



'It is hard for mums to put themselves first': How mothers diagnosed with breast cancer manage the sociological boundaries between paid work, family and caring for the self



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ABSTRACT

This paper aims to increase understanding of how mothers diagnosed with breast cancer while in the paid workforce experience and manage their multiple demands of taking care of themselves, their children and their paid work. In-depth, semi-structured interviews were conducted with 32 women who were mothers of dependent children and in the paid workforce at the time of their breast cancer diagnosis. The sample includes women living in urban and rural Australia. The study found that after a breast cancer diagnosis, participants tended to prioritise their health and wellbeing over paid work. Yet dominance of gendered identity meant that they tended to place the needs of family, especially children, above their own health and wellbeing. The key factors that influenced mothers' decisions to continue in, return to, or leave paid work after a breast cancer diagnosis included: a change in perspective regarding what was important in their lives; level of support from the workplace and home; the extent to which participating in paid work was a financial necessity; the extent to which their identity was connected to paid work, and; ongoing level of pain or fatigue. The paper concludes that using the sociological concepts of the fateful moment, boundary maintenance and a feminist ethic of care produces a more nuanced understanding of women's participation in paid work after breast cancer than examining paid workforce participation, or unpaid responsibilities and mothering, separately. The nature of the permeability or malleability of boundaries between work, family and taking care of the self affects women's participation in paid work during and/or after breast cancer treatment. Increased boundary permeability or malleability brought about more by cooperation than conflict facilitated positive experiences of re-negotiating boundaries, whereas increased permeability or malleability brought about more by conflict than cooperation created difficulties for women in finding an acceptable balance between their family, paid work and taking care of their own health after breast cancer.

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1. Introduction

Improvements over the past few decades in breast cancer early detection and treatment have meant the number of women living at least five years after a breast cancer diagnosis has increased in Australia (AIHW, 2010; Cancer Australia, 2012). Recovery from breast cancer, for many women, is not a simple return to pre-breast cancer health and daily life at the end of acute treatment. Studies indicate that after a breast cancer diagnosis and subsequent treatment, women experience a higher than population level range of physical, mental health and quality of life problems (Boyes et al., 2009; Mrozek and Shapiro, 2005).

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Research findings indicate that women diagnosed with breast cancer at a younger age (under 50) experience greater morbidity and social problems than those diagnosed when they are older (Bloom et al., 2012; Connell et al., 2006). Women diagnosed under 50 years are more likely to be mothers of dependent children and be in the paid workforce than those diagnosed at older ages, yet little is known of their experience of managing their multiple demands post-breast cancer diagnosis (Fisher and O'Connor, 2012). Using in-depth interview data, this paper aims to address those gaps in research by exploring how women diagnosed with breast cancer while mothers of dependent children and in the paid workforce experience and manage their multiple demands of taking care of themselves, their children and their paid work. The paper explores briefly implications for survivorship care and survivorship research.

1.1. Background

Women's experience of returning to work after a breast cancer diagnosis and treatment has become a subject of interest in occupational medicine and survivorship research (de Boer et al., 2011). Occupational studies have shown that returning to the paid workforce is an important aspect of recovery from cancer and cancer treatments. This research is predominantly from the USA, UK, Canada and Scandinavia and has focussed on length of absenteeism (Bradley et al., 2006) work patterns and changes including unemployment (Mols et al., 2009) treatment of workers (e.g. discrimination) and productivity (Villaverde et al., 2008). Several studies have explored women's experiences of returning to work after breast cancer (Hansen et al., 2008; Maunsell et al., 2004; Tiedtke et al., 2009; Villaverde et al., 2008) while a few studies have explored the importance of returning to work as part of recovery in terms of psychosocial health (Tamminga et al., 2010; Wells et al., 2013). There is general agreement among studies, strengthened by findings from systematic reviews, that occupational rehabilitation should be part of overall cancer treatment and survivorship care plans (de Boer et al., 2011).

Very little is known about women's experience of paid work after breast cancer in Australia (Gruszyn and Szuster, 2008). Most Australian studies have focussed on women's general experiences of breast cancer, with paid work being an emergent issue (Connell et al., 2006; Thewes et al., 2004) and one study has looked at the economic impact of breast cancer on breast cancer survivors and their families (Gordon et al., 2007). The international evidence shows that different welfare, health and legislative systems regarding discrimination and disability policy contexts profoundly affects women's experiences and return to work patterns after breast cancer (Amir and Brocky, 2009; Tiedtke et al., 2009). The Australian paid workforce benefits from state prescribed protections of minimum wage, anti-discrimination legislation and workers compensation for work-related injury and disease (Mackenzie et al., 2013). Most Australian workers, including those in temporary positions, are eligible to receive employer superannuation contributions, long service leave and maternity leave, and to claim for unfair dismissal (Burgess et al., 2008). There is a universal health care system in Australia, so health insurance and health care benefits are not tied to employment or prior employment history (Kim et al., 2012).

