Exploring the breast care nurse role in supporting women with breast cancer

Tracey Ahern

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Exploring the Breast Care Nurse Role in Supporting Women with Breast Cancer

Tracey Ahern, BNSc (Hons), BEd

Thesis submitted for the
Degree of Doctor of Philosophy
School of Nursing, Midwifery and Paramedicine

November 2015

Australian Catholic University
Graduate Research Office
PO Box 968
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Statement of Authorship and Sources
This thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma. No parts of this thesis have been submitted towards the award of any other degree or diploma in any other tertiary institution. No other person’s work has been used without due acknowledgement in the main text of the thesis.

The thesis is presented as a *Thesis by Publication* with a list of publications being presented in Appendix A and copies of published papers presented in Appendix B. All research procedures reported in the thesis received the approval of the relevant Human Research Ethics Committee (Appendix C, D and E). I can confirm that Chapters 1, 3a, 7 and 8 of the thesis were copyedited for conventions of language, spelling and grammar by Jacqueline Weening, JM Harvey Consulting.

I declare that I have received financial assistance from a number of organisations to support my doctoral studies. Organisations that have provided financial assistance are listed below.
### Summary of Financial Assistance

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Signature: JAAhern

Date: 5 November 2015
Statement of Appreciation
During the work of this doctoral research, I have received assistance from many individuals and organisations. First and most importantly, I would like to acknowledge my supervisors Professor Anne Gardner and Professor Mary Courtney, for their professional support and advice on all aspects of the work undertaken over the past three years.

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During recruitment for two of the studies undertaken during this research process, I received very good support from two well-known Australian organisations that help researchers find breast cancer participants for their research: Register4 and the Breast Cancer Network Australia Review and Survey Group. Both organisations were instrumental in recruiting participants for this research.

Finally, my family has been very supportive in my endeavours to undertake and complete my PhD. I am very appreciative of the encouragement and support I have received from them throughout this process.
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*Note: Table and figure numbers started at 1 for each chapter to maintain consistency of format of published papers.*
Layout of the Thesis by Publication
This thesis is submitted in the form of a series of published papers. It comprises
doctoral work which sought to investigate the information and support available to
Australian women with breast cancer, exploring particularly the role of the breast care
nurse (BCN), as well as differences experienced based on geographic location.

Chapter one gives background information and describes and justifies the research.
Chapter two provides a review of the literature and chapter three provides a
description of the methodology used throughout the doctoral research. Chapters four
through to six present the results of the three studies undertaken in this doctoral
research. Chapter seven draws together the results of the three studies by
describing and proposing a conceptual model to guide BCN practice in Australia.
Chapter eight provides a conclusion to the thesis.

An introduction to each chapter is provided to explain how the submitted publication
contributes to the overall body of knowledge. Style, structure and content of each
chapter/paper may vary from the actual published paper so as to maintain
consistency of format and referencing style throughout the thesis. Reference lists
are not provided for each chapter, however a full reference list is provided at the
completion of the thesis.

Overall, at the time of submission of the thesis, three papers have been published in
peer-reviewed journals, a forth has been accepted for publication and the fifth
manuscript is being amended after undergoing review. Full details of actual papers,
potential papers and conference presentations are presented in a research portfolio
(Appendix A).
Abstract

Background
Breast cancer is the most common female cancer worldwide and the incidence is increasing. Due to advances in diagnosis and treatment, the number of women surviving breast cancer is also increasing. Those living with and beyond a breast cancer diagnosis need access to a wide variety of information and support which may vary depending on their circumstances. Breast care nurses (BCNs) are well recognised by Australian breast cancer patients for the information and support they provide. However, even though the BCN role has existed within the Australian healthcare system since the 1990’s very little national research has reported on their role, including their different geographical work contexts. The Professional Navigation Framework, used in Canada, provided a useful theoretical framework to inform exploration of these gaps in service to breast cancer patients.

Aim
This national quantitative study exploring the perspectives of both women with breast cancer and breast care nurses had the following aims:

1. To investigate the information and support needs of women following primary treatment for breast cancer.
2. To explore the role of the breast care nurse in supporting women with breast cancer in different geographical locations.
3. To examine the unmet needs and self-efficacy of women diagnosed with breast cancer with and without the support of a breast care nurse.
4. To develop a patient-centred BCN supportive care conceptual model relevant to the Australian context.
Method
This 3-phase study involved the use of three cross-sectional self-report online surveys. Participants for Study One (n=325) and Study Three (n=902) were Australian women diagnosed with breast cancer and were recruited via two well-known Australian organisations providing access to women with breast cancer willing to participate in research. Participants for Study Two (n=50) were BCNs currently working in Australia. For all three studies, data were managed using SPSS statistical software. Statistics used included descriptive statistics as well as chi-square for comparisons where the sample size allowed.

Results
Study One results revealed that when compared to a similar study in 2002, some of the sources of information and support used by women with breast cancer have changed over time. Most notably, findings reveal the internet to be the most common method used in the present day by women with breast cancer seeking health information. The study also found that satisfaction with information sought through the internet was decreased compared to information sought through personal contact with health professionals such as the BCN. A new finding were that women in outer regional, remote and very remote areas were statistically significantly more likely to use the BCN for support ($\rho =0.044$).

Research conducted in Study Two found there were a number of differences between BCNs working in major cities and inner regional areas compared with those working in outer regional areas. Patterns of service indicated higher caseloads in urban areas, with fewer kilometres served. BCNs in outer regional, remote and very remote areas spent longer (an hour or more) consulting patients and were much less likely to be involved in multidisciplinary teams (MDTs). When undertaking their role in
as a BCN, knowledge based limitations, time constraints and servicing large geographical areas were noted as common barriers.

