The experiences, needs and concerns of younger women with breast cancer: A meta-ethnography

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The experiences, needs and concerns of younger women with breast cancer: A meta-ethnography

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Abstract

Objective

This meta-ethnography synthesises the evidence on the experiences, needs and concerns of younger women with breast cancer.

Methods

Using a method called ‘reciprocal translation’ we developed a conceptual model to reflect the local and social contexts, issues, processes, needs and concerns of importance in this literature.

Findings

Key findings relate to the particular point in the life-course at which young women with breast cancer stand. Issues for these women relate to feeling different as a result of cancer, fear of recurrence, feeling ‘out of sync’ and altered embodied subjectivity. Young women with breast cancer use three processes to integrate the changes that cancer brings, namely balancing, normalising and changing. Our conceptual model also highlights young women’s needs, primarily for support, information, childcare, counselling, and spiritual support. Areas of reproduction, fertility and sexuality were also of particular concern. The included papers have methodological limitations which impact on our findings, such as opportunistic data analyses, lack of theoretical frameworks and limited reference to socio-cultural factors.

Conclusion

The conceptual model developed as a result of this meta-ethnography provides a basis for practitioners to address these young women’s concerns more adequately and comprehensively.

Keywords: cancer, oncology, breast, young adults, meta-ethnography

1. BACKGROUND

1.1. Age and cancer

More than one million women worldwide are diagnosed with cancer each year. Breast cancer accounts for 10 per cent of all new cancer cases in the world [1]. According to the latest available figures, 45,508 women were diagnosed with breast cancer in the UK in 2006 [1].

From a clinical perspective, age is a significant variable for understanding epidemiology. The prevalence of cancer in all age groups is rising [2]. In the UK around 1 in 10 of cancers occurs in adults under the age of 50 [1]. A quarter of all cancers in adults under the age of 45 are breast cancers, the most common malignancy in this age group [1].

Experiences of living with cancer vary by age [3] but despite the prevalence of breast cancer in younger women, the specific key issues and concerns of this group are under-researched. Relatively little is known about *how* experiences, needs and concerns of breast cancer patients differ by age. Such knowledge is important to enable tailoring of interventions and to ensure the supportive care needs of different groups are met. Synthesis of existing evidence has been partly hampered by lack of standardised age definitions [4].

From psychological and sociological perspectives, age has traditionally been used to define human stages of development [5,6]. Key developments associated with young adulthood include starting a career, entering long-term relationships, parenthood and stabilization of one's identity [7]. Thus, the experience of cancer for young adults is related to the key issues they encounter socially and psychologically.

This meta-ethnography synthesizes qualitative research on experiences of younger women living with a diagnosis of breast cancer. This focus was chosen because breast cancer is the most common cancer at this age. Focusing on qualitative literature in its own right is particularly important because it draws attention to subjugated, experiential knowledge.

1.2. Women's experiences of breast cancer

It has been argued from a life-stage perspective that younger women have more of their life ahead of them and might therefore feel the impact of cancer more keenly [8,9]. Younger, premenopausal women seem to experience more distress, higher levels of depression, cope less well and report poorer quality of life than older women. [8-10].

Qualitative research into the experiences, needs and concerns of younger women has added detail and depth to our knowledge of the meaning of breast cancer. It has suggested that the experience of breast cancer is dependent on personal and social context [11], and that wider social and historical forces shape the perception of breast cancer and of women more generally [12].

No synthesis currently exists on the wider experiences of this patient group, or indeed, of the qualitative literature alone. In undertaking this meta-ethnography we aimed to synthesize the existing qualitative literature on younger women with breast cancer. Identifying specific experiences, needs and concerns of younger women with breast cancer can inform service development and future research.

2. METHODS

2.1. Type of literature review

We conducted a literature synthesis guided by the principles of meta-ethnography [13]. A meta-ethnography is "the synthesis of interpretive research" (p.10) [13] and aims to preserve the unique character of qualitative studies through the selection of key metaphors (themes) from the original texts; but also to provide a new interpretation of these studies, rather than a simple aggregation. To achieve these aims, it uses a rigorous set of procedures. We adopted a 'reciprocal translation' involving seven phases (see Box 1) [13].

Box 1: Phases of the meta-ethnography

Phase 1: Identifying experiences, needs and concerns of younger women with breast cancer as an intellectual interest.

Phase 2: Conducting a systematic search for relevant qualitative studies.

Phase 3: Reading the articles, paying particular attention to metaphors (i.e. themes, perspectives, concepts) used by the authors to describe and/or explain women's experiences, needs and concerns.

Phase 4: Developing a tabular format to compare studies. Listing key metaphors in each study.

Phase 5: Translating studies into one another. Examining relations between metaphors within a study and between studies.

Phase 6: Synthesizing these translations by determining if some metaphors could encompass other metaphors, thus translating them into each other. The synthesis took the form of a 'reciprocal translation.' That is, similar studies made it possible for each study to be translated into the metaphors of others and vice versa.

Phase 7: Publishing the meta-ethnography.

2.2. Systematic search for literature

For phase one, the development of our intellectual interest and research focus, and phase two, the literature search, we carried out a keyword search in four electronic databases: Medline, Web of Science, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Applied Social Sciences Index and Abstracts (ASSIA). We used the following Medical Subject Headings (MeSH) search terms in accordance with definitions used by the National Library of Medicine [14]:

Adult AND (Neoplasms OR Breast Neoplasms) AND Qualitative Research

The search was conducted in January 2009. We identified papers from references/bibliographies listed in manuscripts that were retrieved from the electronic search (this produced an additional two papers which were included in the review). Search results were managed in Reference Manager v11 [15] and a search log kept, detailing number of studies retrieved, de-duplicated, and included at each stage (see Flowchart 1).

2.3. Inclusion criteria

The inclusion criteria were: i) *Population*: women with breast cancer under the age of 45 at diagnosis; ii) *Topic:* experiences, needs and concerns; iii) *Design:* qualitative; iv) *Language and date of publication:* English language studies published in the last 20 years.

Two reviewers (GH, LM) independently screened titles and abstracts. Full papers were obtained for all studies that appeared to meet the inclusion criteria. Three reviewers (EA, GH, LM) collectively read these papers and through discussion reached agreement on inclusion for each paper.

2.4. Quality appraisal

Though there is no consensus whether structured appraisal methods yield higher reviewer agreement than unprompted judgement [16] quality appraisal allows multiple readers to review papers in a structured way. We therefore appraised studies using Dixon-Woods *et al.*'s [17] five-point approach to assessing methodological quality in qualitative studies (see Box 2).

Box 2: Quality appraisal criteria for empirical papers [17].

1. Are the aims and objectives of the research clearly stated?
2. Is the research design clearly specified and appropriate for the aims and objectives of the research?
3. Do the researchers provide a clear account of the process by which their findings were produced?
4. Do the researchers display enough data to support their interpretation and conclusions?
5. Is the method of analysis appropriate and adequately explicated?

Documents were rated 5 if all questions were answered in the affirmative, 4 if the method or analysis or sample were not clearly outlined or 3 if both the method or analysis and sample were poorly described.

Each included paper received a high quality score therefore no paper was rejected as a result of this appraisal. However, reading through the papers during the first phases of our review, we detected additional differences in the quality of the papers. We therefore developed an additional quality appraisal strategy (see Box 3).

Box 3: Additional quality appraisal criteria

1. Was the recruitment (and resulting sample) specific to the study reported?
2. Does the interview enable the interviewee to raise experiences, issues and concerns or were they raised, and thus introduced, by the researcher?
3. Did the authors make it explicit how they interpreted the data and what theoretical framework they used?
4. Did the authors acknowledge social and cultural factors (e.g. social class, ethnicity) in their analysis?
5. Are strategies employed to verify the coherence of the interpretation and analysis of data (for instance, were strategies such as triangulation used, or was the analysis discussed with user representatives to verify ecological validity)?

Documents were rated 5 if all questions were answered in the affirmative, 4 if only 4 questions were answered in the affirmative, and so on, with 0 indicating the weakest quality of paper based on these additional appraisal issues.

This quality appraisal was applied to all studies and results are shown in Table 1.

Insert TABLE 1 here

2.5. Data extraction

In phases three and four, two reviewers (EA, LM) individually extracted data from the papers into a template holding key information about each paper. The tables containing the extracted data were discussed by three reviewers (EA, LM, GH) to ensure congruence of extraction and to begin the process of identifying patterns and common themes across papers.

2.6. Synthesis

In relation to phase five of the synthesis, the translation of studies into one another, one of the reviewers (GH) identified common concepts in the papers which could be used as a descriptor of younger women's experiences of breast cancer and/or as an explanatory device to account for their experiences. Concepts had to be evident in at least a quarter of papers. These concepts were then discussed by the two reviewers (EA, LM) who had extracted data, and further extended to include other concepts that seemed relevant as a result of the extractions. All concepts were then discussed collectively by the whole research team for validation and to develop understanding of these concepts further.

3. RESULTS

3.1. Description of studies

In total, 17 studies are included in this review. For a summary table see Appendix 1.

3.2. Synthesis: Conceptualising experiences, needs and concerns

Experience is defined here as an interactive and ongoing process of a person's subjective engagement with societal relations (for instance, material, economic or interpersonal practices and discourses), and therefore is thoroughly social [18].

Guided by our extractions, we categorise concepts into those that provide a context for the experiences, those that are issues for younger women with breast cancer, and those that indicate processes found across these issues within these specific contexts (see Box 4). Particular needs and concerns arise from these contexts, issues and processes.

Box 4: Concepts arising from the meta-ethnography

Social contexts
- Life-course
- Cultural context
- Motherhood

Local context
- Family/relationship status
- Social support
- Doctor-patient relationship

Issues
- Reproduction
- Body
- Fear
- Sexual activity
- Feeling 'out of sync'

Processes

- Balancing
- Normalising
- Changing

Needs and concerns

- Support
- Information
- Childcare
- Counselling
- Spiritual support
- Fertility and sexuality

These concepts are inter-related. The three processes – balancing, normalising and changing characterise the issues which themselves are embedded within specific contexts. Contexts, issues and processes will now be described in turn.

3.2.1. Social context

Young women stand at a particular point in the life-course; they have a biological age (primarily defined as being of child-bearing age) and a social age. In countries with relatively high GDP there is a social expectation that young women will raise a family and be in paid employment. Expectations of a woman's role however, may vary within different cultures within a country [7, 19]. Motherhood is a key social context for the experience of breast cancer for young women [20-30]. However, it has long been highlighted as a dominant ideology which shapes the subjectivities of all women [31, 32]. This wider social context, which includes an ideology of motherhood, gets negotiated at the individual level, within a 'local' context.

3.2.2. Local context

The 'local context' consists of an individual woman's circumstances, for instance her relationship status and social support network. Young women are more likely to be in new relationships or no relationships than older women [33] and may therefore be more isolated when diagnosed with breast cancer [34]. The quality of the relationship, in terms of support it can provide, is also a crucial factor. While a recent review [35] has cautioned against assuming that cancer generates relationship distress or dissolution, it did not discuss distress in relation to age. Some studies included in our review show that for young women, cancer may well introduce an element of relationship distress [28, 34, 36]. Similarly, young women's social support networks may be less well established and more fluid than those of older women [22, 37]. A further important aspect of a woman's breast cancer experience is her relationship with her medical team. As part of this relationship, accessibility, information provision, and involvement of the patient in decision making are all important factors [30, 36, 38].

3.2.3. Issues

The changing experiences of young women which are attributable to cancer cluster around key issues. One issue which permeates all others is a feeling of being different and 'out of sync'. A diagnosis of breast cancer under the age of 45 disrupts a normal life-course. This is because a life-threatening illness is socially perceived as normally only occurring among older people. This feeling of being 'out of sync' is in comparison to other young women without cancer and older breast cancer patients [24, 29]. Feeling 'out of sync' connects to issues around reproduction (including pregnancy, fertility, contraception and menopause) [20-30]; altered body image (primarily relating to mastectomised bodies and breast reconstruction, but also to more general feelings of being in an altered body, and therefore, changes in embodied subjectivity) [20, 25-27, 34, 36-39]; decreased levels of and changes to sexual activities [25-27, 34, 36, 38]; and fear (of cancer recurrence, of their own mortality and its potential impact on their families) [20, 21, 23-25, 27-29].

3.2.4. Processes

These issues that connect with being ‘out of sync’ are experienced by young women in particular ways within their local contexts. Different ways of experiencing and responding to these issues are categorised into three different processes, namely *balancing*, *normalising*, and *changing*. These processes are drawn on by young women in various combinations.

3.2.4.1. Balancing

A key process characterising young women’s experience of breast cancer is *balancing*. Young women with children are likely to be diagnosed with cancer when their children are still living at home. The emotional impact of cancer is well-known, with cancer being described as an ‘emotional rollercoaster’ [22]. Maintaining daily life and family routine is balanced against the intrusiveness of cancer-related demands [28]. As a mother and partner a young woman balances priorities of putting her own needs first in order to survive cancer with meeting the needs of her family. She also balances the physical and emotional demands of her children with the demands on her self; balances being honest about pain and fears with protecting her children from the severe impact of cancer on self; and finds a balance between being needed and wanted by her children with recognising that if she dies her children will be looked after by others. Finally, she balances meeting financial needs of the household, by continuing in paid employment, with under-going treatment which is time-consuming and debilitating [20, 22, 25, 26].

Balancing, however, is not only a process pertinent to women with children. Young women, irrespective of motherhood status, balance focussing on the immediate priority to have treatment in order to survive with learning to live with symptoms such as early onset menopause [20, 22, 25-27]. They weigh up the risks and benefits of particular treatments on survival as well as limiting damage for their longer-term health. In addition, young women feel they need to balance their desire for a child after cancer with concerns over their own health and their families’ and partner’s wishes [23, 29].

Balancing different needs and demands is also driven by, and linked to, the process of *normalising*.

3.2.4.2. Normalising

Young women engage in n*ormalising* processes in relation to different issues of their breast cancer experience.

