



Exploring patient support by breast care nurses and geographical residence as moderators of the unmet needs and self-efficacy of Australian women with breast cancer: Results from a cross-sectional, nationwide survey



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ABSTRACT

Purpose: This study investigated whether use of services of a breast care nurse (BCN) at any time during treatment for breast cancer led to reduced unmet needs and increased self-efficacy among women with breast cancer. A secondary aim was to analyse comparisons between urban and rural and remote dwellers.

Method: Participants were Australian women who completed treatment for breast cancer at least 6 months before the survey date, recruited through two national databases of women diagnosed with breast cancer. The cross-sectional online survey consisted of two well validated measures, the SCNS-SF34 and the CASE-Cancer Scale. Statistical data were analysed using SPSS, with chi-square used to measure statistical significance.

Results: A total of 902 participants responded to the survey. Unmet needs in the psychological domain were most prominent. Respondents who used the services of a BCN were significantly less likely to report unmet needs regarding tiredness, anxiety; future outlook; feelings about death and dying; patient care and support from medical staff; and provision of health systems and information. Scores of self-efficacy showed women using the services of a BCN had significantly higher self-efficacy when seeking and obtaining information ($p \leq 0.001$) and understanding and participating in care ($p = 0.032$). Urban dwellers were more likely to have choice of health care service, but overall neither unmet needs nor perceived self-efficacy varied statistically significantly by remoteness.

Conclusions: Women with breast cancer experience a range of unmet needs; however those using BCN services demonstrated positive outcomes in terms of decreased unmet needs and increased self-efficacy.

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1. Background

Breast cancer is the most common cancer among women worldwide and incidence continues to increase (Ferlay et al., 2013). Due to a variety of factors concerning advances in diagnosis and treatment of breast cancer, large numbers of women are now living with and beyond a breast cancer diagnosis (Cheng et al., 2014). Women with breast cancer experience a range of medium to long-term physical and psychological side effects due to treatments

including surgery, chemotherapy, radiation and hormone therapy. Common side effects include chronic pain, fatigue, muscle weakness, joint pains, lymphoedema, menopausal symptoms, sexual problems, anxiety, depression and fear of recurrence (Brennan et al., 2010; Bruce et al., 2014; Maher and Fenlon, 2010).

Predictions of the number of Australians diagnosed with breast cancer in 2015 equate to approximately 15,000 (Cancer Australia, 2012). This population live in a variety of geographical areas and receives information and support from diverse sources. Those living in geographically isolated areas experience decreased psychological and physical resources compared to women living in urban areas, facing more limited access to information, support and health care (Palesh et al., 2006; Sabesan and Piliouras, 2009),

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sometimes resulting in high levels of psychosocial unmet need (Butow et al., 2012; Harrison et al., 2009).

In addition to this, as women move along the continuum of cancer, their information and supportive care needs change. Whether it be dealing with diagnosis, treatment or long-term management of the disease, many can experience a number of stressors as they progress through the cancer trajectory and often they report facing a number of unmet needs, particularly in the psychological domain (Akechi et al., 2011; Philip et al., 2013). Unmet healthcare needs refer to the gap between the healthcare services necessary for an individual to deal with their health needs and the actual services received (von Heymann-Horan et al., 2013). It is recognised that identification of unmet needs and treatment of distress in those surviving breast cancer should be managed much like those living with chronic disease (Philip et al., 2013). Therefore, regular assessment of the needs of these women are necessary, not only to identify unmet needs, but to guide supportive care interventions that are effective (Fiszer et al., 2014).