Study Three revealed that women with breast cancer have unmet needs regardless of time since diagnosis and many of these fall within the psychological domain. However, those with the support of a BCN had significantly lower levels of unmet need in 1/3 of unmet needs measured, with many of these in the psychological domain. Further, those with the support of a BCN had significantly higher levels of perceived self-efficacy in ‘seeking and obtaining information’ ($\rho \geq 0.001$) and ‘understanding and participating in care’ ($\rho = 0.032$).

**Conclusion**
Overall, the findings from the research, in combination with the underpinning theoretical framework, the *Professional Navigation Framework* have led to the development of a new conceptual model to inform Australian BCN practice in the provision of informative and supportive patient-centred care. The *BCN Supportive Care Model* illustrates the *essential elements* supporting the professional practice of BCNs in facilitating continuity of care and promoting patient/family empowerment to the patient/family at the centre of care. Importantly, ensuring the BCN role encompasses the *essential elements* described, requires both individual and organisational commitment with potential outcomes being enhanced BCN job satisfaction and improved patient outcomes.
Chapter 1: Introduction and Overview

Introduction
Estimates based on the most recent data available at the International Agency for Research on Cancer (IARC) show that “breast cancer is the second most common cancer in the world and the most frequent cancer among women with an estimated 1.67 million new cases diagnosed in 2012” (Ferlay et al., 2013, p. 1). Furthermore, breast cancer is now the second highest “cause of cancer death in developed countries (198,000 deaths, 15.4%), after lung cancer per year and the most frequent cause of cancer death in women in less developed countries (324,000 deaths, 14.3%)” (Ferlay et al., 2013, p. 1).

According to estimates published in 2012, breast cancer incidence in Australia follows the worldwide trend, making it the most common cancer among women with 14560 cases diagnosed in 2009 (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2012). By 2020, the number of new breast cancer cases among women is projected to be around 17210 (Australian Institute of Health and Welfare (AIHW), 2012b). However, the number of Australian women surviving breast cancer is increasing due to a variety of factors including advances in diagnosis and treatment.

Breast cancer treatment and care in Australia is delivered in public and private healthcare settings within urban, regional and remote areas. The clinical care of women with early breast cancer may involve surgery, radiotherapy, systemic therapy and supportive care (National Breast Cancer Centre, 2001). Following completion of treatment, follow-up is required and is guided by a document released in Australia in 2010 informed by current, high level evidence about follow-up care of women with early breast cancer (Cancer Australia, 2011).
Despite significant research funding and advances in healthcare in the past decade (Cancer Australia, 2012d) there is evidence nationally and internationally that many women are not given adequate information about their illness and treatment, nor receive enough practical and emotional support from health professionals (Aranda et al., 2006; Davis et al., 2004; Lawler, Spathonis, Masters, Adams, & Eakin, 2011; Raupach & Hiller, 2002; Vivar & McQueen, 2005). Therefore, follow-up care providers need to address not only the clinical management of their patients but also the management of psychological distress, anxiety or depression (Cancer Australia, 2011). Historically, addressing the needs of those residing in rural and remote areas has proven more difficult because cancer service capabilities are constrained by the difficulties servicing large geographical areas and the challenges in attracting and retaining a sufficiently skilled workforce in these areas (Health Workforce Australia, 2013).

The work of this doctoral research program investigates the information and support available to women diagnosed with breast cancer, with an important focus on quantifying the differences experienced in differing geographical regions of Australia. Central to the work of the doctoral program, is an exploration of the role of the BCN in providing information and support to Australian women with breast cancer. Unmet needs and perceived self-efficacy of women with breast cancer are also investigated.

The remainder of this chapter offers background information relevant to the doctoral program. The significance of the study, as well as study aims and research questions will be introduced. Background information provided in the following section provides an overall foundation from which to build on throughout the work of this thesis.
Background

Cancer in Australia
In Australia, cancer death rates have decreased, however the number of people diagnosed with cancer continues to increase (AIHW 2012a). Approximately one-third of people affected by cancer live in rural, regional or remote areas (Clinical Oncological Society of Australia & Medical Oncology Group of Australia, 2010), where people have poorer survival rates than those living in major metropolitan centres and are more likely to die within five years of diagnosis (Cancer Council Queensland (CCQ), 2009; Coory, Ho, & Jordan, 2013; National Rural Health Alliance Inc., 2009; Phillips, 2009; C. R. Underhill, Goldstein, & Grogan, 2006).

Breast Cancer Incidence and Survival in Australia
Breast cancer is the most common cancer among Australian women (Cancer Australia, 2012a) with the incidence of “breast cancer among women living in major cities and inner regional areas significantly higher than those living in outer regional, remote and very remote areas” (Cancer Australia, 2012d, p. 9). Further, “women living in the highest socioeconomic status areas have a significantly higher incidence of breast cancer compared with women living in lower socioeconomic status areas” (Cancer Australia, 2012d, p. 9). The incidence of breast cancer among Aboriginal and Torres Strait Islander women is significantly lower than in non-indigenous women, however breast cancer is “the most common cancer affecting Aboriginal and Torres Strait Islander women” (Cancer Australia, 2012d, p. 9). Variations in incidences of Australian women with breast cancer can be explained by the key protective factors that may reduce the risk of breast cancer. These key protective factors include childbirth before the age of 30, a higher number of full term pregnancies, breastfeeding for at least 12 months in total and undertaking physical
activity for two hours or more per week (National Breast and Ovarian Cancer Centre, 2009).

Due to advances in diagnosis and treatment, there has been an increase in relative survival after diagnosis of breast cancer from 72.6% in the five years 1982-1987 to 89% in the five years 2006-2010 (Cancer Australia, 2012a, 2012d), proving that large numbers of Australian women are now living with, or living beyond a breast cancer diagnosis (143,967 survivors in the previous 25 years). However, disparities in survival rates exist. Five-year relative survival rates in the years 2006-2010 were lower for women living in remote and very remote areas, as well as women with decreased socioeconomic status. “Aboriginal and Torres Strait Islander women had a significantly lower five-year crude survival than non-indigenous women” (Cancer Australia, 2012d, p. 15).