Young women see their mastectomised body as a deviation from a normative female body. While some women choose breast reconstruction as a way of re-gaining a representation of female normality others opt to establish a new sense of normal by normalising bodily imperfection [39]. Young women perceive that they are not achieving developmentally normative milestones, such as having children, and perceive that having a baby will restore a sense of normalcy in their lives in terms of their femininity and sexuality [23, 29]. The ability to have a child proves a marker of their ability to function as a ‘normal’ woman, especially for those who have a mastectomy [23, 29].

Young women manage change in life as a consequence of breast cancer by '*continuing with everyday life'* [20]. At the same time, *normalising* is an important process which helps women minimise the disruption the cancer causes to their children's lives by acting the same as before their cancer diagnosis [20]. The family returning to normal life is a way for them to cope and manage the impact of the breast cancer diagnosis [22].

3.2.4.3. Changing

Changing is a process which is frequently drawn upon by breast cancer patients. For young women reproduction remains a key issue. In some cases, cancer limits reproductive choices for women by rendering them infertile after breast cancer treatment. Other women change their decision-making around reproduction because of fears in relation to their own survival and the potential negative effects of cancer treatments on their future children [29]. Some women worry about the effects of hormonal contraception but at the same time want safe and reliable methods to avoid unwanted pregnancy [21]. Others are concerned that the hormonal changes during pregnancy could stimulate a cancer recurrence [21, 28, 29]. For young women who decide to have children after cancer decision-making around breastfeeding changes because women worry about the ability to detect breast cancer in a lactating breast [21].

Changing is evident in relation to the women's sexual relationships. Depending on the supportiveness and understanding of a woman's partner, changes to sexual functioning are either integrated, and a sexual relationship is resumed after the treatment; or, in cases where the partner is demanding and unsupportive, relationship breakdown and separation or divorce is probable [36].

Most of these aspects of the *changing* process relate to negative changes in the women's lives. In this sense they closely relate to the *normalising* process, signifying a desire to achieve a new sense of normality through changing the status quo. However, some young women experience positive changes. These young women perceive the cancer as a turning point which enables positive changes in their lives, such as engaging more actively in self-care or taking up new activities without feeling guilty about the family [37]. Thus, the experience of cancer facilitates a new sense of self to emerge.

3.2.5. Needs and concerns

Only 2 of the 17 papers explicitly report the needs of young women with breast cancer [26, 30]. Most other papers discuss needs tangentially alongside the experiences of these young women, or refer to them in their recommendations for practice and research.

Young women with breast cancer need support, especially peer support [24, 26, 37] and on-going support for life after treatment [22, 26, 41]. Single women need support, both in terms of dating and talking to new partners about the cancer [26, 34]. There is a need for more education and support for current partners of young women with breast cancer and their family more generally [23, 26, 36, 38]. An important area of need for women with young families is the provision of childcare facilities at hospitals and information on how to communicate the illness to children [20, 22, 24-26, 28]. There is a need for professional counselling [21, 24, 26] and spiritual support [26]. A lack of information is perceived on a range of issues. In particular, information about reproductive issues is needed, ranging from information about potential infertility to information about contraception and pregnancy after cancer [20, 21, 23-27, 29, 30, 41]. Health care professionals need to engage more with reproductive and fertility-related concerns. More information about the potential impact of the cancer on sexuality is needed – in particular, information on treatment side effects and the emotional consequences of having breast cancer [24-26, 34, 36, 38, 41].

There is a need for more information on treatment side effects. In particular, sexuality and fertility are areas of concern along with the more general long term side effects such as osteoporosis [23, 26, 27, 30, 38, 41].

4. DISCUSSION AND CONCLUSIONS

This review is the first synthesis of the qualitative literature on the specific experiences of young women with breast cancer that we are aware of. We have drawn together published evidence of the past twenty years and developed a conceptual model which adds depth and breadth to the existing knowledge base.

Our synthesis provides a systematic overview of the processes (balancing, normalising, and changing), which women use to integrate their new experiences of having cancer into their lives. It discusses how young women apply these to different issues and in different local contexts. Existing papers on young women's experiences have largely only focused on particular aspects of women's experiences, such as sexuality, or menopause, or reproduction. Only 2 of the 17 papers [25, 27] mentioned all five issues (reproduction, body image, fear, sexual activity and feeling 'out of sync') that we identified as important. This focus on particular aspects of the breast cancer experience can be useful, but is less helpful when trying to understand the overall experience of breast cancer diagnosed at a young age. It is useful to tease out this 'overall experience' to provide healthcare professionals with an understanding of the varied aspects of having breast cancer at a young age as well as to enable women newly diagnosed with breast cancer to understand the various ways in which this experience might impinge on them. Our conceptual model is the first to draw together the processes, issues and contexts which define young women's experiences of having breast cancer.

Although our conceptual model was developed on the basis of young women's experiences, it may also be applicable to the experiences of other people living with cancer. Young males who had received treatment for testicular cancer identified a range of comparable issues, such as fertility, physical and emotional challenges and other assaults on their sense of self [42, 43]. Similarly, ovarian cancer may impact on body image and reproductive concerns [44]. Our model may also be relevant to younger people living with other cancers, but this would need further testing.

Limitations

The conceptual model described for young women's experiences of breast cancer has some potential limitations. Mainly, these limitations are related to the original research underlying the model, which became apparent when applying our quality criteria to the papers.

A sizeable number of studies (7/17) focused on this younger age group as a by-product of conducting a larger study. Hence, interview or focus group schedules may not have been targeted to this group specifically, which may have limited the depth and breadth of the topics explored. On the other hand, it could be argued that the fact that the author's felt drawn to issues of young women highlights the uniqueness and significance of their age compared to older women.

Our quality appraisal evaluates the use of theoretical frameworks within the research studies analysed more explicitly than Dixon-Woods *et al.* [17]. Eleven out of 17 of the included studies did not discuss a theoretical framework, or refer to it, in the analysis or discussion of their papers. We believe that the chosen theoretical framework should be made more explicit in qualitative studies, as it is so closely linked to the way in which data are collected and analysed.

Although it is generally acknowledged in qualitative research that social and cultural factors shape our experiences, only 5 out of 17 of the included studies referred to these factors, and the samples of all studies were heavily weighted towards white, middle-class women. The lack of participants from varied cultural backgrounds, and the lack of cultural sensitivity in the analyses, ought to be addressed in future research to more adequately reflect young women with breast cancer in general and the impact of breast cancer on women with different cultural backgrounds.

Lastly, we acknowledge that qualitative data analysis is a creative process and open to interpretation. Thus, it is particularly important to check the coherence of the analysis and test its ecological validity, that is, its meaningfulness. This may be done in conjunction with the participants as experts of their own experience, by providing a clear audit trail of how the researchers arrived at their endpoints, or can take the shape of triangulation with other researchers in the area. Of 17 studies, 10 used some form of verification procedure, though it was not always explicitly described.

However, despite these methodological limitations, our meta-ethnography provides an overview of current evidence on the experiences, needs and concerns of young women with breast cancer.

Clinical services/practice relevance

Since cancer is uncommon in this age group, young women are often worried that cancer services may not address their unique needs and concerns. They are concerned, for instance, that effects such as early onset menopause are not fully acknowledged or understood by professionals, and that the longer-term impact of treatments on younger women are not known [26, 27]. This synthesis describes the experiences, needs and concerns specific to younger women, which health professionals should be aware of and take into account during their interactions with this group. However, a discussion is also necessary about who ought to address these women's needs, and about the boundaries between the responsibilities of clinical services and those of families and friends of patients. Not all needs can be addressed by clinical services, even if they arise out of illness, but clarification with the patients of what can and cannot be addressed might be useful.

Conclusions

To the best of our knowledge this meta-ethnography provides a comprehensive overview of the specific experiences, needs and concerns of young women with breast cancer. The conceptual model developed demonstrates that to understand women's experiences social and local contexts should be taken into account. Aside from experiencing cancer at an unusual age, young women with breast cancer face a number of age-specific issues linked to motherhood and reproduction. Three processes were identified which women use to deal with these issues and integrate cancer-related concerns into their lives. We trust that this model may provide a basis for practitioners to address the concerns of young women with breast cancer more adequately and comprehensively and also provide a platform for further research.

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Table 1: Our quality appraisal

	recruitment specific	**interview open**	**theoretical framework**	**socio-cultural factors**	**verification of analysis**	**SCORE**
Archibald ***et al.***, 2006	Y	N	N	N	Y	2
Billhult & Segesten, 2003	Y	Y	Y	N	N	3
Connell ***et al.***, 2006	N	Y	Y	N	Y	3
Coyne & Borbasi, 2006	Y	Y	Y	N	Y	4
Crompvoets, 2003	N	Y	Y	N	N	2
Dow, 1994	N	Y	N	N	N	1
Dunn & Steginga, 2000	Y	Y	N	N	Y	3
Fitch ***et al.***, 2008	N	Y	N	Y	Y	3
Gluhoski ***et al.***, 1997	N	Y	N	N	N	1
Gould ***et al.***, 2006	Y	Y	N	Y	Y	4
Knobf, 2001	N	Y	N	Y	Y	3
Knobf, 2002	Y	Y	Y	Y	Y	5
Shapiro ***et al.***, 1997	Y	Y	Y	Y	N	4
Siegel ***et al.***, 1997	Y	Y	N	N	N	2
Siegel ***et al.***, 1999	N	Y	N	N	N	1
Takahashi & Kai, 2005	Y	Y	N	N	Y	3
Thewes ***et al.***, 2003	Y	Y	N	N	Y	3

Appendix 1: Summary table

Author	**Country**	**Sample**	**Recruitment**	**Theoretical framework, method and analysis**	**Verification of Data**	**Findings**	**Concepts**
Archibald *et al*., 2006	Canada	N=30,; Mean age[1] = 45 yrs[2]; Range 31-57 yrs; TSD[3]: range 1- 4 yrs	Support groups; adverts, letters through Canadian Cancer Society, New Brunswick	Semi-structured interviews; Thematic analysis	Triangulation Independent coding	Changes in sexual functioning; Emotional impact of sexual changes – worry & uncertainty, frustration & anger, loss, guilt, indifference	Sexual Functioning; Relationships; Sense of Self
Billhult & Segesten, 2003	Sweden	N=10; Mean age = 41.6 yrs; Range 32-48 yrs; TSD = mean 14.1 mths[4]	Information group about lymphodoema post-operatively	Phenomenology; Open-ended Interviews	N/A	Strategies to balance life as mother with having cancer: continuing with daily life & normality; drawing on strength of motherhood to balance conflicting forces	Balancing normal routines; Strength of motherhood
Connell *et al*.,	Australia	Phase 1 n=35 Phase 2 n=13 Mean age = 37 yrs; Range 29-40	Flyers at BC[5] events & venues;	Social constructionism/phenomenology; Longitudinal	Verification with participants; Audit trail;	Perceptions of fertility changed over time; Concerns around use of safe & reliable contraception; Resistance to	Fear of recurrence; Fertility; Confusion

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[1] Where given, this was mean age at diagnosis
[2] Yrs=Years
[3] TSD=Time since diagnosis
[4] Mths=Months
[5] BC= Breast cancer

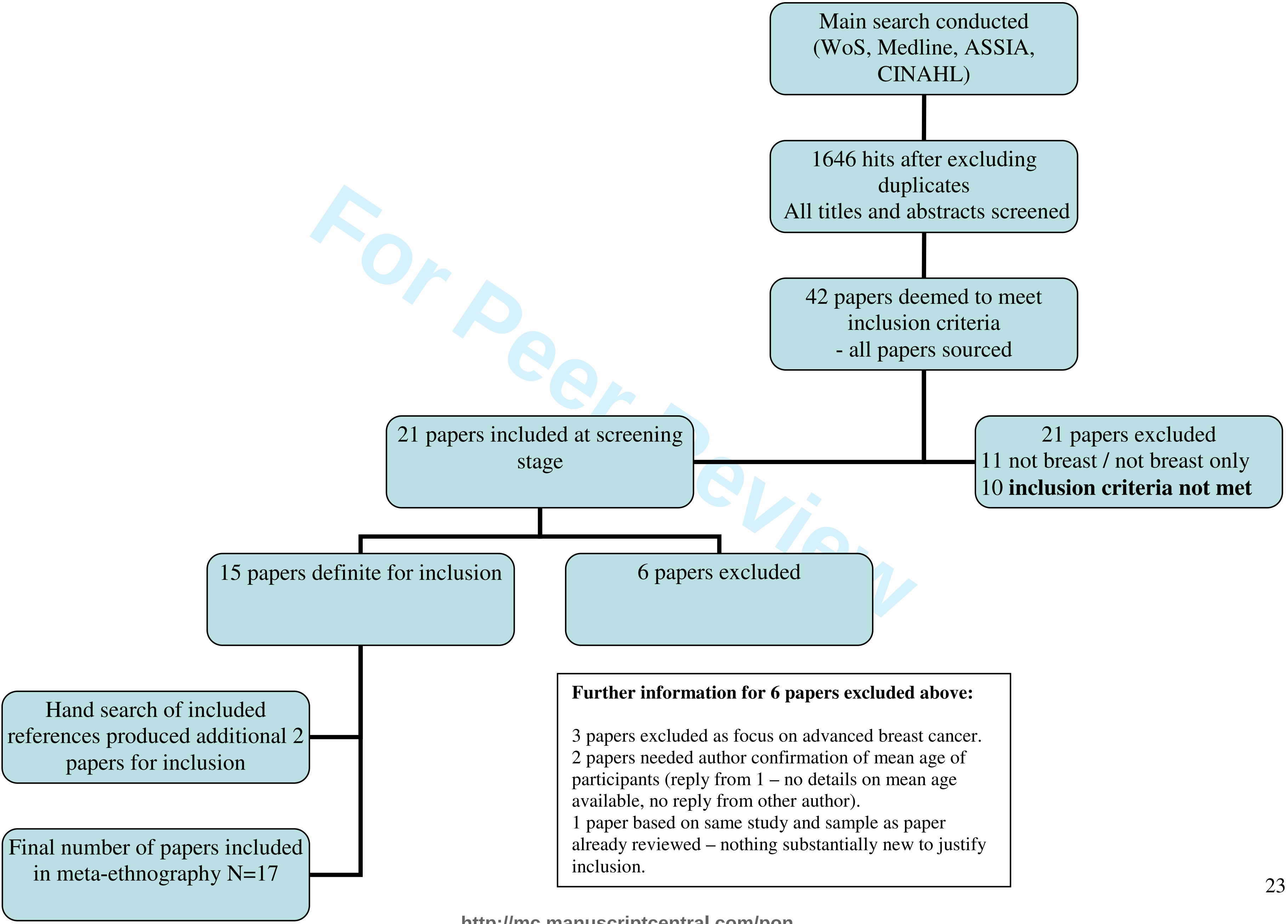
2006		yrs; TSD = median 26 mths (range 5-37 mths)	support groups	Semi-structured interviews	Triangulation	hormonal contraceptives; Breastfeeding decisions changed over time	
Coyne & Borbasi, 2006	Australia	N=6; Median age= 37 yrs; Range 29-43 yrs; TSD: max 12 mths	Unclear	Feminist enquiry; Open-ended interviews; Participatory research process	Verification with participants	Diagnosis – having to be strong; described as most stressful time; Impact on the family: interplay between having BC & being a mother; Life after treatment: family remained on an emotional rollercoaster after treatment	Emotional rollercoaster Balancing act Use of humour 'Having to hold it all together' Uncertainty Optimism about future
Crompvoets, 2003	Australia	N=1; aged 50 yrs; aged 40 yrs at time of first diagnosis, aged 47 yrs at recurrence	Unclear	Feminist enquiry Case study Narrative analysis	N/A	Breasts prior to mastectomies identified as essential part of sense of self; body & self inextricably linked; mastectomised bodies seen as physically & emotionally incomplete; negative feelings about breast loss not anticipated	Normality Complete womanhood Identity Sexuality Being 'complete'
Dow, 1994	USA	N=16; Mean age at diagnosis = 29.6 yrs; Range 25-35 yrs; Mean age at interview = 38.8 yrs (range 32-45 yrs)	Oncology clinic	Semi-structured interviews; Review of radiation treatment records; Thematic & content analysis	N/A	Having children was cherished goal, desire for sense of normalcy, reconnecting with others; Concerns about pregnancy – some related to being young mother but some explicitly related to having BC	Normalcy Fear of recurrence Motherhood Loss Integrating cancer into life
Dunn &	Australi	Phase 1 N=23, Mean age	Newsletter	Multi-angulated method: Literature	Verification with	Worry to not see children grow up; 3 indicators for defining	Defining 'young';

