as general information about all of the people who took part. Here is an example of how your answers will be included in the write-up:

Table 1
Participant characteristics (10 participants)

Age	Number of participants
18-24	2
25-34	3
35-44	1
45-54	1
55-64	2
65+	1

Audio-recording and interview answers
The audio-recording from the interview will be stored on a password protected computer. The only person who will listen to this recording will be me (Grace Moorton). I will listen to the recording and type up everything that has been said as soon as possible after the online interview. This is called a transcript. Once the transcript has been written, the recording will be deleted. The transcript will be anonymous, and a pseudonym will be used instead of your real name. The transcript will be saved as a password protected Word document on a password protected computer. Any details on the transcript that might make you identifiable will be changed. For example, if you talk about people or places, their names will be changed. An expert by experience (a woman who is on the autism spectrum) and I will look for themes in the transcript. The supervisors for this project (Dr Jerry Burgess and Dr Elizabeth Kilbey) may also look at some of these transcripts once they have been anonymised. If you would prefer that the transcripts are only seen by me (Grace Moorton), you can leave this box unchecked on the consent form and I will not share them further. I will also check this with you again once the interview has been completed. I will write about the themes in the final project. I will

sometimes use direct quotes from your transcript to describe the themes. These quotes will be linked to a pseudonym and not your real name. The final project might also be published in an academic journal. The findings will be shared with you once the project has been completed. The transcripts will be stored for 10 years and then destroyed.

All of your information will be kept confidential. Please note that the only time I would have to pass on information about you would be if, because of something you said, I were to become concerned about your safety or the safety of someone else. I would discuss this with you first wherever possible.

What will happen if you no longer want to take part?
If you no longer want to take part in the project, please let me know and all of your information will be deleted. You have the right to say that you no longer want to take part at any point in the project and you will not be made to feel bad for saying this. If you become upset or distressed at any point during the project, the research process will be stopped.

Please be aware that once the project has been written up, it will not be possible to delete any themes, quotes, or demographic information from the overall write-up. The last date to withdraw your responses before they are included as part of an overall write-up, will be 31st December 2022. If you would like to do this anonymously, please call the telephone number listed under “contacts” below and leave a message. If you take part in this study, you will be given two unique ID numbers. One ID number will be on your consent form, and the other will be given to you when you complete the questionnaire. Please quote these ID numbers if you would like to withdraw from the study.

Are there any risks involved in taking part?
Talking about loneliness may be difficult at times. You will not be obliged to answer any questions that I ask. I will continue to check how you are finding the questions throughout the online conversation and will ask you if you need to stop or take a break. If you think that you may become very distressed when talking about loneliness, then we would advise that you do not participate in this study.

Further information about the project
This project is sponsored and funded by Canterbury Christ Church University. This project has been reviewed and given favourable opinion by the Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University. If you would like to read more about how Canterbury Christ Church University processes personal data of research participants and your privacy in relation to this, please follow this link: https://www.canterbury.ac.uk/university-solicitors-office/docs/research-privacy-notice.docx

Contacts
If you would like to take part or have any questions about the project, please email me (Grace Moorton) at ... If you have any concerns about the project, please telephone me by leaving a message on the 24-hour voicemail phone number ... Please leave a contact number and say that the message is for Grace Moorton and I will get back to you as soon as possible. If you remain dissatisfied and wish to

complain formally, you can do this by contacting … Furthermore, if you have any concerns that you do not wish to share with me (Grace Moorton) or anyone else involved in this research, please contact … on the email address above.

Appendix L: Consent Form, Section B

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Ethics approval number: ETH2021-0377
Version number: 2
Participant Identification number for this study:

Consent Form

Title of Project: Loneliness: Experiences of Women on the Autism Spectrum
Researcher: Grace Moorton (Trainee Clinical Psychologist)

Please click box to show agreement (an x will appear)

☐ I confirm that I have read and understand the information sheet dated 13/01/2022 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care or rights being affected.

☐ I understand that the transcripts may be looked at by the supervisors for this project [Dr Jerry Burgess and Dr Elizabeth Kilbey] and a consultant expert by experience once they have been anonymised. I give permission for these individuals to view the transcripts.

☐ I confirm that I agree to be audio recorded for the interview. Once the recording has been transcribed, it will be destroyed.

☐ I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings.

☐ I agree for my anonymous data to be used in further research studies.

☐ I understand that I will not be able to withdraw any data that has been written-up or published as part of overall findings. I understand that the last date to withdraw my responses before they are included as part of an overall write-up, will be 31st December 2022.

☐ I agree to take part in this study.

	/ /	
Name of Participant	**Date**	**Signature**
	/ /	
Name of Researcher	**Date**	**Signature**

Consent to Receive Study Findings

If you would like to receive a summary of the study findings once this project has been completed, please tick the box and provide your email address below:

I would like to receive a summary of the study findings ☐

Email address: _____

Appendix M: Demographic Questions, Section B

Below are some questions about your age, sexual orientation, ethnic group, marital status, level of education, employment status, and living situation.