**Information and Support for Australian Women with Breast Cancer**

Mechanisms are essential to ensure that women with breast cancer and their families are receiving adequate information to make treatment decisions, as well as receiving support in coping with their initial diagnosis and beyond (Davis, Williams, Redman, White, & King, 2002). A search of literature regarding information and support for breast cancer survivors revealed a vast quantity covering many different areas. The information could be categorised into four distinct sections including:

a) quantity of information and support;
b) timing of information and support;
c) models of delivery of information and support and;
d) modes of delivery of information and support.
a) **Quantity of Information and Support**  
Meeting the information needs of patients with breast cancer has been challenging as evidenced by many reports since 2000 (Aranda et al., 2005; Beatty, Oxlad, B., & Wade, 2008; Connell et al., 2006; Davis et al., 2004; Davis et al., 2002; Girgis, Boynes, Sanson-Fisher, & Burrows, 2000; Oxlad, Wade, Hallsworth, & Koczwara, 2008; Vivar & McQueen, 2005). This is partly due to the sheer diversity of the sources of information available. First, treatment and medical care of breast cancer patients is usually managed by a MDT, all of whom provide varying levels of information to women receiving treatment. Information and support is also readily available from a range of breast cancer organisations. There are four major breast cancer organisations in Australia, each with different missions, that have formed a collaborative network aimed at promoting the best possible care and treatment for women diagnosed with breast cancer (Appendix G) (Breast Cancer Network Australia, 2010). Sources of the information and support for breast cancer survivors can also come from other nationwide organisations such as the Cancer Council Australia, Dragons Abreast Australia and Familial Cancer Centres (Breast Cancer Network Australia, 2010). Information and support may also come from community initiatives such as local breast cancer support groups, internet support groups, family, friends and fellow breast cancer survivors (National Breast Cancer Centre and National Cancer Control Initiative, 2003).

Despite the various sources of information and support available, studies suggest that patients with cancer and their families still experience dissatisfaction due to lack of coordination, lack of information as well as unmet psychological needs, (Beatty et al., 2008; Boynes, Girgis, D'Este, & Zucca, 2012; Cancer Australia, 2011; Connell et al., 2006; Fillion et al., 2012). Furthermore, the limited time constraints of providers
working in very busy clinics often cause challenges in meeting the needs of patients with cancer (Lawler et al., 2011; McCaughan & McSorley, 2007).

Increasingly, patients are turning to the internet in an attempt to meet some of their information and support needs. Due to the expansion of internet access, there are now thousands of websites offering cancer related information of variable quality and veracity (National Breast Cancer Centre and National Cancer Control Initiative, 2003). It is also well documented that some of the information available via the internet can be false, misleading or not applicable to the Australian context and use of the internet for health information regarding breast cancer should be undertaken with caution (National Breast Cancer Centre and National Cancer Control Initiative, 2003). Beaver et al. (2006) argue that information received from a professional and specialised source such as a BCN may be more useful and appropriate to women than sifting through the overwhelming and diverse amount of information on the internet.

b) Timing of Information and Support
Throughout the breast cancer continuum, survivors require information and support at various times. Mullan (1985) classified survivorship into three phases. The first phase, termed ‘acute survival’ begins with diagnosis and is a time which is dominated by cancer treatment. The second phase, known as ‘extended survival’ commences when the patient completes treatment and enters a phase of ‘watchful waiting’. The final phase described by Mullan (1985) termed ‘permanent survival’, occurs when the individual has remained disease free for some time and the likelihood of recurrence of disease is small.

In most countries, breast cancer patients enter a surveillance period after they have completed treatment whereby follow-up appointments with the treatment team aim to
detect any recurrence, monitor for treatment related side effects and provide psychosocial support (Jiwa, Halkett, Deas, & Meng, 2011). Many studies have found that women receive adequate information and support in the acute survival phase, however, as time goes on and women enter the second and third phases of survivorship, they report that the information and support provided to them diminishes (Beaver et al., 2006; Oxlad et al., 2008; Raupach & Hiller, 2002). With the growing numbers of breast cancer survivors in Australia, it is important that these women are adequately supported with accessible, quality treatment and psychosocial care (Lawler et al., 2011), regardless of the phase of survivorship.

c) Delivery Models for Information and Support
The provision of information and support is part of the follow-up care provided to women. However, often follow-up care tends to focus on the detection of cancer recurrence or new primary tumours and thus fails to address other information and support needs of breast cancer survivors, indicating a traditional medical focus rather than a nursing care focus (Bettencourt, Schlegel, Talley, & Molix, 2007; Thewes, Butow, Girgis, & Pendebury, 2004; Vivar & McQueen, 2005). In Australia, follow-up after completion of treatment is generally provided by oncology specialists (Brennan, Butow, Spillane, & Boyle, 2010; Brennan, Butow, Spillane, Marven, & Boyle, 2011). Alternatively, in other parts of the world, follow-up care can be the responsibility of primary care physicians, general practitioners(GPs) and BCNs (Brennan et al., 2010).

There have been a number of studies conducted both nationally and internationally to investigate preferred methods of follow-up for patients with breast cancer. A number of studies have found that most patients preferred the medical specialist to perform their follow-up (Brennan et al., 2010; Davis et al., 2004; Kimman, Dellaert, Boersma, Lambin, & Dirksen, 2010), but an alternating combination of medical specialist and
BCN was also acceptable (Kimman et al., 2010). With such an approach, Halkett et al., (2006) suggests that patients can take advantage of the dual methods of follow-up, expressing emotional concerns more easily to a BCN, while complementing this with regular contact with the medical specialist has been reported by women as important to promoting feelings of security (Kimman et al., 2010). A similar shared care arrangement between the medical specialist and the GP was also found to be preferred to follow-up care provided fully by the GP (Brennan et al., 2011).