Steginga, 2000	a	37 yrs, Range 31-47 yrs; Phase 2, N=21; Phase 3, N=21		Review, focus groups, semi-structured interviews & 3-round iterative survey	participants	young as relates to BC – the woman is of child bearing age, the woman has young children the woman hasn't yet reached menopause	Infertility Loss of choice about children; different to women your age; too young to get cancer; Unrealistic media portrayal of young women
Fitch *et al.*, 2008	Canada	N=28; Age range 28-42 yrs; Mean TSD since diagnosis = 3.8 yrs	Random selection of cancer registry sub-sample	Open-ended interviews; Telephone interviews; Content & theme analysis	Triangulation	Everything depends on acting now – intense desire to stay alive; Everything is out of sync – feeling different to women of your age; Cancer invaded whole life –different lives as result of breast cancer	Balancing act – 'being a woman' & 'being a mother'; Identity Unfairness of cancer Guilt Putting oneself first Betraying bodies
Gluhoski *et al.*, 1997	USA	N=16; Mean age = 33.5 yrs; Range 22-42 yrs; TSD = mean 37 mths (range 8 mths – 8 yrs)	Cancer organisations; Memorial Sloan-Kettering Cancer Center	Sociodemographic & medical information questionnaire Open-ended interviews Thematic analysis	N/A	Pessimism regarding future relationships; fears about disclosing illness; Negative body image; Impaired sexuality Fears of rejection by partners Sense of isolation & inadequate support	Isolation Rejection Fear Sexuality Changes in appearance Relationships

Gould *et al.*, 2006	Canada	N=65; Mean age 37 yrs; Range 26-45 yrs; Mean age 41 yrs at time of study	Newspaper; Canadian Breast Cancer Network newsletter; Support groups; Community cancer organisations; Cancer centres & clinics	Relativist Paradigm Focus Groups Thematic & content analysis	Verification with participants	Information, support & services did not match women’s age or life stage; Lack of emotional & instrumental support for themselves & families; Diagnostic challenges associated with being ‘atypical case’	‘Nothing fit me’ Lack of support & information Unique, age-specific challenges
Knobf, 2001	USA	N=27; Mean age 40.8 yrs (+/- 3.7); TSD = mean 4.5 yrs (+/- 0.43; range 1-9 yrs).	Oncology clinic	Grounded Theory Semi-structured Interviews; Informal discussions with specialists; Fieldnotes, memos & lay women’s writings; Constant comparative method	Triangulation Audit trail	Variety of changes –none to severe; Variety of symptoms, e.g. hot flashes, insomnia, vaginal dryness, changes in libido; long term effects of menopause - osteoporosis & heart disease	Sexual Functioning Distress Menopausal Symptom Experience Lack of Communication
Knobf, 2002	USA	N=27; Mean age = 40.8 yrs; TSD: mean 4.5 yrs (range 1-9 yrs)	Oncology clinic	Grounded Theory Semi-structured Interviews Informal	Triangulation Audit trail	Vulnerability is the basic social psychological problem for women with treatment-induced premature menopause	Carrying on Vulnerability Uncertainty Loss

				discussions with specialists Fieldnotes, memos & lay women's writings Constant comparative method		Basic process of responding to vulnerability: 'carrying on' (4 stages) Movement through stages not linear - moved back & forth	Isolation Resiliency Carrying On
Shapiro *et al.*, 1997	Canada	N=3 married couples: Ages of women at diagnosis 35, 42, 48 yrs Ages of husbands at diagnosis 37, 44, 45 yrs TSD: mean=4 yrs	Oncology clinic Cancer centre Individuals in community	Grounded Theory Open-ended Interviews Narrative analysis	N/A	Concept of change permeated accounts; continuum of change from no change to complete changes; Three core themes: Back to 'normal'; Rebirth & Turning Point; Main changes in relation to self, treatment effects, menopause, relationships, lifestyle	Change Meaning Identity Self-awareness Individual context
Siegel *et al.*, 1997	USA	N=50; Mean age = 33.4 yrs; Range 22 – 44 yrs); TSD= mean 33 mths (range 8mths – 8 yrs)	Share, American Cancer Society & Cancer Care; Memorial Sloan-Kettering Cancer Centre	Open-ended interviews; Content analysis	N/A	Deterrents and incentives to becoming pregnant	Fear of recurrence Risk Loss Motherhood Child as Life Affirming Normalcy
Siegel *et al.*, 1999	USA	N=34; Mean age = 30.6 yrs; Range 22-35 yrs; TSD= mean 38 mths	Same as Siegel et al. 1997 above	Sociodemographic & medical information questionnaire	N/A	Reactions to untimely diagnosis; Guilt about impact of illness on partner; Lost opportunities for childbearing	Loss Motherhood Untimely diagnosis

		(range 13 mths – 8 yrs)		Open–ended interviews Thematic Analysis		Feeling different & isolated; Uncertainty about the future; Concerns about children	Fear Uncertainty about the future Relationships
Takahashi & Kai, 2005	Japan	N=21; Mean age = 42.2 yrs; Range 28-54 yrs Median length between surgery & first interview = 17 mths (range 4-123 mths) Second interview with n=11 Third interview with n=1	Breast surgery clinics	Grounded Theory Semi-structured interviews	Verification with participants Triangulation	Hesitation in resuming sex after surgery; Changes after resuming sex; Coping attitudes to the change Long-term sexual relationship	Sexual Functioning Change Relationships Fear of rejection
Thewes *et al.*, 2003	Australia	N=24; Median age = 34 yrs; Range 26-45 yrs; TSD= N=6 max 12 mths prior; N=11 diagnosed > 2 years prior	Oncology clinic	'Transcendental realism' Focus Groups Semi-structured telephone interviews Quantitative assessment of preferred communication strategies Thematic analysis	Yes – not specified, informed by Miles & Huberman approaches	fertility & menopause related information: satisfaction, Preferred timing & mode, Preferred media; Psychosocial impact of unmet fertility & menopause related information needs	Fertility Change Loss Information Needs Menopause Support



Further information for 6 papers excluded above:

3 papers excluded as focus on advanced breast cancer.
2 papers needed author confirmation of mean age of participants (reply from 1 – no details on mean age available, no reply from other author).
1 paper based on same study and sample as paper already reviewed – nothing substantially new to justify inclusion.

A1.

The experiences, needs and concerns of younger women with breast cancer: A meta-ethnography

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Abstract

Objective

This meta-ethnography synthesises the evidence on the experiences, needs and concerns of younger women with breast cancer.

Methods

Using a method called ‘reciprocal translation’ we developed a conceptual model to reflect the local and social contexts, issues, processes, needs and concerns of importance in this literature.

Findings

Key findings relate to the particular point in the life-course at which young women with breast cancer stand. Issues for these women relate to feeling different as a result of cancer, fear of recurrence, feeling ‘out of sync’ and altered embodied subjectivity. Young women with breast cancer use three processes to integrate the changes that cancer brings, namely balancing, normalising and changing. Our conceptual model also highlights young women’s needs, primarily for support, information, childcare, counselling, and spiritual support. Areas of reproduction, fertility and sexuality were also of particular concern. The included papers have methodological limitations which impact on our findings, such as opportunistic data analyses, lack of theoretical frameworks and limited reference to socio-cultural factors.

Conclusion

The conceptual model developed as a result of this meta-ethnography provides a basis for practitioners to address these young women’s concerns more adequately and comprehensively.

Keywords: cancer, oncology, breast, young adults, meta-ethnography

1. BACKGROUND

1.1. Age and cancer

More than one million women worldwide are diagnosed with cancer each year. Breast cancer accounts for 10 per cent of all new cancer cases in the world [1]. According to the latest available figures, 45,508 women were diagnosed with breast cancer in the UK in 2006 [1].

From a clinical perspective, age is a significant variable for understanding epidemiology. The prevalence of cancer in all age groups is rising [2]. In the UK around 1 in 10 of cancers occurs in adults under the age of 50 [1]. A quarter of all cancers in adults under the age of 45 are breast cancers, the most common malignancy in this age group [1].

Experiences of living with cancer vary by age [3] but despite the prevalence of breast cancer in younger women, the specific key issues and concerns of this group are under-researched. Relatively little is known about *how* experiences, needs and concerns of breast cancer patients differ by age. Such knowledge is important to enable tailoring of interventions and to ensure the supportive care needs of different groups are met. Synthesis of existing evidence has been partly hampered by lack of standardised age definitions [4].

From psychological and sociological perspectives, age has traditionally been used to define human stages of development [5,6]. Key developments associated with young adulthood include starting a career, entering long-term relationships, parenthood and stabilization of one's identity [7]. Thus, the experience of cancer for young adults is related to the key issues they encounter socially and psychologically.

This meta-ethnography **synthesizes qualitative research on experiences of younger women living with a diagnosis of breast cancer. This focus was chosen because breast cancer is the most common cancer at this age.** Focusing on qualitative literature in its own right is particularly important because it draws attention to subjugated, experiential knowledge.

1.2. Women's experiences of breast cancer

It has been argued from a life-stage perspective that younger women have more of their life ahead of them and might therefore feel the impact of cancer more keenly [8,9]. Younger, premenopausal women seem to experience more distress, higher levels of depression, cope less well and report poorer quality of life than older women. [8-10].

Qualitative research into the experiences, needs and concerns of younger women has added detail and depth to our knowledge of the meaning of breast cancer. It has suggested that the experience of breast cancer is dependent on personal and social context [11], and that wider social and historical forces shape the perception of breast cancer and of women more generally [12].

No synthesis currently exists on the wider experiences of this patient group, or indeed, of the qualitative literature alone. In undertaking this meta-ethnography we aimed to synthesize the existing qualitative literature on younger women with breast cancer. Identifying specific experiences, needs and concerns of younger women with breast cancer can inform service development and future research.

2. METHODS

2.1. Type of literature review

We conducted a literature synthesis guided by the principles of meta-ethnography [13]. A meta-ethnography is “the synthesis of interpretive research” (p.10) [13] and aims to preserve the unique character of qualitative studies through the selection of key metaphors (themes) from the original texts; but also to provide a new interpretation of these studies, rather than a simple aggregation. To achieve these aims, it uses a rigorous set of procedures. We adopted a ‘reciprocal translation’ involving seven phases (see Box 1) [13].

Box 1: Phases of the meta-ethnography

Phase 1: **Identifying** experiences, needs and concerns of younger women with breast cancer as an intellectual interest.

Phase 2: Conducting a systematic search for relevant qualitative studies.

Phase 3: Reading the articles, paying particular attention to metaphors (i.e. themes, perspectives, concepts) used by the authors to describe and/or explain women’s experiences, needs and concerns.

Phase 4: Developing a tabular format to compare studies. Listing key metaphors in each study.

Phase 5: Translating studies into one another. Examining relations between metaphors within a study and between studies.

Phase 6: Synthesizing these translations by determining if some metaphors could encompass other metaphors, thus translating them into each other. The synthesis took the form of a ‘reciprocal translation.’ That is, similar studies made it possible for each study to be translated into the metaphors of others and vice versa.

Phase 7: Publishing the meta-ethnography.

2.2. Systematic search for literature

For phase one, the development of our intellectual interest and research focus, and phase two, the literature search, we carried out a keyword search in four electronic databases: Medline, Web of Science, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Applied Social Sciences Index and Abstracts (ASSIA). We used the following Medical Subject Headings (MeSH) search terms in accordance with definitions used by the National Library of Medicine [14]:

Adult AND (Neoplasms OR Breast Neoplasms) AND Qualitative Research

The search was conducted in January 2009. We identified papers from references/bibliographies listed in manuscripts that were retrieved from the electronic search (this produced an additional two papers which were included in the review). Search results were managed in Reference Manager v11 [15] and a search log kept, detailing number of studies retrieved, de-duplicated, and included at each stage (see Flowchart 1).