In Australia more than three quarters of women become mothers and of these women, the majority have their first child in their late twenties or early thirties (ABS, 2010b). Around three quarters of women aged between 20 and 54 are in the paid workforce (ABS, 2010a) and women with dependent children are increasingly likely to be in the workforce (Holmes, 2009). Women who are diagnosed with breast cancer are therefore ever more likely to be mothers of dependent children and also in the paid workforce.

Several studies have explored the effects of maternal breast cancer on children, including the effects on relationships between mothers and their dependent children (Brown et al., 2007; Mazzotti et al., 2012; Vannatta et al., 2010). A few studies have explored women's experiences of mothering after a diagnosis of breast cancer (Fisher and O'Connor, 2012). With the exception of Sulik (2007a, 2007b) very few studies have specifically explored how women manage mothering, working and caring for their own health after breast cancer.

Central to current feminist theorising of mothering are the ways in which motherhood, the ideologies and the practices, affects the status of women in relation to men, plus a range of intersecting social inequities and tensions such as class (Reay, 2004), culture, race/ethnicity, paid work, time/time constraints (Craig, 2006, 2007;

Hochschild, 2001) and sexuality (Cahloun, 1997; McCullough, 2004). The motherhood literature suggests there is little social (particularly partner or workplace) support for women in the role of raising children at least in Western societies (Hays, 1996). Hays (1996) highlights contradictions between the ideologies of motherhood and the market, particularly for mothers who are in the paid workforce.

Pertinent to the current study is how mothers construct motherhood in terms of their multiple roles: caring for their children, caring for themselves and being in the paid workforce in the context of having/had breast cancer. Feminist literature on motherhood includes some studies of how women negotiate care work, particularly in the context of illness. Included in this literature is the feminist ethic of care, first coined by Gilligan (1982). Gilligan (1982) argues that men tend to respond to moral dilemmas in the abstract, by weighing up differences between the rights of competing agents and deciding on what is fairest. She describes this approach as a male ethics of justice (Tong, 1989). Women, she contends, solve moral dilemmas relationally in terms of responsibilities (Gilligan, 1982). Rather than choose one right answer, women tend to change the dilemma, for example by introducing negotiation between the competing agents who find consensus (Tong, 1989). The female point of view on moral dilemmas, she argues, is based on an ethic of care. Gilligan views these differences as stemming from men viewing themselves as autonomous agents and women's identities being formed in relation to others – as being interdependent rather than independent (Tong, 1989).

While Gilligan's conclusions have been debated intensely, not least by feminists, her theorising has led to new fields of scholarship investigating the nature, meanings and ethics of care (Held, 2006; Larrabee, 1993). Her insights have been taken up by some feminists to theorise the ideologies of motherhood and practices of mothering in terms of an ethic of care, where mothers are at once embodying dominant ideologies of motherhood and often solely responsible for negotiating decisions about the daily work of caring for children. It is this use of a feminist ethic of care, particularly where women are in a position where they must negotiate care for themselves because of a diagnosis of breast cancer, as well as for their children (Sulik, 2007a, 2007b), and also manage their paid work, that is of interest to the current paper.

A qualitative study in the United States (Sulik, 2007a) found that women struggled with dominant expectations of gendered care work for others (rather than the self) after a breast cancer diagnosis. The concept of 'gendered care work' refers to the unequal distribution of care work, whereby women take on the greater burden of unpaid care work within the family and paid care work outside the home (Craig and Powell, 2011; Hochschild, 2001). When women are diagnosed with breast cancer, they necessarily need to direct care work towards themselves, yet Sulik (2007b, p. 875) found that 'care work for the self exposes the power of internalized gender expectations that even breast cancer cannot easily transform'. The women in Sulik's study attempted to negotiate a 'balancing act' between the care work they did for others and the care work they needed to do for themselves. Further, many of the participants reconciled their felt individualism of engaging in care work for the self by 'giving back' to other women diagnosed with breast cancer, for example by being involved in peer support groups or breast cancer awareness and fundraising activities (Sulik, 2007b).

In contrast to Sulik's (2007a, 2007b) studies, other studies have found that the experience of breast cancer can be a catalyst for women to re-evaluate their lives, including their workforce participation and time spent outside paid work (Shannon and Shaw, 2005; Wilkinson, 2000, 2001). Reassessing everyday life activities in response to a breast cancer diagnosis resonates with Giddens's (1991) 'fateful moment', which occurs when an

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