I am collecting this information for this piece of research because I want to ensure that research includes all groups of people, however they identify. When I look at everyone's answers combined it may also be that I see some important patterns that may impact on how I interpret my findings.

All of your answers to these questions will be kept confidential and they will not be linked to your interview answers. However, if you do not wish to disclose this information, please select "prefer not to say".

If you identify differently to the options given, please describe this in the box that says "other". The word "other" cannot be changed in the form builder programme, however, I realise that this term can sometimes imply that how you identify is not the "norm" if this is "other". Please be assured that this is not a reflection of my views or the research but how the form is programmed. All identities are welcomed and highly valued.

If you have any questions or concerns about these questions, please contact the researcher with the information outlined on the information sheet.

Please select the category that includes your age
18-24
25-34
35-44
45-54
55-64
65-74
75-84
85-94
95 or above
Prefer not to say

Please tick the sexual orientation category that best describes you
Bisexual
Pansexual
Heterosexual
Gay
Lesbian
Prefer to self-describe, please specify
Prefer not to say

What is your ethnic group?

Choose one option that best describes your ethnic group or background
Mixed/Multiple ethnic groups 1. White and Black Caribbean 2. White and Black African 3. White and Asian 4. Any other Mixed/Multiple ethnic background, please describe
White 5. English/Welsh/Scottish/Northern Irish/British 6. Irish 7. Gypsy or Irish Traveller 8. Any other White background, please describe
Asian/Asian British 9. Indian 10. Pakistani 11. Bangladeshi 12. Chinese 13. Any other Asian background, please describe
Black/ African/Caribbean/Black British 14. African 15. Caribbean 16. Any other Black/African/Caribbean background, please describe
Other ethnic group 17. Arab 18. Any other ethnic group, please describe
Prefer not to say

What best describes your marital status?
Single
Married
Living with partner
Separated
Divorced
Widowed
Other, please specify
Prefer not to say

What best describes your highest level of completed education?
University postgraduate degree at Doctoral level or equivalent (e.g. PhD, MD, PharmD)
University postgraduate degree at Masters level or equivalent (e.g. MA, MSc)
University undergraduate degree or equivalent (e.g. BA, BSc, Higher National Diploma, Higher Apprenticeship)
College (e.g. AS, A Levels, BTEC, IB, Advanced Apprenticeship)
Secondary school (e.g. GCSEs)
Other, please specify
Prefer not to say

What best describes your current employment status?
Unemployed/looking for work
Unemployed/not looking for work
Full-time employment
Part-time employment
Self employed
Retired
Student
Other, please specify
Prefer not to say

What best describes your living situation?
Living with support at home
Living with some external support
Living with no external support
Other, please specify
Prefer not to say

Appendix N: Further Support Information Sheet, Section B

Links to Further Support

Thank you for taking part in this interview today.

Loneliness is a sensitive topic and you may be left with some difficult feelings.

Please see below for some contact information for further support.

If you are feeling very distressed please dial **999** or go to your nearest Accident & Emergency (A&E) department.

Samaritans: To speak to someone at any time of day or night, 7 days a week, call the Samaritans on **116 123**.

National Autistic Society
Autism Services Directory
https://www.autism.org.uk/directory

The National Autistic Society are a charity in the UK for autistic people. They have an online directory of autism services. Type in "women" in the "I am looking for…" box to find more information about autism services for women in your area.

National Autistic Society
https://community.autism.org.uk/

The National Autistic Society are a charity in the UK for autistic people. They have lots of different online discussion forums - you can join an existing discussion or set up your own.

SEE Autistic Women
https://seeautisticwomen.wordpress.com/about/

A group run by and for autistic women. They have a website and Facebook group. They organise social events in London and South East England, including, Kent, Surrey, East Sussex, West Sussex, Berkshire, Buckinghamshire, The Isle of Wight, Hampshire, and Oxfordshire.

Women with Autism/Aspergers UK Support Group
https://www.facebook.com/groups/688411908330520/about/

This is a Facebook group for women who have been diagnosed or are waiting to be diagnosed, also includes self-diagnosed with autism/Aspergers. This group is for UK women.

The Curly Hair Project
https://thegirlwiththecurlyhair.co.uk/

The Curly Hair Project is an organisation that supports autistic people and those around them. It is founded by autistic author, Alis Rowe. The website includes a blog, as well as other resources that can be accessed through a subscription fee.

Aspiring to Be You
https://aspiringtobeu.com/about-us/

This is an online platform for autistic women, which discusses current research in the field, stories from individuals, and opinion pieces surrounding the challenges and strengths of being on the autistic spectrum.

Aspiring to Be You: Forum
https://www.aspiringtobeuforum.com/

This is an online forum designed by autistic women for autistic women. There is a cost to joining, which is £9.99 per year.

If you are aware of any other organisations or support and think they should be included on these pages, please let Grace know at ...

Your expertise and knowledge is greatly appreciated!