2.3. Inclusion criteria

The inclusion criteria were: i) *Population*: women with breast cancer under the age of 45 at diagnosis; ii) *Topic:* experiences, needs and concerns; iii) *Design:* qualitative; iv) *Language and date of publication:* English language studies published in the last 20 years.

Two reviewers (GH, LM) independently screened titles and abstracts. Full papers were obtained for all studies that appeared to meet the inclusion criteria. Three reviewers (EA, GH, LM) collectively read these papers and through discussion reached agreement on inclusion for each paper.

2.4. Quality appraisal

Though there is no consensus whether structured appraisal methods yield higher reviewer agreement than unprompted judgement [16] quality appraisal allows multiple readers to review papers in a structured way. We therefore appraised studies using Dixon-Woods *et al.*'s [17] five-point approach to assessing methodological quality in qualitative studies (see Box 2).

Box 2: Quality appraisal criteria for empirical papers [17].

1. Are the aims and objectives of the research clearly stated?
2. Is the research design clearly specified and appropriate for the aims and objectives of the research?
3. Do the researchers provide a clear account of the process by which their findings were produced?
4. Do the researchers display enough data to support their interpretation and conclusions?
5. Is the method of analysis appropriate and adequately explicated?

Documents were rated 5 if all questions were answered in the affirmative, 4 if the method or analysis or sample were not clearly outlined or 3 if both the method or analysis and sample were poorly described.

Each included paper received a high quality score therefore no paper was rejected as a result of this appraisal. However, reading through the papers during the first phases of our review, we detected additional differences in the quality of the papers. We therefore developed an additional quality appraisal strategy (see Box 3).

Box 3: Additional quality appraisal criteria

1. Was the recruitment (and resulting sample) specific to the study reported?
2. Does the interview enable the interviewee to raise experiences, issues and concerns or were they raised, and thus introduced, by the researcher?
3. Did the authors make it explicit how they interpreted the data and what theoretical framework they used?
4. Did the authors acknowledge social and cultural factors (e.g. social class, ethnicity) in their analysis?
5. Are strategies employed to verify the coherence of the interpretation and analysis of data (for instance, were strategies such as triangulation used, or was the analysis discussed with user representatives to verify ecological validity)?

Documents were rated 5 if all questions were answered in the affirmative, 4 if only 4 questions were answered in the affirmative, and so on, with 0 indicating the weakest quality of paper based on these additional appraisal issues.

This quality appraisal was applied to all studies and results are shown in Table 1.

Insert TABLE 1 here

2.5. Data extraction

In phases three and four, two reviewers (EA, LM) individually extracted data from the papers into a template holding key information about each paper. The tables containing the extracted data were discussed by three reviewers (EA, LM, GH) to ensure congruence of extraction and to begin the process of identifying patterns and common themes across papers.

2.6. Synthesis

In relation to phase five of the synthesis, the translation of studies into one another, one of the reviewers (GH) identified common concepts in the papers which could be used as a descriptor of younger women's experiences of breast cancer and/or as an explanatory device to account for their experiences. Concepts had to be evident in at least a quarter of papers. These concepts were then discussed by the two reviewers (EA, LM) who had extracted data, and further extended to include other concepts that seemed relevant as a result of the extractions. All concepts were then discussed collectively by the whole research team for validation and to develop understanding of these concepts further.

3. RESULTS

3.1. Description of studies

In total, 17 studies are included in this review. For a summary table see Appendix 1.

3.2. Synthesis: Conceptualising experiences, needs and concerns

Experience is defined here as an interactive and ongoing process of a person's subjective engagement with societal relations (for instance, material, economic or interpersonal practices and discourses), and therefore is thoroughly social [18].

Guided by our extractions, we categorise concepts into those that provide a context for the experiences, those that are issues for younger women with breast cancer, and those that indicate processes found across these issues within these specific contexts (see Box 4). Particular needs and concerns arise from these contexts, issues and processes.

Box 4: Concepts arising from the meta-ethnography

Social contexts
- Life-course
- Cultural context
- Motherhood

Local context
- Family/relationship status
- Social support
- Doctor-patient relationship

Issues
- Reproduction
- Body
- Fear
- Sexual activity
- Feeling 'out of sync'

Processes

- Balancing
- Normalising
- Changing

Needs and concerns

- Support
- Information
- Childcare
- Counselling
- Spiritual support
- Fertility and sexuality

These concepts are inter-related. The three processes – balancing, normalising and changing characterise the issues which themselves are embedded within specific contexts. Contexts, issues and processes will now be described in turn.

3.2.1. Social context

Young women stand at a particular point in the life-course; they have a biological age (primarily defined as being of child-bearing age) and a social age. In countries with relatively high GDP there is a social expectation that young women will raise a family and be in paid employment. Expectations of a woman's role however, may vary within different cultures within a country [7, 19]. Motherhood is a key social context for the experience of breast cancer for young women [20-30]. However, it has long been highlighted as a dominant ideology which shapes the subjectivities of all women [31, 32]. This wider social context, which includes an ideology of motherhood, gets negotiated at the individual level, within a 'local' context.

3.2.2. Local context

The 'local context' consists of an individual woman's circumstances, for instance her relationship status and social support network. Young women are more likely to be in new relationships or no relationships than older women [33] and may therefore be more isolated when diagnosed with breast cancer [34]. The quality of the relationshi**p, in terms of support it can provide,** is also a crucial factor. While a recent review [35] has cautioned against assuming that cancer generates relationship distress or dissolution, it did not discuss distress in relation to age. Some studies included in our review show that for young women, cancer may well introduce an element of relationship distress [28, 34, 36]. Similarly, young women's social support networks may be less well established and more fluid than those of older women [22, 37]. A further important aspect of a woman's breast cancer experience is her relationship with her medical team. As part of this relationship, accessibility, information provision, and involvement of the patient in decision making are all important factors [30, 36, 38].

3.2.3. Issues

The changing experiences of young women which are attributable to cancer cluster around key issues. One issue which permeates all others is a feeling of being different and 'out of sync'. A diagnosis of breast cancer under the age of 45 disrupts a normal life-course. This is because a life-threatening illness is socially perceived as normally only occurring among older people. This feeling of being 'out of sync' is in comparison to other young women without cancer and older breast cancer patients [24, 29]. Feeling 'out of sync' connects to issues around reproduction (including pregnancy, fertility, contraception and menopause) [20-30]; altered body image (primarily relating to mastectomised bodies and breast reconstruction, but also to more general feelings of being in an altered body, and therefore, changes in embodied subjectivity) [20, 25-27, 34, 36-39]; decreased levels of and changes to sexual activities [25-27, 34, 36, 38]; and fear (of cancer recurrence, of their own mortality and its potential impact on their families) [20, 21, 23-25, 27-29].

3.2.4. Processes

These issues that connect with being 'out of sync' are experienced by young women in particular ways within their local contexts. Different ways of experiencing and responding to these issues are categorised into three different processes, namely *balancing*, *normalising*, and *changing*. These processes are drawn on by young women in various combinations.

3.2.4.1. Balancing

A key process characterising young women's experience of breast cancer is *balancing*. Young women with children are likely to be diagnosed with cancer when their children are still living at home. The emotional impact of cancer is well-known, with cancer being described as an 'emotional rollercoaster' [22]. Maintaining daily life and family routine is balanced against the intrusiveness of cancer-related demands [28]. As a mother and partner a young woman balances priorities of putting her own needs first in order to survive cancer with meeting the needs of her family. She also balances the physical and emotional demands of her children with the demands on her self; balances being honest about pain and fears with protecting her children from the severe impact of cancer on self; and finds a balance between being needed and wanted by her children with recognising that if she dies her children will be looked after by others. Finally, she balances meeting financial needs of the household, by continuing in paid employment, with under-going treatment which is time-consuming and debilitating [20, 22, 25, 26].

Balancing, however, is not only a process pertinent to women with children. Young women, irrespective of motherhood status, balance focussing on the immediate priority to have treatment in order to survive with learning to live with symptoms such as early onset menopause [20, 22, 25-27]. They weigh up the risks and benefits of particular treatments on survival as well as limiting damage for their longer-term health. In addition, young women feel they need to balance their desire for a child after cancer with concerns over their own health and their families' and partner's wishes [23, 29].

Balancing different needs and demands is also driven by, and linked to, the process of *normalising*.

3.2.4.2. Normalising

Young women engage in n*ormalising* processes in relation to different issues of their breast cancer experience.

Young women see their mastectomised body as a deviation from a normative female body. While some women choose breast reconstruction as a way of re-gaining a representation of female normality others opt to establish a new sense of normal by normalising bodily imperfection [39]. Young women perceive that they are not achieving developmentally normative milestones, such as having children, and perceive that having a baby will restore a sense of normalcy in their lives in terms of their femininity and sexuality [23, 29]. The ability to have a child proves a marker of their ability to function as a 'normal' woman, especially for those who have a mastectomy [23, 29].

Young women manage change in life as a consequence of breast cancer by '*continuing with everyday life'* [20]. At the same time, *normalising* is an important process which helps women minimise the disruption the cancer causes to their children's lives by acting the same as before their cancer diagnosis [20]. The family returning to normal life is a way for them to cope and manage the impact of the breast cancer diagnosis [22].

3.2.4.3. Changing

Changing is a process which is frequently drawn upon by breast cancer patients. For young women reproduction remains a key issue. In some cases, cancer limits reproductive choices for women by rendering them infertile after breast cancer treatment. Other women change their decision-making around reproduction because of fears in relation to their own survival and the potential negative effects of cancer treatments on their future children [29]. Some women worry about the effects of hormonal contraception but at the same time want safe and reliable methods to avoid unwanted pregnancy [21]. Others are concerned that the hormonal changes during pregnancy could stimulate a cancer recurrence [21, 28, 29]. For young women who decide to have children after cancer decision-making around breastfeeding changes because women worry about the ability to detect breast cancer in a lactating breast [21].

Changing is evident in relation to the women's sexual relationships. Depending on the supportiveness and understanding of a woman's partner, changes to sexual functioning are either integrated, and a sexual relationship is resumed after the treatment; or, in cases where the partner is demanding and unsupportive, relationship breakdown and separation or divorce is probable [36].

Most of these aspects of the *changing* process relate to negative changes in the women's lives. In this sense they closely relate to the *normalising* process, signifying a desire to achieve a new sense of normality through changing the status quo. However, some young women experience positive changes. These young women perceive the cancer as a turning point which enables positive changes in their lives, such as engaging more actively in self-care or taking up new activities without feeling guilty about the family [37]. Thus, the experience of cancer facilitates a new sense of self to emerge.

3.2.5. Needs and concerns

Only 2 of the 17 papers explicitly report the needs of young women with breast cancer [26, 30]. Most other papers discuss needs tangentially alongside the experiences of these young women, or refer to them in their recommendations for practice and research.

Young women with breast cancer need support, especially peer support [24, 26, 37] and on-going support for life after treatment [22, 26, 41]. Single women need support, both in terms of dating and talking to new partners about the cancer [26, 34]. There is a need for more education and support for current partners of young women with breast cancer and their family more generally [23, 26, 36, 38]. An important area of need for women with young families is the provision of childcare facilities at hospitals and information on how to communicate the illness to children [20, 22, 24-26, 28]. There is a need for professional counselling [21, 24, 26] and spiritual support [26]. A lack of information is perceived on a range of issues. In particular, information about reproductive issues is needed, ranging from information about potential infertility to information about contraception and pregnancy after cancer [20, 21, 23-27, 29, 30, 41]. Health care professionals need to engage more with reproductive and fertility-related concerns. More information about the potential impact of the cancer on sexuality is needed – in particular, information on treatment side effects and the emotional consequences of having breast cancer [24-26, 34, 36, 38, 41].

There is a need for more information on treatment side effects. In particular, sexuality and fertility are areas of concern along with the more general long term side effects such as osteoporosis [23, 26, 27, 30, 38, 41].

4. DISCUSSION AND CONCLUSIONS

This review is the first synthesis of the qualitative literature on the specific experiences of young women with breast cancer that we are aware of. We have drawn together published evidence of the past twenty years and developed a conceptual model which adds depth and breadth to the existing knowledge base.

Our synthesis provides a systematic overview of the processes (balancing, normalising, and changing), which women use to integrate their new experiences of having cancer into their lives. It discusses how young women apply these to different issues and in different local contexts. Existing papers on young women's experiences have largely only focused on particular aspects of women's experiences, such as sexuality, or menopause, or reproduction. Only 2 of the 17 papers [25, 27] mentioned all five issues (reproduction, body image, fear, sexual activity and feeling 'out of sync') that we identified as important. This focus on particular aspects of the breast cancer experience can be useful, but is less helpful when trying to understand the overall experience of breast cancer diagnosed at a young age. It is useful to tease out this 'overall experience' to provide healthcare professionals with an understanding of the varied aspects of having breast cancer at a young age as well as to enable women newly diagnosed with breast cancer to understand the various ways in which this experience might impinge on them. Our conceptual model is the first to draw together the processes, issues and contexts which define young women's experiences of having breast cancer.

Although our conceptual model was developed on the basis of young women's experiences, it may also be applicable to the experiences of other people living with cancer. Young males who had received treatment for testicular cancer identified a range of comparable issues, such as fertility, physical and emotional challenges and other assaults on their sense of self [42, 43]. Similarly, ovarian cancer may impact on body image and reproductive concerns [44]. Our model may also be relevant to younger people living with other cancers, but this would need further testing.

Limitations

The conceptual model described for young women's experiences of breast cancer has some potential limitations. Mainly, these limitations are related to the original research underlying the model, which became apparent when applying our quality criteria to the papers.