There are also studies that demonstrate that both nurse-led and GP follow-up have been comparable to hospital based care led by specialist consultants in terms of disease detection and psychological outcomes (Baildam et al., 2002; Grunfeld et al., 2006). Baildam et al., (2002) suggests that follow-up care by BCNs may be superior to doctors as the BCNs were better able to detect psychological distress than medical practitioners. However, a systematic review of four randomised controlled trials comparing nurse-led follow up with physician-led follow-up for cancer patients cautioned that more research is needed before equivalence to physician-led follow-up can be confirmed, especially in relation to measures such as survival, recurrence, patient well-being and cost effectiveness (Lewis et al., 2009). Furthermore, a Canadian study found that patients were willing to be referred to their own primary care physician for follow-up treatment and few patients returned to oncology follow-up (Grunfeld et al., 2011). This reflects the ‘norm’ in British Columbia, where it is common to discharge patients solely into the care of their primary care physician soon after completion of treatment (Smith, Singh-Carlson, Downie, Payeur, & Wai, 2011).

A range of studies have also found that follow-up by GPs was not preferred by patients. Kimman et al. (2010) suggests that the GP was not preferred due to the
concerns patients had about communication between their oncologist and their GP. This view is also supported by Mao et al. (2009). A study of rural women in Canada also identified a problem with poor communication between local doctors and cancer specialists, leading to patients feeling that they received inadequate medical care (Gray, James, Manthorne, Gould, & Fitch, 2004). In addition, an Australian study by Jiwa et al., (2011) reported that most patients preferred to consult a BCN instead of their GP on matters related to their breast cancer, possibly because patients prefer practitioners who have been involved in their care from the initial diagnosis and therefore may offer the necessary support within the context of an established relationship (Halkett et al., 2006; Jiwa et al., 2011).

There are many models of follow-up care, however more research investigating the effectiveness of these models in Australia is needed. As more and more women enter phase two and three of survivorship as described by Mullan (1985), there is a continued need for health professionals to provide follow-up care (Brennan et al., 2010). Brennan et al. (2010) argue that specialist oncologists who predominantly look after follow-up care in Australia have massive clinical loads and new and sustainable ways of delivering care need to be considered to better utilise primary care physicians, breast physicians and BCNs in delivery of follow-up cancer care. To address this problem, a national project exploring models of shared care and their effectiveness is currently underway in Australia (Cancer Australia, 2012e).

In the literature, there is little current empirical evidence about the role of the BCN in providing follow-up care for women in Australia. When the role of the BCN was first introduced in Australia, some studies were conducted, but most were pilot studies or single site studies with small sample sizes (Hordern, 2000; Liebert & Furber, 2004; Liebert, Parle, White, & Rodger, 2001; K. White & Wilkes, 1998, 1999). In recent
times, little has been done to evaluate the effectiveness of the role and the gap in the literature has provided the focus of this doctoral research (See Chapter 3).

**d) Delivery Modes of Information and Support**
While there are various models of delivery of information and support offered through follow-up care, there are also various modes in which this can be delivered. For example, information and support can be delivered through face-to-face contact, telephone contact and through electronic media such as videoconferencing, Skype or email. While researching women’s preferences for the delivery of follow-up care, Kimman’s quantitative study (n=331) found that women prefer face-to-face contact to telephone contact during follow-up appointments for breast cancer (Kimman et al., 2010). Researchers undertaking a randomised control trial reported that telephone follow-up by BCNs was well received by participants, and is suitable for women at low to moderate risk of recurrence and those with long travelling distances or mobility problems (Beaver et al., 2009). This particular study however, was conducted in Britain and such initiatives in Australia have not been adequately researched to date (Shepherd, Goldstein, Olver, & Parle, 2008).

Where face-to-face contact is difficult, support via remote methods such as telephone, videoconferencing and the internet is promising but more research is needed in this area (Minstrell, Winzenberg, Rankin, Hughes, & Walker, 2008; Shepherd et al., 2008). These telehealth or telemedicine consultation methods have gained momentum in recent years, thereby allowing people in isolated areas better access to their urban based healthcare team as well as decreasing the need for outreach specialists to travel long distances to see patients (Sabesan et al., 2012).
The background literature provided here has enabled the identification of problems which this research study aims to address. These are presented in the next section of the paper.

**Problem Identification**
Through a synthesis of the literature about breast cancer in Australia and the information and support available to Australian women with breast cancer, four distinct problems have been identified:

1. **Unmet Information and Support Needs of Australian Women with Breast Cancer**
   Women diagnosed with breast cancer need large amounts of information and support (Minstrell et al., 2008; Raupach & Hiller, 2002), especially in the psychological domains and many authors identify that these needs remain unmet (Beatty et al., 2008; Davis et al., 2004; Fiszer, Dolbeault, Sultan, & Brédart, 2014; Girgis et al., 2000; Lam et al., 2013; Lawler et al., 2011; McGrath et al., 1999). Information provided to women with breast cancer in the form of patient education guides have been found to address physical and medical concerns, whilst lacking detailed information related to psychological concerns (Beatty et al., 2008). In addition, follow-up of breast cancer survivors tends to focus on the detection of recurrent disease by clinical examination, but little attention is given to patient education and meeting psychological needs (Brennan, Butow, Spillane, & Boyle, 2008). Studies have demonstrated that meeting the educational and informational needs of women with breast cancer is associated with better psychological outcomes as well as increasing the likelihood that patients will adhere with medical recommendations and treatments (Mallinger, Griggs, & Shields, 2004). Increasing adherence with medical treatments results in better health outcomes (Hibbard & Greene, 2013).
2 Dissatisfaction with Current Service Provision
Historically, cancer service provision has been described as inefficient, fragmented, confusing, and difficult to coordinate due to patients moving from one professional group to another in response to services required to meet their clinical needs (Carroll et al., 2010; Drury & Inma, 2009). Therefore, it has been recommended that all cancer patients have a central person who coordinates their care (Drury & Inma, 2009).

