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Review article

‘Marginalised malignancies’: A qualitative synthesis of men's accounts of living with breast cancer

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ABSTRACT

Rationale: Breast cancer in men is a rare, under-researched illness frequently overlooked within both clinical and third-sector healthcare systems. Increased prevalence and high profile awareness-raising, advocacy and activism around breast cancer in women has led to pervasive feminisation of the disease, prompting a misperception of breast cancer as a women-only illness. This deters men from seeking medical attention, professional and social support, and increases sensitivity to body image concerns.
Methods: Drawing on the principles of critical health psychology, we offer an interpretive and evaluative qualitative synthesis of existing academic literature in the field, and reveal how the marginalisation of men with breast cancer poses a host of psychosocial and psychosexual difficulties for patient-survivors beyond the primary cancer challenge at all stages of the illness trajectory.
Results: We discuss how identities, masculinities, coping responses and resources, and relationships are often affected, and demonstrate how current approaches to breast cancer serve to isolate men who develop the illness, potentially alienating and emasculating them.
Conclusion: Our analysis integrates and enhances the findings of the original papers through more theorised considerations of stigma, masculinity and marginalisation. Further, we briefly consider some of the ways men's experiences diverge and converge with women's accounts, and discuss the importance of re-appraising ‘pink ribbon culture’ for both men and women. We conclude with some recommendations for advocacy and intervention in professional and lay contexts.

1. Introduction

Breast cancer is the most common cancer in the United Kingdom (UK) (Cancer Research UK, 2014). However, its incidence among men is low, accounting for less than 1% of all UK breast cancer cases, a ratio of 1:143 men to women (Office for National Statistics, 2014). Around 350–400 new cases present in men yearly in the UK, compared to the estimated 50,000 women diagnosed (NHS, 2014). Subsequently, breast cancer in men is frequently overlooked within both lay and expert healthcare systems (Iredale et al., 2006), despite breast cancer in men being responsible for proportionally more deaths than penile or testicular cancer (Cancer Research UK, 2014). Prognosis for men and women is similar, yet outcomes tend to be poorer for men due to reduced illness awareness and resultant late detection. For example, recorded five-year survival rates are poorer for men (80.8%, *CI* 95%) than women (86.6%, *CI* 95%) (Public Health England, 2014).

Causes of breast cancer in men remain unclear, though a number of possible risk factors are proposed. Incidence, as with women, has strong links with aging, and is most common in men aged over 60 (NHS, 2014). A family history of breast cancer, high oestrogen levels, radiation exposure, obesity and some genetic and medical conditions (e.g., Klinefelter's syndrome; Cirrhosis) suggest an elevated lifetime risk for men. Clinical diagnosis and treatment are the same for men and women, and though there are different types, invasive ductal breast cancer presents most frequently in both sexes (Giodarno, 2005).

Therefore, from an oncologic perspective, breast cancer manifests in men and women for similar biological reasons, yet socially, breast cancer in men is distinct from the disease in women. Consistently afforded a gendered status, breast cancer is notably a ‘women's illness’. Increased prevalence, awareness-raising, advocacy and activism around breast cancer in women has reinforced a perception of breast cancer as a women-only concern. This deters

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men from seeking prompt medical attention and professional and social support, and increases body image concerns (Iredale et al., 2006).

Existing ideologies about breast cancer and femininity oppose central masculine ideals and social constructions of what it means to be a man (Williams et al., 2014). Breasts are symbolic of women's femininity and sexuality. Anatomically, both sexes have breasts, but society often ridicules the idea of men's breasts (Williams et al., 2014). Thus, the prototypical breast cancer patient is *she*: *she* is a woman, somebody's wife, mother, sister, daughter, blameless in *her* cancer plight, in need of support (King, 2006). Breast cancer is frequently culturally depicted as synonymous with vulnerability and distress whereas society expects men to be strong, stoical and invulnerable when faced with adversity (Puntoni et al., 2011). Breast cancer is therefore incongruent with conceptions of manliness, threatens men's identities and has the propensity to create further psychosocial crises (Robertson, 2007; Branney et al., 2014). Current approaches towards breast cancer and the related 'pink ribbon culture' further perpetuate gendered ideas about the illness (Sulik, 2011). The pink ribbon has come to symbolise breast cancer resulting in interventions to improve research, patient support and services for women (Kaiser, 2008; King, 2006). 'Pink ribbon culture' engages the wider community in support of women with breast cancer (Gibson et al., 2015), making this the dominant representation, despite its non-inclusive nature. Such feminised campaigns can thereby foster marginalisation and disempowerment of those on the periphery, including men (and nonconformist women) (Bunkley et al., 2000).