A sizeable number of studies (7/17) focused on this younger age group as a by-product of conducting a larger study. Hence, interview or focus group schedules may not have been targeted to this group specifically, which may have limited the depth and breadth of the topics explored. On the other hand, it could be argued that the fact that the author's felt drawn to issues of young women highlights the uniqueness and significance of their age compared to older women.

Our quality appraisal evaluates the use of theoretical frameworks within the research studies analysed more explicitly than Dixon-Woods *et al.* [17]. Eleven out of 17 of the included studies did not discuss a theoretical framework, or refer to it, in the analysis or discussion of their papers. We believe that the chosen theoretical framework should be made more explicit in qualitative studies, as it is so closely linked to the way in which data are collected and analysed.

Although it is generally acknowledged in qualitative research that social and cultural factors shape our experiences, only 5 out of 17 of the included studies referred to these factors, and the samples of all studies were heavily weighted towards white, middle-class women. The lack of participants from varied cultural backgrounds, and the lack of cultural sensitivity in the analyses, ought to be addressed in future research to more adequately reflect young women with breast cancer in general and the impact of breast cancer on women with different cultural backgrounds.

Lastly, we acknowledge that qualitative data analysis is a creative process and open to interpretation. Thus, it is particularly important to check the coherence of the analysis and test its ecological validity, that is, its meaningfulness. This may be done in conjunction with the participants as experts of their own experience, by providing a clear audit trail of how the researchers arrived at their endpoints, or can take the shape of triangulation with other researchers in the area. Of 17 studies, 10 used some form of verification procedure, though it was not always explicitly described.

However, despite these methodological limitations, our meta-ethnography provides an overview of current evidence on the experiences, needs and concerns of young women with breast cancer.

Clinical services/practice relevance

Since cancer is uncommon in this age group, young women are often worried that cancer services may not address their unique needs and concerns. They are concerned, for instance, that effects such as early onset menopause are not fully acknowledged or understood by professionals, and that the longer-term impact of treatments on younger women are not known [26, 27]. This synthesis describes the experiences, needs and concerns specific to younger women, which health professionals should be aware of and take into account during their interactions with this group. However, a discussion is also necessary about who ought to address these women’s needs, and about the boundaries between the responsibilities of clinical services and those of families and friends of patients. Not all needs can be addressed by clinical services, even if they arise out of illness, but clarification with the patients of what can and cannot be addressed might be useful.

Conclusions

To the best of our knowledge this meta-ethnography provides a comprehensive overview of the specific experiences, needs and concerns of young women with breast cancer. The conceptual model developed demonstrates that to understand women’s experiences social and local contexts should be taken into account. Aside from experiencing cancer at an unusual age, young women with breast cancer face a number of age-specific issues linked to motherhood and reproduction. Three processes were identified which women use to deal with these issues and integrate cancer-related concerns into their lives. We trust that this model may provide a basis for practitioners to address the concerns of young women with breast cancer more adequately and comprehensively and also provide a platform for further research.

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1 **Table 1: Our quality appraisal**

	recruitment specific	**interview open**	**theoretical framework**	**socio-cultural factors**	**verification of analysis**	**SCORE**
Archibald ***et al.***, 2006	Y	N	N	N	Y	2
Billhult & Segesten, 2003	Y	Y	Y	N	N	3
Connell ***et al.***, 2006	N	Y	Y	N	Y	3
Coyne & Borbasi, 2006	Y	Y	Y	N	Y	4
Crompvoets, 2003	N	Y	Y	N	N	2
Dow, 1994	N	Y	N	N	N	1
Dunn & Steginga, 2000	Y	Y	N	N	Y	3
Fitch ***et al.***, 2008	N	Y	N	Y	Y	3
Gluhoski ***et al.***, 1997	N	Y	N	N	N	1
Gould ***et al.***, 2006	Y	Y	N	Y	Y	4
Knobf, 2001	N	Y	N	Y	Y	3
Knobf, 2002	Y	Y	Y	Y	Y	5
Shapiro ***et al.***, 1997	Y	Y	Y	Y	N	4
Siegel ***et al.***, 1997	Y	Y	N	N	N	2
Siegel ***et al.***, 1999	N	Y	N	N	N	1
Takahashi & Kai, 2005	Y	Y	N	N	Y	3
Thewes ***et al.***, 2003	Y	Y	N	N	Y	3

Appendix 1: Summary table

Author	Country	Sample	Recruitment	Theoretical framework, method and analysis	Verification of Data	Findings	Concepts
Archibald *et al.*, 2006	Canada	N=30,; Mean age[1] = 45 yrs[2]; Range 31-57 yrs; TSD[3]: range 1- 4 yrs	Support groups; adverts, letters through Canadian Cancer Society, New Brunswick	Semi-structured interviews; Thematic analysis	Triangulation Independent coding	Changes in sexual functioning; Emotional impact of sexual changes – worry & uncertainty, frustration & anger, loss, guilt, indifference	Sexual Functioning; Relationships; Sense of Self
Billhult & Segesten, 2003	Sweden	N=10; Mean age = 41.6 yrs; Range 32-48 yrs; TSD = mean 14.1 mths[4]	Information group about lymphodoema post-operatively	Phenomenology; Open-ended Interviews	N/A	Strategies to balance life as mother with having cancer: continuing with daily life & normality; drawing on strength of motherhood to balance conflicting forces	Balancing normal routines; Strength of motherhood
Connell *et al.*,	Australia	Phase 1 n=35 Phase 2 n=13 Mean age = 37 yrs; Range 29-40	Flyers at BC[5] events & venues;	Social constructionism/phenomenology; Longitudinal	Verification with participants; Audit trail;	Perceptions of fertility changed over time; Concerns around use of safe & reliable contraception; Resistance to	Fear of recurrence; Fertility; Confusion

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[1] Where given, this was mean age at diagnosis
[2] Yrs=Years
[3] TSD=Time since diagnosis
[4] Mths=Months
[5] BC= Breast cancer

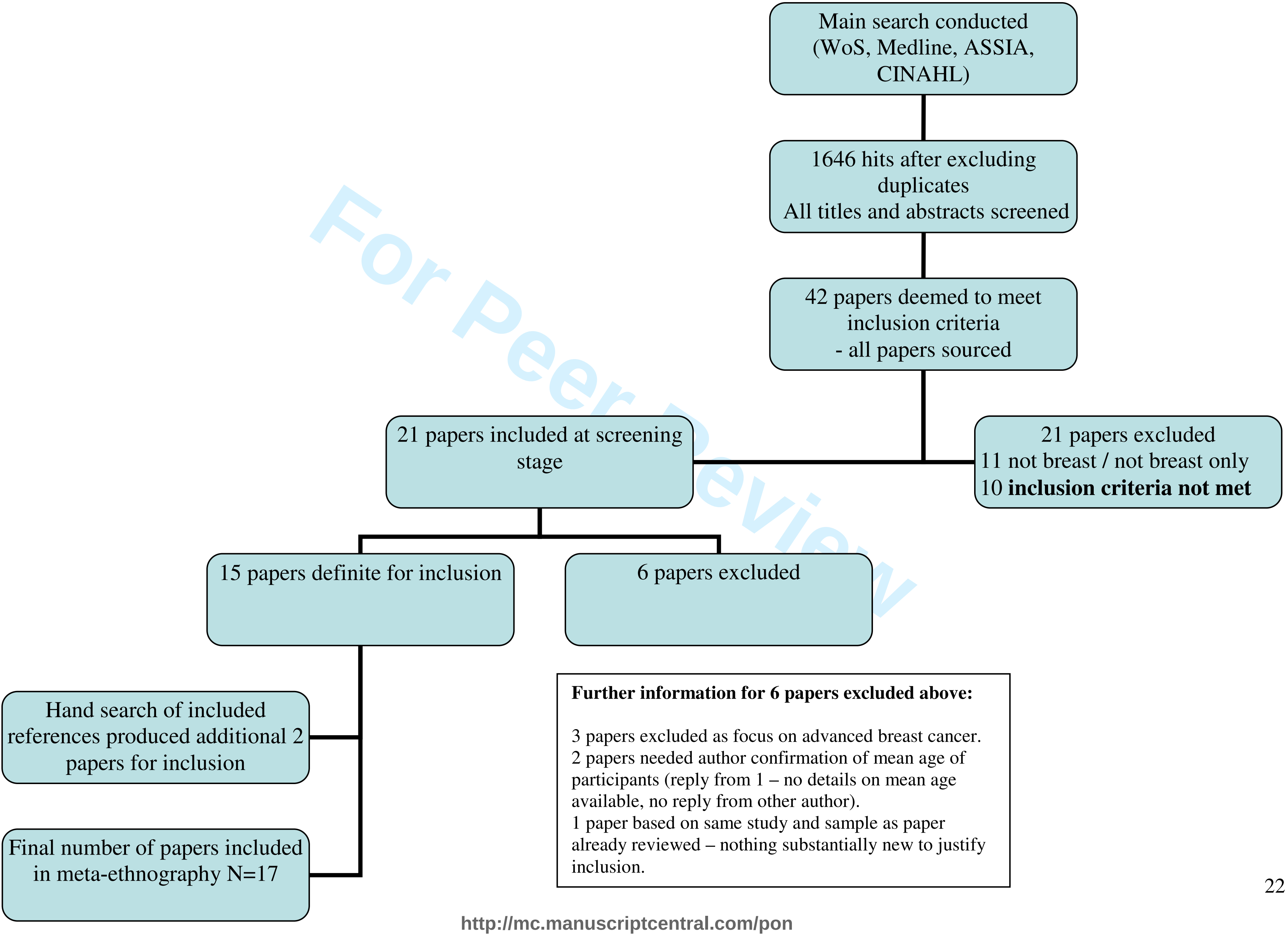
2006		yrs; TSD = median 26 mths (range 5-37 mths)	support groups	Semi-structured interviews	Triangulation	hormonal contraceptives; Breastfeeding decisions changed over time	
Coyne & Borbasi, 2006	Australia	N=6; Median age= 37 yrs; Range 29-43 yrs; TSD: max 12 mths	Unclear	Feminist enquiry; Open-ended interviews; Participatory research process	Verification with participants	Diagnosis – having to be strong; described as most stressful time; Impact on the family: interplay between having BC & being a mother; Life after treatment: family remained on an emotional rollercoaster after treatment	Emotional rollercoaster Balancing act Use of humour 'Having to hold it all together' Uncertainty Optimism about future
Crompvoets, 2003	Australia	N=1; aged 50 yrs; aged 40 yrs at time of first diagnosis, aged 47 yrs at recurrence	Unclear	Feminist enquiry Case study Narrative analysis	N/A	Breasts prior to mastectomies identified as essential part of sense of self; body & self inextricably linked; mastectomised bodies seen as physically & emotionally incomplete; negative feelings about breast loss not anticipated	Normality Complete womanhood Identity Sexuality Being 'complete'
Dow, 1994	USA	N=16; Mean age at diagnosis = 29.6 yrs; Range 25-35 yrs; Mean age at interview = 38.8 yrs (range 32-45 yrs)	Oncology clinic	Semi-structured interviews; Review of radiation treatment records; Thematic & content analysis	N/A	Having children was cherished goal, desire for sense of normalcy, reconnecting with others; Concerns about pregnancy – some related to being young mother but some explicitly related to having BC	Normalcy Fear of recurrence Motherhood Loss Integrating cancer into life
Dunn &	Australia	Phase 1 N=23, Mean age	Newsletter	Multi-angulated method: Literature	Verification with	Worry to not see children grow up; 3 indicators for defining	Defining 'young';

Steginga, 2000	a	37 yrs, Range 31-47 yrs; Phase 2, N=21; Phase 3, N=21		Review, focus groups, semi-structured interviews & 3-round iterative survey	participants	young as relates to BC – the woman is of child bearing age, the woman has young children the woman hasn't yet reached menopause	Infertility Loss of choice about children; different to women your age; too young to get cancer; Unrealistic media portrayal of young women
Fitch *et al.*, 2008	Canada	N=28; Age range 28-42 yrs; Mean TSD since diagnosis = 3.8 yrs	Random selection of cancer registry sub-sample	Open-ended interviews; Telephone interviews; Content & theme analysis	Triangulation	Everything depends on acting now – intense desire to stay alive; Everything is out of sync – feeling different to women of your age; Cancer invaded whole life –different lives as result of breast cancer	Balancing act – 'being a woman' & 'being a mother'; Identity Unfairness of cancer Guilt Putting oneself first Betraying bodies
Gluhoski *et al.*, 1997	USA	N=16; Mean age = 33.5 yrs; Range 22-42 yrs; TSD = mean 37 mths (range 8 mths – 8 yrs)	Cancer organisations; Memorial Sloan-Kettering Cancer Center	Sociodemographic & medical information questionnaire Open-ended interviews Thematic analysis	N/A	Pessimism regarding future relationships; fears about disclosing illness; Negative body image; Impaired sexuality Fears of rejection by partners Sense of isolation & inadequate support	Isolation Rejection Fear Sexuality Changes in appearance Relationships