3 Disparities in Survival Rates
Survival rates for people diagnosed with cancer are reduced for some groups (Australian Institute of Health and Welfare (AIHW), 2012b). From 2006-2010, women living in remote and very remote areas had lower five-year relative survival than women living in all other areas (Cancer Australia, 2012d). Evidence shows that regardless of the cancer type, people living in rural, remote and very remote areas experience poorer cancer outcomes and lower rates of survival than people living in metropolitan areas (Cancer Australia, 2015; Coory et al., 2013; Olver, Marine, & Grogan, 2011). A large proportion of people living in remote and very remote areas include Aboriginal and Torres Strait Islander women. This population experienced a significantly lower five-year crude survival rate than non-indigenous women during the years 2006-2010 (Cancer Australia, 2012b). Women with lower socioeconomic status had a slightly decreased five-year relative survival from 2006-2010 (Cancer Australia, 2012d).

4 Barriers Regarding Access to Health Services in Rural and Remote Areas
Australians reside in urban, rural and remote locations with varying access to health services. In particular, people living in regional and remote areas do not always have access to the services or resources that are appropriate to their needs, leading to dissatisfaction with health service provision, as well as poorer patient outcomes.
(Drury & Inma, 2009; Olver et al., 2011). Some groups of people experience substantial barriers when seeking timely screening, diagnosis and treatment of cancer, leading to poor outcomes. Women with breast cancer living in rural and remote areas often have additional barriers to overcome such as lengthy travel distances for specialised treatment, the financial burdens of travel and accommodation, disruption to family lives, lack of treatment choice and lack of access to information (Bettencourt et al., 2007; Clavarino, Lowe, Carmount, & Balanda, 2002; Girgis et al., 2000; McGrath et al., 1999). Those in rural and remote areas also have higher risk of unmet psychosocial needs due to the unique set of needs that may be experienced by this group. Examples may include feelings of isolation due to lack of psychosocial support, greater stress resulting from the higher demands of traditional gender roles in rural and remote areas, and feelings of greater loss of privacy as a result of living in smaller communities (Bettencourt et al., 2007).

Health care models, such as that of the BCN were introduced in Australia to address the various needs of Australian women with breast cancer. Their role is to provide physical, psychological and emotional support to families experiencing breast cancer from the time of diagnosis, through and beyond treatment. It is recommended that treatment and follow-up of Australian women diagnosed with breast cancer should be managed by a MDT including a supportive care provider such as a BCN (National Breast Cancer Centre, 2005a). Breast care nurses have proven to be instrumental in ensuring continuity of care and hence better quality of care (Eley & Rogers-Clark, 2012). However, despite the introduction of models of care such as the BCN, unmet needs and dissatisfaction with service provision remain, as does the disparity in cancer survival and cancer health service provision. Therefore, additional research is necessary to investigate the provision of BCNs and their role in a range of geographical areas (Halkett et al., 2006; Jones, Leach, Chambers, & Occhipinti,
2010). In addition, exploring the ability of the BCN to address the unmet needs of women with breast cancer in rural areas is an area that is worthy of more research (Minstrell et al., 2008; Vivar & McQueen, 2005). These and other issues focusing on the role of BCNs in the provision of information and support for Australian breast cancer patients will be introduced in the following section.

**Specialised Nursing Roles for Cancer Patients**

The role of nurses working with cancer patients in order to address the many informational and supportive needs of patients, as well as improve continuity of care from diagnosis, through to the treatment phase and into survivorship has evolved over several decades in a number of countries in the Western world, including Australia, Canada, Europe, the United Kingdom (UK) and the United States (US) (Eicher et al., 2012; Shockney, 2010). Depending on the country and context in which they work, these nurses can be referred to as case managers, cancer care coordinators, cancer support nurses, follow-up nurses, breast specialist, breast cancer coordinator, BCNs or professional patient navigators (PPNs) (Fillion et al., 2012). These specialised nursing roles differ depending on the country and context in which the nurse works and historically the lack of clarity surrounding the scope of the role, skill level required as well as educational preparation has been an issue (Cruickshank, Kennedy, Lockhart, Dosser, & Dallas, 2008; National Breast Cancer Centre, 2005c). As the specialised nursing role continues to evolve, improvements are being implemented to address the lack of clarity surrounding the role, but evidence suggests there is more work to be done in this area (Cruickshank et al., 2008).
Breast Cancer Nursing Roles Worldwide
Over the past 25 years, the role of the BCN has evolved in many countries worldwide, leading to a variety of education models and programs being developed to prepare BCNs for their role (Cruickshank et al., 2008). The BCN in the Australian context is defined by Yates (2007) as:

‘a registered nurse who applies advanced knowledge of the health needs, preferences and circumstances of women with breast cancer to optimise the individual’s health and well-being at various stages across the continuum of care, including diagnosis, treatment, rehabilitation and palliative care’. (p. 13)

In the UK, breast cancer is managed by a MDT, where it is mandatory to have a BCN as a core member of the MDT (Taylor, Shewbridge, Harris, & Green, 2013). In Europe, the growing role of the BCN resulted in the need to develop European agreed guidelines on breast care nursing and training, commissioned in 2009 (Eicher et al., 2012). In the US and Canada, BCNs are referred to as PPNs and this role has been well documented since the navigator concept was introduced by Harold P. Freeman in 1990 (Case, 2011). Literature surrounding professional patient navigators has influenced the design of this study, particularly a theoretical framework known as the Professional Navigation Framework (Fillion et al., 2012). The relevance of this framework to the Australian BCN role holds promise but requires further investigation.