Despite the plethora of literature on breast cancer in women and an increased interest in men's health (Wilkins and Kemple, 2011), there is a dearth of psychosocial research exploring breast cancer in men. Inadequate knowledge and awareness about breast cancer and breast health in men persist at public and professional levels (Al-Naggar and Al-Naggar, 2012), potentially having grave implications for men, leading to unnecessary deaths. In order to improve understandings regarding disease manifestation in men and the extent of the apparent inequities faced by men with breast cancer, further experiential research is required from the patient-survivor perspective. Specifically, there is a need to determine how some of the needs of men with breast cancer differ from those of women.

The purpose of this interpretive qualitative synthesis was to consider men's accounts of the breast cancer experience from a critical health psychology perspective (Murray, 2015). Through explorations of the embodied experience, discursive landscape and social positioning of men with breast cancer at all stages of the illness, the synthesis illustrates how marginalisation of men with breast cancer poses a range of psychosocial and psychosexual difficulties for men in addition to the challenge of diagnosis. Though coverage of breast cancer in men in existing literature is sparse, in a collective evaluation of earlier research we expand current knowledge and generate further insight upon which to build further research, through a meta-ethnographic synthesis.

Meta-ethnography is a well-established method, widely advocated as a successful means by which to synthesise qualitative research (Britten et al., 2002; Campbell et al., 2011), especially experiential data, allowing for systematic examination of existing research, facilitating a higher level of analysis and fresh perspectives (Noblit and Hare, 1988). Allowing researchers to explore phenomena from the insider's perspective, meta-ethnography is often chosen for research syntheses on health and illness-related experiences (Atkins et al., 2008; Röing and Sanner, 2015).

2. Method

Adopting Noblit and Hare's (1988) seven-step procedure, the synthesis process comprised the following phases (See Fig. 1). Firstly, the research focus and core lines of enquiry were established in order to develop the synthesis question, i.e. '*How do men describe breast cancer and their experience of the illness?*'

Secondly, a literature search was conducted, according to specific criteria, identifying research studies for inclusion in the synthesis. No parameter was set for start date and the search took place over a 28 day period in April and May 2014. The databases selected included; British Library EThOS, CINAHL Plus with Full Text, E-Journals, MEDLINE, PsycARTICLES, PsycINFO, Science Direct and SCOPUS. Relevant search terms and Boolean operators were 'men' OR 'male' AND/WITH 'breast cancer' AND 'experiences'. The All Text (TX) search parameter was also applied. Selection was limited to full-text English-language articles reporting qualitative research conducted with men.

Initial analysis involved careful reading and re-reading to identify core themes and concepts within each study, recognising contextual aspects governing the interpretations and explanations offered. To assist with comparing and merging outcomes from the studies, we tabulated key methodological information as reported by the original authors (i.e. second-order interpretations, see Britten et al., 2002).

Next, emergent similarities and differences were considered to determine conceptual relationships among studies. Phases five and six involved recognising 'reciprocal translations' (Noblit and Hare, 1988); identifying key shared inferences emerging from the studies, gaining a deeper, comprehensive understanding of the research phenomenon from which a line of argument could be established and deliberated. Finally, findings are expressed in a written discussion of inferences drawn from the whole dataset and how the studies serve collectively to inform understanding of men's accounts.

The synthesis is grounded in data reported by the studies' original authors, assuming that the interpretive findings presented are a fair representation of the data. Noblit and Hare (1988) prescribed this approach of synthesising researchers' interpretations, and later publications describe how these secondary interpretations inform the tertiary-level inferences and findings presented in the synthesis that go beyond those offered in the original studies (see Britten et al., 2002; Campbell et al., 2011).

3. Results

Our search yielded 8418 potential reports; 8404 of those were discarded after removing duplicates and non-relevant articles. The remaining 14 studies were screened for inclusion by title and abstract, of which eight studies met the inclusion criteria (Fig. 1).

Studies were published from 2000 to 2013; involving 92 men with different populations and methodologies (Table 1).

Four overarching meta-themes emerged each of which are divided into a series of sub-headings, allowing for structured presentation and discussion of the synthesis findings. Quotation marks denote original participant quotes, and studies are referenced by the number that appears in Tables 1 and 2.

3.1. Negotiating the complexities of diagnosis and disclosure

This first meta-theme describes initial help-seeking practices and disclosure strategies following diagnosis.

3.1.1. Delay, disbelief and disarray surrounding diagnosis

Participants described seeking help throughout diagnosis as a complex process. Prior to their own illness experience, most had little-to-no knowledge of breast cancer in men (1,2,4,6,7,8), and many felt that health professionals also lacked relevant knowledge