Gould *et al*., 2006	Canada	N=65; Mean age 37 yrs; Range 26-45 yrs; Mean age 41 yrs at time of study	Newspaper; Canadian Breast Cancer Network newsletter; Support groups; Community cancer organisations; Cancer centres & clinics	Relativist Paradigm Focus Groups Thematic & content analysis	Verification with participants	Information, support & services did not match women's age or life stage; Lack of emotional & instrumental support for themselves & families; Diagnostic challenges associated with being 'atypical case'	'Nothing fit me' Lack of support & information Unique, age-specific challenges
Knobf, 2001	USA	N=27; Mean age 40.8 yrs (+/- 3.7); TSD = mean 4.5 yrs (+/- 0.43; range 1-9 yrs).	Oncology clinic	Grounded Theory Semi-structured Interviews; Informal discussions with specialists; Fieldnotes, memos & lay women's writings; Constant comparative method	Triangulation Audit trail	Variety of changes –none to severe; Variety of symptoms, e.g. hot flashes, insomnia, vaginal dryness, changes in libido; long term effects of menopause - osteoporosis & heart disease	Sexual Functioning Distress Menopausal Symptom Experience Lack of Communication
Knobf, 2002	USA	N=27; Mean age = 40.8 yrs; TSD: mean 4.5 yrs (range 1-9 yrs)	Oncology clinic	Grounded Theory Semi-structured Interviews Informal	Triangulation Audit trail	Vulnerability is the basic social psychological problem for women with treatment-induced premature menopause	Carrying on Vulnerability Uncertainty Loss

				discussions with specialists Fieldnotes, memos & lay women's writings Constant comparative method		Basic process of responding to vulnerability: 'carrying on' (4 stages) Movement through stages not linear - moved back & forth	Isolation Resiliency Carrying On
Shapiro *et al.*, 1997	Canada	N=3 married couples: Ages of women at diagnosis 35, 42, 48 yrs Ages of husbands at diagnosis 37, 44, 45 yrs TSD: mean=4 yrs	Oncology clinic Cancer centre Individuals in community	Grounded Theory Open-ended Interviews Narrative analysis	N/A	Concept of change permeated accounts; continuum of change from no change to complete changes; Three core themes: Back to 'normal'; Rebirth & Turning Point; Main changes in relation to self, treatment effects, menopause, relationships, lifestyle	Change Meaning Identity Self-awareness Individual context
Siegel *et al.*, 1997	USA	N=50; Mean age = 33.4 yrs; Range 22 – 44 yrs); TSD= mean 33 mths (range 8mths – 8 yrs)	Share, American Cancer Society & Cancer Care; Memorial Sloan-Kettering Cancer Centre	Open-ended interviews; Content analysis	N/A	Deterrents and incentives to becoming pregnant	Fear of recurrence Risk Loss Motherhood Child as Life Affirming Normalcy
Siegel *et al.*, 1999	USA	N=34; Mean age = 30.6 yrs; Range 22-35 yrs; TSD= mean 38 mths	Same as Siegel et al. 1997 above	Sociodemographic & medical information questionnaire	N/A	Reactions to untimely diagnosis; Guilt about impact of illness on partner; Lost opportunities for childbearing	Loss Motherhood Untimely diagnosis

		(range 13 mths – 8 yrs)		Open–ended interviews Thematic Analysis		Feeling different & isolated; Uncertainty about the future; Concerns about children	Fear Uncertainty about the future Relationships
Takahashi & Kai, 2005	Japan	N=21; Mean age = 42.2 yrs; Range 28-54 yrs Median length between surgery & first interview = 17 mths (range 4-123 mths) Second interview with n=11 Third interview with n=1	Breast surgery clinics	Grounded Theory Semi-structured interviews	Verification with participants Triangulation	Hesitation in resuming sex after surgery; Changes after resuming sex; Coping attitudes to the change Long-term sexual relationship	Sexual Functioning Change Relationships Fear of rejection
Thewes *et al*., 2003	Australia	N=24; Median age = 34 yrs; Range 26-45 yrs; TSD= N=6 max 12 mths prior; N=11 diagnosed > 2 years prior	Oncology clinic	‘Transcendental realism’ Focus Groups Semi-structured telephone interviews Quantitative assessment of preferred communication strategies Thematic analysis	Yes – not specified, informed by Miles & Huberman approaches	fertility & menopause related information: satisfaction, Preferred timing & mode, Preferred media; Psychosocial impact of unmet fertility & menopause related information needs	Fertility Change Loss Information Needs Menopause Support



Further information for 6 papers excluded above:

3 papers excluded as focus on advanced breast cancer.
2 papers needed author confirmation of mean age of participants (reply from 1 – no details on mean age available, no reply from other author).
1 paper based on same study and sample as paper already reviewed – nothing substantially new to justify inclusion.

A1.

The experiences, needs and concerns of younger women with breast cancer: A meta-ethnography

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Changes in bold

Abstract

Objective

This meta-ethnography synthesises the evidence on the experiences, needs and concerns of younger women with breast cancer.

Methods

Using a method called ‘reciprocal translation’ we developed a conceptual model to reflect the local and social contexts, issues, processes, needs and concerns of importance in this literature.

Findings

Key findings relate to the particular point in the life-course at which young women with breast cancer stand. Issues for these women relate to feeling different as a result of cancer, fear of recurrence, feeling ‘out of sync’ and altered embodied subjectivity. Young women with breast cancer use three processes to integrate the changes that cancer brings, namely balancing, normalising and changing. Our conceptual model also highlights young women’s needs, primarily for support, information, childcare, counselling, and spiritual support. Areas of reproduction, fertility and sexuality were also of particular concern. The included papers have methodological limitations which impact on our findings, such as opportunistic data analyses, lack of theoretical frameworks and limited reference to socio-cultural factors.

Conclusion

The conceptual model developed as a result of this meta-ethnography provides a basis for practitioners to address these young women’s concerns more adequately and comprehensively.

1. BACKGROUND

1.1. Age and cancer

More than one million women worldwide are diagnosed with cancer each year. Breast cancer accounts for 10 per cent of all new cancer cases in the world, making it a significant health problem [1]. According to the latest available figures, 45,508 women were diagnosed with breast cancer in the UK in 2006 [1].

From a clinical perspective, age is a significant variable for understanding epidemiology. The prevalence of cancer in all age groups is rising [2]. In the UK around 1 in 10 of all cancers occurs in adults under the age of 50 [1]. A quarter of all cancers in adults under the age of 45 are breast cancers, the most common malignancy in this age group [1].

Experiences of living with cancer are likely to vary by age [3] but despite the prevalence of breast cancer in younger women, the specific key issues and concerns of this group are relatively under-researched. Relatively little is known about *how* experiences, needs and concerns of breast cancer patients differ by age. Such knowledge is important to enable tailoring of interventions and to ensure the supportive care needs of different groups are met. Synthesis of existing evidence has been partly hampered by lack of standardised age definitions [4].

From psychological and sociological perspectives, age has traditionally been used to define human stages of development [5,6]. Key developments associated with young adulthood include starting a career, entering long-term relationships, parenthood and stabilization of one’s identity [7]. Thus, the experience of cancer for young adults is related to the key issues they encounter socially and psychologically.

This meta-ethnography synthesizes qualitative research on experiences of younger women living with a diagnosis of breast cancer chosen because they represent the most prevalent group of patients with cancer of this age. Focusing on qualitative literature in its own right is particularly important because it draws attention to subjugated, experiential knowledge.

1.2. Women’s experiences of breast cancer

It has been argued from a life-stage or developmental perspective that younger women have more of their life ahead of them and might therefore feel the impact of cancer more keenly [8,9]. Psychosocial breast cancer research reports that younger, premenopausal women experience more distress, higher levels of depression, cope less well and report poorer quality of life than older women. [8-10].

Qualitative research into the experiences, needs and concerns of younger women has added detail and depth to our knowledge of the meaning of breast cancer. It has suggested that the experience of breast cancer is dependent on individual personal and social context [11]. It has also highlighted that wider social and historical forces shape the perception of breast cancer and of women more generally [12].

No synthesis currently exists on the wider experiences of this patient group, or indeed, of the qualitative literature alone. In undertaking this meta-ethnography we aimed to synthesize the existing qualitative literature on younger women with breast cancer. Identifying specific experiences, needs and concerns of younger women with breast cancer can inform service development and future research.

2. METHODS

2.1. Type of literature review

We conducted a literature synthesis guided by the principles of meta-ethnography [13]. A meta-ethnography is "the synthesis of interpretive research" (p.10) [13] and aims to preserve the unique character of qualitative studies through the selection of key metaphors (themes) from the original texts; but also to provide a new interpretation of these studies, rather than a simple aggregation. To achieve these aims, it uses a rigorous set of procedures. We adopted a 'reciprocal translation' involving seven phases (see Box 1) [13].

Box 1: Phases of the meta-ethnography

Phase 1: Identification of experiences, needs and concerns of younger women with breast cancer as an intellectual interest.
Phase 2: Conducting a systematic search for relevant qualitative studies.
Phase 3: Reading the articles, paying particular attention to metaphors (i.e. themes, perspectives, concepts) used by the authors to describe and/or explain women's experiences, needs and concerns.
Phase 4: Developing a tabular format to compare studies. Listing key metaphors in each study.
Phase 5: Translating studies into one another. Examining relations between metaphors within a study and between studies.
Phase 6: Synthesizing these translations by determining if some metaphors could encompass other metaphors, thus translating them into each other. The synthesis took the form of a 'reciprocal translation.' That is, similar studies made it possible for each study to be translated into the metaphors of others and vice versa.
Phase 7: Publishing the meta-ethnography.

2.2. Systematic search for literature

A combination of strategies were necessary to carry out phase one, the development of our intellectual interest and research focus, and phase two, the literature search. We carried out a keyword search in four electronic databases: Medline, Web of Science, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Applied Social Sciences Index and Abstracts (ASSIA). We used the following Medical Subject Headings (MeSH) search terms in accordance with definitions used by the National Library of Medicine [14]:

Adult AND (Neoplasms OR Breast Neoplasms) AND Qualitative Research

The search was conducted in January 2009. We identified papers from references/bibliographies listed in manuscripts that were retrieved from the electronic search (this produced an additional two papers which were included in the review). Search results were managed in Reference Manager v11 [15] and a search log kept, detailing number of studies retrieved, de-duplicated, and included at each stage (see Flowchart 1).

2.3. Inclusion criteria

The inclusion criteria were: i) *Population*: women with breast cancer under the age of 45 at diagnosis; ii) *Topic:* experiences, needs and concerns; iii) *Design:* qualitative; iv) *Language and date of publication:* English language studies published in the last 20 years.

Two reviewers (GH, LM) independently screened titles then abstracts. Full papers were obtained for all studies that appeared to meet the inclusion criteria. Three reviewers (EA, GH, LM) then collectively read these papers and through discussion reached agreement on inclusion or exclusion for each paper.

2.4. Quality appraisal

Though there is no consensus whether structured appraisal methods yield higher reviewer agreement than unprompted judgement [16] quality appraisal allows multiple readers to critically review papers in a structured way. We therefore appraised studies using Dixon-Woods *et al.*'s [17] five-point approach to assessing methodological quality in qualitative studies (see Box 2).

Box 2: Quality appraisal criteria for empirical papers [17].

1. Are the aims and objectives of the research clearly stated?
2. Is the research design clearly specified and appropriate for the aims and objectives of the research?
3. Do the researchers provide a clear account of the process by which their findings were produced?
4. Do the researchers display enough data to support their interpretation and conclusions?
5. Is the method of analysis appropriate and adequately explicated?

Documents were rated 5 if all questions were answered in the affirmative, 4 if the method or analysis or sample were not clearly outlined or 3 if both the method or analysis and sample were poorly described.

Each included paper received a high quality score, and therefore no paper was rejected as a result of this appraisal. However, reading through the papers during the first phases of our review, we detected additional differences in the quality of the papers. We therefore developed an additional quality appraisal strategy (see Box 3).

Box 3: Additional quality appraisal criteria

1. Was the recruitment (and resulting sample) specific to the study reported?
2. Does the interview enable the interviewee to raise experiences, issues and concerns or were they raised, and thus introduced, by the researcher?
3. Did the authors make it explicit how they interpreted the data and what theoretical framework they used?
4. Did the authors acknowledge social and cultural factors (e.g. social class, ethnicity) in their analysis?
5. Are strategies employed to verify the coherence of the interpretation and analysis of data (for instance, were strategies such as triangulation used, or was the analysis discussed with user representatives to verify ecological validity)?

Documents were rated 5 if all questions were answered in the affirmative, 4 if only 4 questions were answered in the affirmative, and so on, with 0 indicating the weakest quality of paper based on these additional appraisal issues.

This quality appraisal was applied to all studies and results are shown in Table 1.

Insert TABLE 1 here

2.5. Data extraction

In phases three and four, two reviewers (EA, LM) individually extracted data from the papers into a template holding key information about each paper. The tables containing the extracted data were discussed by three reviewers (EA, LM, GH) to ensure congruence of extraction and to begin the process of identifying patterns and common themes across papers.

2.6. Synthesis

In relation to phase five of the synthesis, the translation of studies into one another, one of the reviewers (GH) identified common concepts in the papers which could be used as a descriptor of younger women's experiences of breast cancer and/or as an explanatory device to account for their experiences. Concepts had to be evident in at least a quarter of papers. These concepts were then discussed by the two reviewers (EA, LM) who had extracted data, and further extended to include other concepts that seemed relevant as a result of the extractions. All concepts were then discussed collectively by the whole research team for validation and to develop understanding of these concepts further.

3. RESULTS

3.1. Description of studies

In total, 17 studies are included in this review. For a summary table see Appendix 1.

3.2. Synthesis: Conceptualising experiences, needs and concerns

Experience is defined here as an interactive and ongoing process of a person's subjective engagement with societal relations (for instance, material, economic or interpersonal practices and discourses), and therefore is thoroughly social [18].

Guided by our extractions, we categorise concepts into those that provide a context for the experiences, those that are issues for younger women with breast cancer, and those that indicate processes found across these issues within these specific contexts (see Box 4). Particular needs and concerns arise from these contexts, issues and processes.

Box 4: Concepts arising from the meta-ethnography

Social contexts
- Life-course
- Cultural context
- Motherhood

Local context
- Family/relationship status
- Social support
- Doctor-patient relationship

Issues
- Reproduction
- Body
- Fear
- Sexual activity

- Feeling 'out of sync'

Processes
- Balancing
- Normalising
- Changing

Needs and concerns
- Support
- Information
- Childcare
- Counselling
- Spiritual support
- Fertility and sexuality

Importantly, these concepts are inter-related. The three processes – balancing, normalising and changing characterise the issues which themselves are embedded within specific contexts. Contexts, issues and processes will now be described in turn.

3.2.1. Social context

Young women stand at a particular point in the life-course; they have a biological age (primarily defined as being of child-bearing age) and a social age. In countries with relatively high GDP there is a social expectation that young women will raise a family and be in paid employment. Expectations of a woman's role however, may vary within different cultures within a country [7, 19]. Motherhood is a key dominant social context for experience of breast cancer for young women [20-30]. However, it has long been highlighted as a dominant ideology which shapes the subjectivities of all women irrespective of age [31, 32]. This wider social context, which includes an ideology of motherhood, gets negotiated at the individual level, within a 'local' context.