Professional Patient Navigator Model
In Canada and the US, patient navigator models were originally introduced to assist low income and medically underserved patients in overcoming barriers to cancer diagnosis and treatment (Freeman, 2004). However, over time, the model has evolved to assist people from all socioeconomic backgrounds (Wilcox & Bruce,
Since inception, patient navigators have proven to have the potential to improve cancer outcomes and transform complex, fragmented health care to a more patient-centred model of care (Koh, Nelson, & Cook, 2011). There are two types of patient navigators, including lay-patient navigators and professional patient navigators. White and Hall (2006) point out that PPNs must possess clinical expertise in oncology, have highly developed therapeutic communication and problem solving skills, and have a broad knowledge of the healthcare system and cancer resources. Their role extends beyond that of a cancer coordinator and “corresponds to a more comprehensive medical or social model of case management that values humanization of the care trajectory and empowerment of the patient and family” (Fillion et al., 2006, p. E59).

**Australian Breast Care Nurses**

In Australia during the 1990s, specialist BCNs were formally introduced to the health care system to facilitate better continuity of care and psychosocial support (Jones et al., 2010) for people diagnosed with breast cancer. The BCN model of practice is defined as a specialist practice, therefore requiring a higher level of knowledge and skill in the care of women with breast cancer (National Breast Cancer Centre, 2005c). Educational requirements include experience in oncology nursing as well as recommended minimum educational requirements such as a Bachelor of Nursing and a Post Graduate Diploma of Breast Care Nursing (Yates et al., 2007). The scope of specialist breast nursing practice is defined as occurring in the context of a model of care that enables the nurse to work collaboratively with patients contributing to patient-centred care, while also working collaboratively within the MDT (National Breast Cancer Centre, 2005c). Evidence suggests that this scope of practice results in enhanced continuity of care and collaborative practice resulting in improved outcomes for women with breast cancer (National Breast Cancer Centre, 2005c).
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. Evaluations of both McGrath BCNs and other BCNs have found that women under the care of a BCN have improved quality of care, impacting positively on their quality of life (Black & Farmer, 2013; Paynter, Fodero, Scuteri, Kerin-Ayres, & Tink, 2013). Since the introduction of the model of specialist care, the consensus view is that BCNs are valued highly by their patients (Eicher, Marquard, & Aebi, 2006; Halkett et al., 2006; Jones et al., 2010; Paynter et al., 2013; Reed, Scanlon, & Fenlon, 2010), however, there has been little contemporary, Australian-wide research which investigates and reports on the role of the BCN (Halkett et al., 2006; Jones et al., 2010). The information throughout this thesis responds to this gap in the literature.

**Underpinning Theoretical Framework**

A theoretical framework developed in the Canadian context has been chosen to underpin this research (Fillion et al., 2012). The *Professional Navigation Framework* as defined by Fillion et al. (2012) is presented in Appendix F. Fillion et al’s framework (2012) was developed in response to research reporting there to be no generally accepted definition for patient navigation and little agreement about the actual roles and responsibilities of professional nurse navigators (Wilcox & Bruce, 2010). While navigation was shown to increase patient satisfaction and decrease barriers to care, the key components of successful navigation were not clearly understood. Subsequently, there was a call for more research to explore and define the processes and roles of patient navigation (Fillion et al., 2012; Fillion et al., 2009).

In earlier work, Fillion et al. (2009) attempted to clarify the role of professional cancer navigation, proposing it was a professional role aiming to facilitate continuity of care.
and promote patient empowerment. The study resulted in the identification of a theoretical definition or framework. Further work was conducted to validate this bi-dimensional framework through empirical content validation involving three cancer care units in Canada and thus resulted in the elaboration and refinement of the Professional Navigation Framework (Fillion et al., 2012). This framework acknowledges the bi-dimensional nature of the role of the PPN as both patient-centred and healthcare-system orientated. The framework defines key roles, functions and concepts within the first dimension of ‘continuity of care’ (healthcare-system orientated) and the second dimension of ‘empowerment’ (patient-centred) and offers related concepts within each dimension.

Continuity of Care
Within this dimension of the framework there are three related concepts, namely: informational continuity, management continuity and relational continuity, which Fillion (2012) suggests were three organisational and health system-orientated concepts contributing together to create a consistent and connected experience of care for patients with cancer.

Informational continuity involves PPNs providing timely and tailored advice to the patient within the MDT (Fillion et al., 2012). The key to improving the continuity of information is the PPN’s ability to work closely with the MDT.

Management continuity involves PPNs screening for unmet needs at all stages of the cancer continuum and matching needs with appropriate services, resources and supportive care. Again, in maintaining management continuity, PPNs have a major role to play in collaborating with other health professionals within the hospital and community settings in coordinating patient care (Fillion et al., 2012).
Whilst the PPN works closely within the MDT, they remain an advocate for the patient and therefore work closely with the patient and family in all aspects of cancer care. Relational continuity refers to the ability of the PPN to maintain a constant therapeutic relationship with patients and family throughout the care trajectory (Fillion et al., 2012).

**Promoting Patient and Family Empowerment**

This dimension of the framework requires the PPN to work under a patient-centred model of care, whereby care is given in response to patient needs and preferences and clinicians and patients share decision-making surrounding their treatment and care (Rogers, Kennedy, Nelson, & Robinson, 2005). Therefore, the PPN contributes to clinical care by promoting patient and family empowerment through three concepts, including facilitating active coping, cancer self-management and access to supportive care (Fillion et al., 2012).