Appendix O: Transcript Excerpt for Emily With Exploratory Notes and Experiential Statements, Section B

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Appendix P: Example of Personal Experiential Themes (PETs) for Emily, Section B

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Appendix Q: Example of Personal Experiential Themes (PETs) for two Participants, Section B

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Appendix R: Overview of Group Experiential Themes, Section B

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Appendix S: Ethical Approval for Study, Section B

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Appendix T: Project Report for Participants and Ethics Committee, Section B

Report of Study Findings

"Feeling unconnected when you want to be connected": The Experience of Loneliness in Autistic Women

Grace Moorton, Trainee Clinical Psychologist, December 2024

Emily* Rebecca Jane Lauren Sarah Jessica Megan Hannah Claire Nicola

Background & Aims

"I just want people that have autism to know that they're not alone" (Megan)

Loneliness has been described as an unpleasant feeling that happens when an individual believes that there is something missing that they need from their social relationships[1]. Loneliness has been linked to poor physical and mental health when experienced for long periods of time[2].

Although all autistic women are different, they may be likely to experience loneliness. Some people think that this might be because: The experience of autism in women is not well understood[3]; women may be more likely to be diagnosed at an older age[3]; and women may be more likely to mask how they really are, to try and fit in with other people[4].

There is not enough scientific research about autistic women[5]. Ideas about what loneliness is, and ways to measure loneliness, are based on descriptions of loneliness about everyone[6]. Autistic women might experience loneliness in a unique way. It is important to understand how autistic women experience loneliness to get a clearer picture of what might help them to feel less lonely. This, in turn, could help to improve their mental health.

This study aimed to find out how autistic women experience loneliness b asking autistic women about this.

Method

Language: The women in the study who had a preference, identified as "autistic women", but this study recognises that some people may wish to identify with autism in different ways.

Ten people who identified as women, and autistic, took part in this study. They were interviewed online about their experiences of loneliness. These interviews were typed up word-for-word. Time was then spent looking for themes and connections using a method called interpretative phenomenological analysis (IPA).

As a neurotypical researcher, I wanted to make sure the experiences of the women I interviewed were the focus of the study. I had advice from a consultant expert by experience, an autistic woman, who looked through the themes and gave me very valuable feedback about this.

*Fake names have been used for all participants

Findings

Loneliness was experienced by women in different ways linked to living in a social world where connection was needed but sometimes difficult. At the core of this, women felt that being autistic was part of their identity as a unique individual. Everything that the women said in the interviews was so powerful, interesting and important, that it was hard to fit it all into the findings. Six themes and eight sub-themes (themes within themes) were created:

Theme 1: Experiencing loneliness through feeling different

Women spoke about feeling different when being left out and feeling different compared to other autistic people. This made them feel lonely.

Talking about a late diagnosis: "So it's more like feeling lonely in the discovery as well cause a lot of erm other autistic women that I've met and know would have known that they have autism in childhood " (Lauren)

Theme 2: Experiencing loneliness through trying to fit in

Women spoke about how fitting in felt difficult but was needed. They also spoke about changing parts of themselves to try and fit in.

"I don't know what percentage of autistic [people] I'm talking for but we want connection even if it's difficult" (Jane)

"I did want to have friends I did want to feel like I fit in, but then I kind of didn't want to have to change who I was to do that" (Jessica)

Theme 3: Experiencing loneliness through understandings of autism

A lack of understanding from others about autism made some women feel lonely. Some understood themselves better through their autism diagnosis, which empowered them and made them feel less lonely.

"So the position I'm at now if something doesn't kind of like serve me or I suppose I'm just kinder to myself because I understand why I'm the way I am" (Hannah)

Theme 4: Experiencing loneliness as part of a balancing act

Women worked hard to balance connecting with others to avoid feeling lonely, with time alone to recover and recharge. Too much time feeling unconnected made some women feel lonely. Some time alone was enjoyable for many of the women.

"I think it [loneliness] means feeling unconnected when you want to be connected […] because sometimes feeling unconnected is fine. Sometimes feeling unconnected is good" (Nicola)

Theme 5: Making connections is everyone's responsibility
Some women spoke about how it felt lonely when they were the ones doing all the hard work to make connections, especially compared to neurotypical people. Some women felt that it was important for both autistic women and neurotypical people to make the effort.

"And now feeling lonely and isolated and because of erm feeling well cross about that and yeah a bit jolly put out [laughs] by the fact that erm we're the ones doing all the work" (Sarah)

Theme 6: Being autistic is "part of who I am"
Women spoke about how being autistic was part of them. Their experiences of loneliness were linked to being autistic but also linked to them being a unique individual.

"It is just you know part of who I am" (Emily)

"Is that general parenting, autism, or worried about just the general state of world. And is that complicated by autism? Who knows" (Claire)

"Everybody's individual right we all experience autism in a very different and separate way" (Rebecca)

Conclusions

These findings add to what we already know about loneliness. They tell us something about the unique ways that autistic women might experience loneliness. For example, that some autistic women need connections to stop feeling lonely, but making connections is hard.

People should be better at seeing beyond the label of autism for autistic women and taking the time to ask them about what autism means for them, and what might help to support them in interactions. It is important to raise awareness of what it means to be an autistic woman.

These findings will not apply to all autistic women and other autistic women will have different experiences. It is important to remember that all autistic women are unique.

Thank you

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