3.2.2. Local context

The 'local context' consists of an individual woman's circumstances, for instance her relationship status and social support network. Young women are more likely to be in new relationships or no relationships than older women [33] and may therefore be more isolated when diagnosed with breast cancer [34]. The quality of the relationship in terms of support it can provide is also a crucial factor. While a recent review [35] has cautioned against assuming that cancer generates relationship distress or dissolution, it did not discuss distress in relation to age. Some studies included in our review show that for young women, cancer may very well introduce an element of relationship distress [28, 34, 36]. Similarly, young women's social support network is likely to be less well established and more fluid than that of older women [22, 37]. A further important aspect of a woman's breast cancer experience is her relationship with her medical team. As part of this relationship, accessibility, information provision, and involvement of the patient in decision making are all important factors [30, 36, 38].

3.2.3. Issues

The changing experiences of young women which are attributable to cancer cluster around key issues. One issue which permeates others is a feeling of being different and 'out of sync'. A diagnosis of breast cancer under the age of 45 disrupts a normal life-course. This is because a life-threatening illness is socially perceived as normally only occurring among older people. This feeling of being ‘out of sync’ is in comparison to other young women without cancer and older breast cancer patients [24, 29]. Feeling ‘out of sync’ connect to issues around reproduction (including pregnancy, fertility, contraception and menopause) [20-30]; altered body image (primarily relating to mastectomised bodies and breast reconstruction, but also to more general feelings of being in an altered body, and therefore, changes in embodied subjectivity) [20, 25-27, 34, 36-39]; decreased levels of and changes to sexual activities [25-27, 34, 36, 38]; and fear (of cancer recurrence, of their own mortality and its potential impact on their families) [20, 21, 23-25, 27-29].

3.2.4. Processes

These issues that connect with being ‘out of sync’ are experienced by young women in particular ways within their particular local contexts. Different ways of experiencing and responding to these issues are categorised into three different processes, namely *balancing*, *normalising*, and *changing*. These processes are drawn on by young women, albeit in various combinations.

3.2.4.1. Balancing

A key process characterising young women’s experience of breast cancer is *balancing*. Young women with children are likely to be diagnosed with cancer when their children are still young and living at home. The emotional impact of cancer is well-known, with cancer being described as an ‘emotional rollercoaster’ [22]. Maintaining daily life and family routine is balanced against the intrusiveness of cancer-related demands [28]. As a mother and wife a young woman balances priorities of putting her own needs first in order to survive cancer with meeting the needs of her family. She also balances the physical and emotional demands of her children with the physical and emotional demands on self; balances being truthful and honest about pain and fears with protecting her children from the severe impact of cancer on self; and finds a balance between being needed and wanted by her children with recognising that if she dies her children will be looked after by others. Finally, she balances meeting financial needs of the household, by continuing in paid employment, with under-going treatment which is time-consuming and debilitating [20, 22, 25, 26].

Balancing, however, is not only a process pertinent to women with children. Young women, irrespective of motherhood status, balance focussing on the immediate priority to have treatment in order to survive with learning to live with symptoms such as early onset menopause [20, 22, 25-27]. They weigh up the risks and benefits of particular treatments on survival as well as limiting damage for their longer-term health. In addition, young women feel they need to balance their desire for a child after cancer with concerns over their own health and their families’ and partner’s wishes [23, 29].

Balancing different needs and demands is also driven by, and linked to, the process of *normalising*.

3.2.4.2. Normalising

Young women engage in n*ormalising* processes in relation to different issues of their breast cancer experience.

Young women see their mastectomised body as a deviation from a normative female body. While some women choose breast reconstruction as a way of re-gaining a representation of female normality others opt to establish a new sense of normal by normalising bodily imperfection [39]. Young women perceive that they are not achieving developmentally normative milestones, such as having children, and perceive that having a baby will restore a sense of normalcy in their lives in terms of their femininity and sexuality [23, 29]. The ability to have a child proves a marker of their ability to function as a 'normal' woman, especially for those who have a mastectomy [23, 29].

Young women manage change in life as a consequence of breast cancer by '*continuing with everyday life'* [20]. At the same time, *normalising* is an important process which helps women minimise the disruption the cancer causes to their children's lives by acting the same, particularly with their children, as before their cancer diagnosis [20]. The family returning to normal life is a way for the family to cope and manage the impact of the breast cancer diagnosis [22].

3.2.4.3. Changing

Changing is a process which is frequently drawn upon by breast cancer patients. For young women reproduction remains a key issue. In some cases, cancer limits reproductive choices for women by rendering them infertile after breast cancer treatment. Other women change their decision-making around reproduction because of fears in relation to their own survival and the potential negative effects of cancer treatments on their future children [29]. Some women worry about the effects of hormonal contraception but at the same time, want safe and reliable methods to avoid unwanted pregnancy [21]. Others are concerned that the hormonal changes during pregnancy could stimulate a recurrence of their cancer [21, 28, 29]. For young women who decide to have children after their cancer diagnosis decision-making around breastfeeding changes. This is because women worry about the ability to detect breast cancer in a lactating breast [21].

Changing is evident in relation to the women's sexual relationships. Depending on the supportiveness and understanding of a woman's partner, changes to sexual functioning are either integrated, and a sexual relationship is resumed after the treatment; or, in cases where the partner is demanding and unsupportive, relationship breakdown and separation or divorce is probable [36].

Most of these aspects of the *changing* process relate to negative changes in the women's lives. In this sense they closely relate to the *normalising* process, signifying a desire to achieve a new sense of normality through changing the status quo. However, some young women experience positive changes. These young women perceive the cancer as a turning point which enables positive changes in their lives, such as engaging more actively in self-care or taking up new activities without feeling guilty about the family [37]. Thus, the experience of cancer facilitates a new sense of self to emerge.

3.2.5. Needs and concerns

Only 2 of the 17 papers explicitly report the needs of young women with breast cancer [26, 30]. Most other papers discuss needs tangentially alongside the experiences of these young women, or refer to them in their recommendations for practice and research.

Young women with breast cancer need support, especially peer support [24, 26, 37] and on-going support for life after treatment [22, 26, 41]. Single women need support, both in terms of dating and talking to new partners about the cancer [26, 34]. There is a need for more education and support for current partners of young women with breast cancer and their family more generally [23, 26, 36, 38]. An important area of need for women with young families is the provision of childcare facilities at hospitals and information on how to communicate the illness to children [20, 22, 24-26, 28]. There is a need for professional counselling [21, 24, 26] and spiritual support [26]. There is a perceived lack of information on a range of issues. In particular, information about reproductive issues is needed, ranging from information about potential infertility to information about contraception and pregnancy after cancer [20, 21, 23-27, 29, 30, 41]. There is a need for health care professionals to engage more with reproductive and fertility-related concerns. There is a need for more information about the potential impact of the cancer on sexuality – in particular, information on treatment side effects and the emotional consequences of having breast cancer [24-26, 34, 36, 38, 41].

There is a need for more information on treatment side effects. In particular, sexuality and fertility are areas of concern along with the more general long term side effects such as osteoporosis [23, 26, 27, 30, 38, 41].

4. DISCUSSION AND CONCLUSIONS

This review is the first synthesis of the qualitative literature on the specific experiences of young women with breast cancer that we are aware of. We have drawn together published evidence of the past twenty years and developed a conceptual model which adds depth and breadth to the existing knowledge base.

Our synthesis provides a systematic overview of the processes (balancing, normalising, and changing), which women use to integrate their new experiences of having cancer into their lives. It discusses how young women apply these to different issues and in different local contexts. Existing papers on young women's experiences have largely only focused on particular aspects of women's experiences, such as sexuality, or menopause, or reproduction. Only 2 of the 17 papers [25, 27] mentioned all five issues (reproduction, body image, fear, sexual activity and feeling 'out of sync') that we identified as important. This focus on particular aspects of the breast cancer experience can be useful, but is less helpful when trying to understand the overall experience of breast cancer diagnosed at a young age. It is useful to tease out this 'overall experience' to provide healthcare professionals with an understanding of the varied aspects of having breast cancer at a young age as well as to enable women newly diagnosed with breast cancer to understand the various ways in which this experience might impinge on them. Our conceptual model is the first to draw together the processes, issues and contexts which define young women's experiences of having breast cancer.

Although our conceptual model was developed on the basis of young women's experiences, it may also be applicable to the experiences of other people living with cancer. Young males who had received treatment for testicular cancer identified a range of comparable issues, such as fertility, physical and emotional challenges and other assaults on their sense of self [42, 43]. Similarly, ovarian cancer may impact on body image and reproductive concerns [44]. Our model may also be relevant to younger people living with other cancers, but this would need further testing.

Limitations

The conceptual model described for young women's experiences of breast cancer has some potential limitations. Mainly, these limitations are related to the original research underlying the model, which became apparent when applying our quality criteria to the papers.

A sizeable number of studies (7/17) focused on this younger age group as a by-product of conducting a larger study. Hence, interview or focus group schedules may not have been targeted to this group specifically, which may have limited the depth and breadth of the topics explored. On the other hand, it could be argued that the fact that the author's felt drawn to issues of young women highlights the uniqueness and significance of their age compared to older women.

Our quality appraisal evaluates the use of theoretical frameworks within the research studies analysed more explicitly than Dixon-Woods *et al*. [17]. Eleven out of 17 of the included studies did not discuss a theoretical framework, or refer to it, in the analysis or discussion of their papers. We believe that the chosen theoretical framework should be made more explicit in qualitative studies, as it is so closely linked to the way in which data are collected and analysed.

Although it is generally acknowledged in qualitative research that social and cultural factors shape our experiences, only 5 out of 17 of the included studies referred to these factors, and the samples of all studies were heavily weighted towards white, middle-class women. The lack of participants from varied cultural backgrounds, and the lack of cultural sensitivity in the analyses, ought to be addressed in future research to more adequately reflect young women with breast cancer in general and the impact of breast cancer on women with different cultural backgrounds.

Lastly, we acknowledge that qualitative data analysis is a creative process and open to interpretation. Thus, it is particularly important to check the coherence of the analysis and test its ecological validity, that is, its meaningfulness. This may be done in conjunction with the participants as experts of their own experience, by providing a clear audit trail of how the researchers arrived at their endpoints, or can take the shape of triangulation with other researchers in the area. Of 17 studies, 10 used some form of verification procedure, though it was not always explicitly described.

However, despite these methodological limitations, our meta-ethnography provides an overview of current evidence on the experiences, needs and concerns of young women with breast cancer.

Clinical services/practice relevance

Since cancer is uncommon in this age group, young women are often worried that cancer services may not address their unique needs and concerns. They are concerned, for instance, that effects such as early onset menopause are not fully acknowledged or understood by professionals, and that the longer-term impact of treatments on younger women are not known [26, 27]. This synthesis describes the experiences, needs and concerns specific to younger women, which health professionals should be aware of and take into account during their interactions with this group. However, a discussion is also necessary about who ought to address these women’s needs, and about the boundaries between the responsibilities of clinical services and those of families and friends of patients. Not all needs can be addressed by clinical services, even if they arise out of illness, but clarification with the patients of what can and cannot be addressed might be useful.

Conclusions

To the best of our knowledge this meta-ethnography provides a comprehensive overview of the specific experiences, needs and concerns of young women with breast cancer. The conceptual model developed demonstrates that to understand women’s experiences social and local contexts should be taken into account. Aside from experiencing cancer at an unusual age, young women with breast cancer face a number of age-specific issues linked to motherhood and reproduction. Three processes were identified which women use to deal with these issues and integrate cancer-related concerns into their lives. We trust that this model may provide a basis for practitioners to address the concerns of young women with breast cancer more adequately and comprehensively and also provide a platform for further research.

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1 **Table 1: Our quality appraisal**

	recruitment specific	**interview open**	**theoretical framework**	**socio-cultural factors**	**verification of analysis**	**SCORE**
Archibald ***et al.***, 2006	Y	N	N	N	Y	2
Billhult & Segesten, 2003	Y	Y	Y	N	N	3
Connell ***et al.***, 2006	N	Y	Y	N	Y	3
Coyne & Borbasi, 2006	Y	Y	Y	N	Y	4
Crompvoets, 2003	N	Y	Y	N	N	2
Dow, 1994	N	Y	N	N	N	1
Dunn & Steginga, 2000	Y	Y	N	N	Y	3
Fitch ***et al.***, 2008	N	Y	N	Y	Y	3
Gluhoski ***et al.***, 1997	N	Y	N	N	N	1
Gould ***et al.***, 2006	Y	Y	N	Y	Y	4
Knobf, 2001	N	Y	N	Y	Y	3
Knobf, 2002	Y	Y	Y	Y	Y	5
Shapiro ***et al.***, 1997	Y	Y	Y	Y	N	4
Siegel ***et al.***, 1997	Y	Y	N	N	N	2
Siegel ***et al.***, 1999	N	Y	N	N	N	1
Takahashi & Kai, 2005	Y	Y	N	N	Y	3
Thewes ***et al.***, 2003	Y	Y	N	N	Y	3

Appendix 1: Summary table

Author	Country	Sample	Recruitment	Theoretical framework, method and analysis	Verification of Data	Findings	Concepts
Archibald ***et al.***, 2006	Canada	• **N=30** • **Mean age**[1] = 45 yrs[2] • Range 31-57 yrs • TSD[3]: range 1- 4 yrs	• Support groups • Adverts • Letters distributed through Canadian Cancer Society in New Brunswick	• Semi-structured interviews • Thematic analysis	• Triangulation • Independent coding	• Changes in sexual functioning: positive, no or negative changes • Emotional impact of sexual changes – worry & uncertainty, frustration & anger, loss, guilt, indifference	• Sexual Functioning • Relationships • Sense of Self
Billhult & Segesten, 2003	Sweden	• **N=10** • Mean age = 41.6 yrs • Range 32-48 yrs • TSD = mean 14.1 mths[4]	• Information group about lymphoedema post-operatively	• Phenomenology • Open-ended Interviews	• N/A	• **Strategies to balance life as mother with having cancer involved continuing with daily life & normality** • Essence of being mother with dependent children involved drawing on strength of motherhood to balance conflicting forces	• Balancing • Normal Routines • Strength of Motherhood
Connell ***et al.***,	Austr	• Phase 1 n=35	• Flyers at **BC**[5] events & venues	• Social constructionism/	• Verification with	• Perceptions of fertility changed over time	• Fear of recurrence