Active coping is facilitated through education and support to assist patients (and family) to maintain their sense of control and quality of life through problem solving and decision making. Professional patient navigators can be actively involved in promoting cancer self-management by working with patients to increase self-efficacy enabling them to better deal with health problems and symptom management, leading to an increased ability to accept the illness and regain control (Fillion et al., 2012). Supportive care encompasses the PPN roles of educating, supporting, modelling and coaching patients and families and advocating on their behalf for patient-centred care (Fillion et al., 2012).

The developers of this framework claim that the framework offers clarity to the roles and functions of professional navigators and as such believe that the framework can improve the effectiveness of cancer navigation programs. This framework has been
chosen to underpin this study because of the similarities between the roles of the PPN in the Canadian context and also that of the BCN in the Australian context. The literature surrounding BCNs revealed that the role varies much like the role of the professional navigator and more clarity is needed surrounding the role of the BCN, particularly in different geographical and clinical practice contexts. Therefore, the Professional Navigation Framework was selected to test its relevance to that of the role of BCNs in the Australian context and this evaluation will be discussed further in Chapter 7.

The Doctoral Research Program

Significance of the Research
Breast cancer is the most common cancer among women in Australia (Cancer Australia, 2012d) and worldwide (Ferlay et al., 2013). Breast cancer survivors are the largest group of cancer survivors in the western world (Fiszer et al., 2014). National and international guidelines recommend women with breast cancer to be cared for by a MDT, including a specialised BCN (Fillion et al., 2012; Kowalski, Ferencz, Brucker, Kreienberg, & Wesselmann, 2015; National Breast Cancer Centre, 2005c). The lack of defined roles for the Australian BCN is a major gap identified in the literature. This doctoral research program addressed this gap by gathering evidence on the roles BCNs play in the provision of information and support to Australian women with breast cancer Australia-wide. Importantly, this is the first Australian-wide study to examine the role of the BCN in the provision of information and supportive care comparing the responses of those residing in urban areas with those residing in rural and remote areas.
Aims of the Research
1. To investigate the information and support needs of women following primary treatment for breast cancer.
2. To explore the role of the breast care nurse in supporting women with breast cancer in different geographical locations.
3. To examine the unmet needs and self-efficacy of women diagnosed with breast cancer with and without the support of a breast care nurse.
4. To develop a patient-centred BCN supportive care conceptual model relevant to the Australian context.

This doctoral research consists of three studies, which are predominantly quantitative in design. The information that follows outlines the aim of each study and the research questions under investigation.

Study Aims and Research Questions

Study One: Information and support needs of women following primary treatment of breast cancer: a 10 year replication study

Background
Over a decade ago, Raupach and Hiller (2002) examined the use of and satisfaction with information and support following treatment of breast cancer from a sample of participants in South Australia. After gaining permission from the authors of this study, a new study was designed to replicate this needs analysis survey. The sample for the replication study was extended Australia-wide so that comparisons could be made between those living in urban areas with those living in rural and remote areas.
**Aim**
The purpose of this study was to examine the use of and satisfaction with information and support following treatment of primary breast cancer in the present day and compare the findings to the 2002 study. Additionally, performing geographical comparisons on a national scale were an important aim of this study.

**Research Questions**
1. What information is currently available to Australian women with breast cancer?
2. What is the level of satisfaction with information sources used by Australian women with breast cancer?
3. What sources of support are currently available to Australian women with breast cancer?
4. What is the level of satisfaction with sources of support used by Australian women with breast cancer?
5. What are the findings compared to a decade ago?
6. Are there geographic differences with information and support sources used by Australian women with breast cancer?

**Study Two:** A survey of the breast care nurse role in the provision of information and supportive care to Australian women diagnosed with breast cancer.

**Background**
This study responded to the research gaps identified in the literature by exploring the role of the Australian BCN in the provision of information and support to women diagnosed with breast cancer.
**Aim**
The purpose of this study was to investigate the self-report role of the Australian BCN in the provision of information and support to women with breast cancer. Additionally, performing geographical comparisons on a national scale were an important aim of this study.

**Research Questions**
1. What role differences occur between rural/remote and urban BCNs in Australia?
2. How does the self-report role of an Australian BCN compare with Australian Specialist Breast Care Nurse Competency Standards relating to the provision of education, information and support?

**Study Three: A survey of the unmet needs and self-efficacy of women diagnosed with breast cancer and the role of the breast care nurse.**

**Background**
This study was a follow-up study to the previous two studies and therefore the aim of this study was informed by the findings of the previous studies. The first two studies provided insight into the information and support available to women with breast cancer and the role of the BCN in providing such information and support, therefore aligning with the dimension of ‘continuity of care’ within the Professional Navigation Framework. However, there was a need to delve further to examine the concepts of ‘active-coping’ and ‘cancer self-management’ within the dimension of ‘promoting patient and family empowerment’ as outlined in the Professional Navigation Framework. Therefore, this study was designed to examine the differences in unmet needs and self-efficacy of women who have a BCN compared with women who do not have a BCN.
**Aim**
The purpose of this study was to compare the unmet needs and perceived self-efficacy of women who have the support of a BCN to women who do not have the support of a BCN.

**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 under the care of a BCN compared to those who do not have BCN care?
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 access to BCNs reported by women with breast cancer living in urban areas compared to women with breast cancer living in regional, rural or remote areas?

**Summary**
This doctoral research comprises three studies and forms a multi-perspective descriptive study investigating the information and support available to women in Australia with breast cancer, focussing particularly on the involvement of the BCN and the differences experienced according to geographical location. The research was designed after completion of a systematic literature review which revealed a number of research gaps (See Chapter 2). The perspectives of both BCNs and those living with a breast cancer diagnosis were explored in this study leading to results which serve as a knowledge base to expand theory and inform research and practice.
The thesis is organised as follows:

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Chapter 2: Literature Review

This chapter is presented in the form of a research publication, accepted on 1 December 2013 and published in print, March 2015.