The supportive care of women living with a breast cancer diagnosis centres on addressing informational and psychological needs, but is also influenced by individual factors such as demographic, clinical, emotional, and psychosocial factors (Fiszer et al., 2014). Central to the transition from treatment to survivorship is one's ability to cope. Coping self-efficacy, or confidence in coping with a disease such as breast cancer is associated with better disease management and quality of life (QOL) (Lev and Owen, 2001; Northouse et al., 2002). Self-efficacy can be defined as, an individual's perceived ability to perform specified behaviours in order to adapt to changed circumstances (Bandura, 1997). Those with greater perceived confidence or belief about performing a task, skill or action may be more likely to engage in the behaviour (Wolf et al., 2005) which may result in successful outcomes being achieved (Lev and Owen, 2001). Previous research has indicated the existence of unmet needs to be strongly associated with psychological distress and/or poorer QOL (Akechi et al., 2011). Conversely, evidence suggests that among cancer patients, higher levels of self-efficacy are associated with decreased psychological distress and increased QOL (Philip et al., 2013; Rottmann et al., 2010). Importantly, high self-efficacy achieved early in the disease trajectory is predictive of positive long-term adaptation (Rottmann et al., 2010). Good quality communication with health care professionals is also associated with improved QOL for breast cancer patients (Engel et al., 2003) and higher levels of coping self-efficacy among this patient group (Alder and Bitzer, 2003; Collie et al., 2005).

The breast care nurse (BCN) is well positioned to provide the informational and supportive care needs required by women living with and beyond a breast cancer diagnosis, including women in geographically distant areas (Ahern et al., 2014). A recent study of "information and support needs of Australian women diagnosed with breast cancer" found that 89% of women surveyed were satisfied with the information received from the BCN and this level of satisfaction outweighed that received from other health professionals such as the surgeon and the cancer specialist (Ahern et al., 2014). Similarly, women surveyed also indicated a high level of satisfaction with support received from BCNs and those in the more regional or remote areas were statistically significantly more likely to rely on the BCN as a source of support (Ahern et al., 2014).

In Australia, best practice guidelines suggest that all women with breast cancer have access to a BCN to enable enhanced continuity of care and psychosocial support (Jones et al., 2010; National Breast Cancer Centre, 2005). However, studies have shown that not all women have access to such services (Campbell et al., 2006; Eley and Rogers-Clark, 2012). Breast care nurse service provision in Australia varies widely, often dependent on the work context and

with variation about when patients are discharged (Yates et al., 2007). Australian BCNs can be either McGrath BCNs, employed by the McGrath Foundation, or BCNs employed independently through various government health departments or other private healthcare organisations. In some large hospitals, BCNs have involvement typically from the point of diagnosis. Regardless, any patient with a diagnosis of breast cancer can self-refer to a BCN and receive physical, psychological and emotional support free of charge (McGrath Foundation, 2013). Breast care nurses can continue to provide support to patients long after treatment has been completed if patients continue to seek support (McGrath Foundation, 2013).

In earlier work, researchers "explored the role of the Australian BCN in the provision of information and support to women with breast cancer" (Ahern et al., 2014; Ahern et al., 2015). To explore this further, in this study it was hypothesized that Australian women with breast cancer who used the services of a BCN would have lower levels of unmet needs and higher levels of perceived self-efficacy. A secondary area of investigation was the potential for differences based on geographical residence.

2. Purpose and specific aims

The purpose of this study was to compare the unmet needs and perceived self-efficacy of women using the services of a BCN and based on geographical residency.

This study aimed to address the following research questions:

1. What are the most prominent unmet needs reported by women with breast cancer?
2. Are there differences in unmet needs or self-efficacy of women with breast cancer who use the services of a BCN compared with those who do not use BCN services?
3. Are there differences in unmet needs or self-efficacy of women with breast cancer living in urban areas compared to women with breast cancer living in regional, rural or remote areas?
4. What are the differences in frequency of use of services of a BCN reported by women with breast cancer living in urban areas compared to women with breast cancer living in regional, rural or remote areas?

3. Research design

This study involved the use of a cross sectional online survey.

4. Methodology

4.1. Instrument

The instrument consisted of three sections. Section One collected demographic information and items used in this section were consistent with an instrument used for a previous study (Ahern et al., 2014). The remaining sections of the instrument consisted of two well validated measures: the *Supportive Care Needs Survey (SCNS-SF34)* and the *Communication and Attitudinal Self-efficacy Scale for cancer (CASE-cancer)* (Boyes et al., 2009; Wolf et al., 2005).

The SCNS-SF34 is a tool for assessing the cancer patient's perceived level of need using 34 items divided into five domains: (1) physical/daily living needs; (2) psychological needs; (3) patient care/support needs; (4) health care system/information needs; and (5) sexuality (Boyes et al., 2009). Participants were asked to consider their breast cancer needs over the previous month and indicate their level of need using a Likert scale ranging from (1) no

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