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[1] Where given, this was mean age at diagnosis

[2] Yrs=Years

[3] TSD=Time since diagnosis

[4] Mths=Months

2006	alia	- Phase 2 n=13 - Mean age = 37 yrs - Range 29-40 yrs - TSD = median 26 mths (range 5-37 mths)	- **S**upport groups	phenomenology - Longitudinal - Semi-structured interviews	participants - **A**udit trail - **T**riangulation	- Concerns around use of safe & reliable contraception - **R**esistance to hormonal contraceptives - Breastfeeding decisions changed over time	- **Fe**rtility - **C**onfusion
Coyne & Borbasi, 2006	Australia	- **N**=6 - Median age= 37 yrs - Range 29-43 yrs - TSD: max 12 mths	- Unclear	- Feminist enquiry - Open-ended interviews - **P**articipatory research process	- Verification with participants	- Diagnosis – having to be strong - Point **of** diagnosis described as most stressful time in their lives - Impact on the family: interplay between having **BC** & being a mother - particular distress - Life after treatment: family remained on an emotional rollercoaster after treatment	- Emotional rollercoaster - **B**alancing act - **U**se of humour - ‘**H**aving to hold it all together’ - **U**ncertainty - **O**ptimism about future
Crompvoets, 2003	Australia	- **N**=1 - Aged 50 yrs - Aged 40 yrs at time of first diagnosis, aged 47 yrs at recurrence	- Unclear	- Feminist enquiry - Case study - Narrative analysis	- N/A	- Breasts prior to mastectomies identified as essential part of sense of self - Body & self inextricably linked - Mastectomised bodies seen as physically & emotionally	- Normality - **Co**mplete womanhood - **I**dentity - **S**exuality - **B**eing ‘complete’

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[5] BC= Breast cancer

						incomplete • Negative feelings about breast loss not anticipated	
Dow, 1994	USA	• **N**=16 • Mean age at diagnosis = 29.6 yrs • Range 25-35 yrs • **M**ean age at interview = 38.8 yrs (range 32-45 yrs)	• Oncology clinic	• Semi-structured interviews • Review of radiation treatment records • Thematic & content analysis	• N/A	• Having children was a cherished goal, desire for sense of normalcy, reconnecting with others • Concerns expressed about pregnancy – some related to being young mother but some explicitly related to having **BC**	• Normalcy • Fear of recurrence • Motherhood • Loss • Integrating cancer into life
Dunn & Steginga, 2000	Australia	Phase 1 • **N**=23 • Mean age 37 yrs • Range 31-47 yrs • Phase 2 N=21 • Phase 3 N=21	• Newsletter distributed to women who had been visited by a Breast Cancer Support Service volunteer	• Multi-angulated method: Literature Review, focus groups, semi-structured interviews & 3-round iterative survey	• Verification with participants	• Worry that women won’t see their children grow up • 3 indicators for defining young as relates to BC – the woman is of child bearing age, the woman has young children the woman hasn’t yet reached menopause	• Defining ‘young’ • **I**nfertility • **L**oss of choice about having children • **F**eeling different to women your age • **F**eeling too young to get cancer • Unrealistic media portrayal of

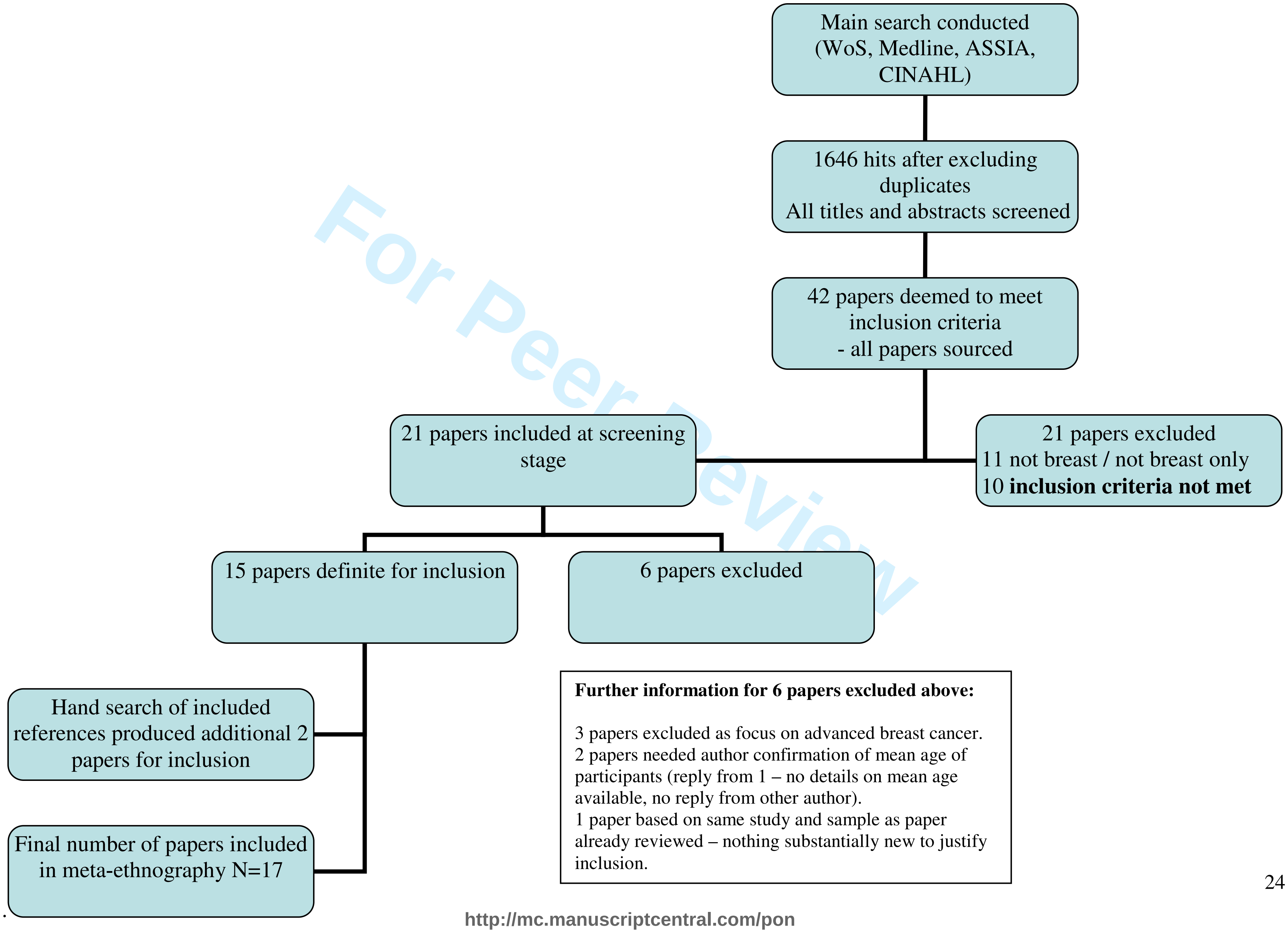
							young women
Fitch *et al.*, 2008	Canada	**N**=28 Age range 28-42 yrs Mean TSD since diagnosis = mean 3.8 yrs	Random selection of cancer registry sub-sample	Open-ended interviews Telephone interviews Content & theme analysis	**T**riangulation	Everything depends on acting now – intense desire expressed by all women to stay alive Everything is out of sync – feeling different to women of your age Cancer invaded whole life – different lives as result of breast cancer	Balancing act – roles of 'being a woman' & 'being a mother' **I**dentity **U**nfairness of cancer diagnosis **G**uilt **P**utting oneself first **B**etraying bodies
Gluhoski *et al.*, 1997	USA	**N**=16 Mean age = 33.5 yrs **R**ange 22-42 yrs TSD = mean 37 mths (range 8 mths – 8 yrs)	Cancer organisations Memorial Sloan-Kettering Cancer Center	Sociodemographic & medical information questionnaire Open-ended interviews Thematic analysis	N/A	Pessimism regarding future relationships Fears about disclosing illness Negative body image **I**mpaired sexuality Fears of rejection by partners Sense of isolation & inadequate support	**I**solation **R**ejection **F**ear **S**exuality **C**hanges in appearance **R**elationships
Gould *et al.*, 2006	Canada	**N**=65 Mean age 37 yrs Range 26-45 yrs	Newspaper adverts, **A**dverts in Canadian Breast Cancer Network	Relativist Paradigm Focus Groups Thematic & content analysis	Verification with participants	**I**nformation, support & programmes / services did not match women's age or life stage Lack of emotional &	'Nothing fit me' Lack of support & information

		• Mean age 41 yrs at time of study	newsletter • Support groups • Community cancer organisations • Cancer treatment centres & clinics			instrumental support for themselves & families • Diagnostic challenges associated with being ‘atypical case’	• Unique, age-specific challenges
Knobf, 2001	USA	• **N=27** • Mean age 40.8 yrs (+/-3.7) • TSD = mean 4.5 yrs (+/-0.43; range 1-9 yrs).	• Oncology clinic	• Grounded Theory • Semi-structured Interviews • Informal discussions with specialists • Fieldnotes, memos & lay women’s writings • Constant comparative method	• Triangulation • Audit trail	• Variety of changes – from none to severe • Variety of symptoms reported, e.g. hot flashes, insomnia, vaginal dryness, changes in libido • Some women concerned about long term effects of menopause - osteoporosis & heart disease	• Sexual Functioning • Distress • Menopausal Symptom Experience • Lack of Communication
Knobf, 2002	USA	• **N=27** • Mean age = 40.8 yrs • TSD: mean 4.5 yrs (range 1-9 yrs)	• Oncology clinic	• Grounded Theory • Semi-structured Interviews • Informal discussions with specialists • Fieldnotes, memos & lay women’s writings • Constant	• Triangulation • Audit trail	• **Vulnerability is the basic social psychological problem for women with treatment-induced premature menopause** • Basic process of responding to vulnerability: ‘carrying on’ (4 stages) • Movement through stages not linear - moved back &	• Carrying on • Vulnerability • Uncertainty • Loss • Isolation • Resiliency • Carrying On

				comparative method		forth	
Shapiro ***et al.***, 1997	Canada	• **N**=3 married couples (3 men & 3 women) • Ages of women at diagnosis 35, 42, 48 yrs • Ages of husbands at diagnosis 37, 44, 45 yrs • TSD: mean=4 yrs	• Oncology clinic • Cancer centre • Individuals in community	• Grounded Theory • Open-ended Interviews • Narrative analysis	• N/A	• Concept of change permeated accounts • Women covered continuum of change from no change to complete changes • Three core themes: Back to 'normal'; Rebirth & Turning Point • **Main changes in relation to self, treatment effects, menopause, relationships, lifestyle**	• Change • Meaning • Identity • Self-awareness • **I**ndividual context
Siegel ***et al.***, 1997	USA	• **N**=50 • Mean age = 33.4 yrs • Range 22 – 44 yrs) • TSD= mean 33 mths (range 8mths – 8 yrs)	• Organisations such as Share, **American Cancer Society & Cancer Care provided study information, women then self-referred** • Memorial Sloan-Kettering Cancer Centre	• Open-ended interviews • Content analysis	• N/A	• Deterrents and incentives to becoming pregnant	• Fear of recurrence • Risk • Loss • Motherhood • Child as Life Affirming • Normalcy
Siegel ***et al.***, 1999	USA	• **N**=34 • Mean age = 30.6 yrs	• **S**ame as Siegel **et al.** 1997 above	• Sociodemographic & medical information questionnaire	• N/A	• Reactions to untimely diagnosis • Guilt about impact of illness on one's partner	• Loss • Motherhood • **U**ntimely

		• **R**ange 22-35 yrs • TSD= mean 38 mths (range 13 mths – 8 yrs)		• Open–ended interviews • Thematic Analysis		• Lost opportunities for childbearing • Feelings of being different & isolated • Uncertainty about the future • Concerns about children	diagnosis • Fear • Uncertainty about the future • Relationships
Takahashi & Kai, 2005	Japan	• **N**=21 • Mean age = 42.2 yrs • **R**ange 28-54 yrs • Median length between surgery & first interview = 17 mths (range 4-123 mths) • Second interview with n=11 • Third interview with n=1	• Breast surgery clinics	• Grounded Theory • Semi-structured interviews	• Verification with participants • **T**riangulation	• Hesitation in resuming sex after surgery • Changes after resuming sex • Coping attitudes to the change • Long-term sexual relationship	• Sexual Functioning • Change • Relationships • Fear of rejection
Thewes *et al.*, 2003	Australia	• **N**=24 • Median age = 34 yrs • **Ra**nge 26-45 yrs • TSD= N=6 max 12 mths	• Oncology clinic	• 'Transcendental realism' • Focus Groups • **Se**mi-structured telephone interviews • Quantitative	• Yes – not specified, informed by Miles & Huberman approaches	• Perceived importance of receiving fertility & menopause related information • Satisfaction with information provision • Preferred timing & mode of	• Fertility • Change • Loss • Information Needs • Menopause • Support

		prior; N=11 diagnosed > 2 years prior		assessment of preferred communication strategies - Thematic analysis following Miles & Huberman,1994		fertility & menopause related information provision - Preferred media of fertility & menopause related information provision - Psychosocial impact of unmet fertility & menopause related information needs	



Further information for 6 papers excluded above:

3 papers excluded as focus on advanced breast cancer.
2 papers needed author confirmation of mean age of participants (reply from 1 – no details on mean age available, no reply from other author).
1 paper based on same study and sample as paper already reviewed – nothing substantially new to justify inclusion.

A1.