Reference:

Significance to the Overall Thesis
The review was written during a systematic search of the literature surrounding the information and support available to Australian women with breast cancer undertaken in June-September 2012. The paper introduces key information and concepts guiding the development and implementation of subsequent research studies (Chapters 4-6). Overall, the paper presents gaps in the research literature and justifies the need for further quantitative research exploring the role of the Australian BCN in the provision of information and support to women with breast cancer.

In short, the identified research gaps were:

- Much of the contemporary research surrounding this topic has been based on qualitative data.
- The majority of contemporary research was based at single sites, often in a metropolitan city.
- There was a need for more investigation of the role of the BCN in different practice contexts and geographical areas.
Additional Literature since Publication
The paper presented in this chapter was written in 2012 and published in March 2015. To provide an update to this literature review, a new search was conducted in February 2015 using the same search terms. This search revealed one new paper matching the inclusion criteria.

This paper presents an evaluation of the McGrath Foundation’s Breast Cancer Nurses initiative. The evaluation involved surveying McGrath BCNs and conducting interviews with health professionals, interviews and focus groups of women who had been diagnosed with breast cancer and interviews with key stakeholders from breast cancer and cancer related fields (Paynter et al., 2013). This qualitative study involved 60 participants and provided data to demonstrate that the McGrath BCN initiative has had a positive impact on women diagnosed with breast cancer as well as on health services where a McGrath BCN is employed and on the health system. However, authors recommended further research gathering quantitative data to evaluate the economic benefits of the initiative and produce a more precise measure of the impact of a McGrath BCN after specific periods of time (Paynter et al., 2013). Unlike most studies included in the published review, this later study had a national focus. However the sample was confined to McGrath BCNs.
Literature Review: An exploration of the role of the Australian Breast Care Nurse in the provision of information and supportive care.

Abstract
Breast care nurses (BCNs) were introduced to the Australian health care system in the 1990s to facilitate better continuity of care and increase psychosocial support to women with breast cancer. Yet women with breast cancer, particularly those in rural and remote Australia have high levels of unmet supportive needs. The purpose of this literature review was to examine the role of the Australian breast care nurse in the provision of information and support to women with breast cancer.

A literature review was conducted using a number of databases from January 2006 to November 2012. Pre-set criteria were used, and nine research papers were identified; one randomised control trial, five quantitative studies, two qualitative studies and one mixed method study. Of the nine studies identified, only one attempted to explore the national perspective, however participants from Tasmania were not used.

Overall, the review revealed very few published Australian studies evaluating the role of the BCN since 2006. The results demonstrate a need for larger studies conducted on a national scale, using participants from diverse geographical areas to gain more insight into the level of access to BCN care experienced by Australian women from both urban and rural and remote areas. It is recommended that further research be undertaken in order to build up a body of quantitative data about the role of the Australian BCN in providing information and support to women.
Introduction
Cancer is a major cause of death in Australia (AIHW 2012a). Approximately one-third of people affected by cancer live in rural, regional or remote areas (Clinical Oncological Society of Australia & Medical Oncology Group of Australia, 2010). A number of studies have revealed that people with cancer in these areas have poorer survival rates than those living in major metropolitan centres (Australian Institute of Health and Welfare (AIHW), 2010, 2012a; Cancer Council Queensland (CCQ), 2009; National Rural Health Alliance Inc., 2009; Phillips, 2009; C. R. Underhill et al., 2006). The further from a metropolitan centre patients with cancer live, the more likely they are to die within five years of diagnosis (CCQ 2009). Therefore, there is still more work to be done to assist the many people who are diagnosed with cancer, especially those living in rural or remote areas.

Breast cancer is the most common cancer among Australian women with 12,567 cases diagnosed in 2007 (AIHW 2012b). By 2015, the number of new breast cancer cases among women is projected to be 22% higher than in 2006, with the numbers of women diagnosed with breast cancer estimated to be around 15,409 (AIHW 2012a). Despite the growing numbers of women being diagnosed with cancer, there has been an increase in relative survival after diagnosis of breast cancer from 72.6% in the five years 1982-1987 to 88.3% in the five years 2000-2006 (Cancer Australia, 2012a). In 2006, it was estimated that there were 143,967 breast cancer survivors who had been diagnosed in the previous 25 years (Cancer Australia, 2012a).

With the growing numbers of breast cancer survivors, there is a high need for accessible and quality post-treatment medical and psychosocial care (Lawler et al., 2011). There is evidence that many women do not have adequate information about their disease and treatment, nor receive enough practical and emotional support from health professionals (Aranda et al., 2006; Davis et al., 2004; Girgis et al., 2000;
Lawler et al., 2011; McGrath et al., 1999; Raupach & Hiller, 2002). Addressing these needs for rural women can prove even more difficult with rural health service provision challenged by issues of equity, coverage and supply (National Breast Cancer Centre, 2001).

In Australia in the 1990s, breast care nurses (BCNs) were formally introduced to the Australian health care system to facilitate better continuity of care and psychosocial support (Jones et al., 2010). The consensus is that BCNs are valued highly by their patients (Eicher et al., 2006; Halkett et al., 2006; Jones et al., 2010; Reed et al., 2010), however, there has been little contemporary research conducted to investigate and report the role of the Australian BCN (Halkett et al., 2006; Jones et al., 2010). The following review identified Australian research papers where breast care nurses and the provision of information and support were a component of research and discussion.

**Aim**
To conduct a review of the literature examining the Australian breast care nurse role in supporting women with breast cancer. The research questions the literature review aims to answer include:

1. What is the role of the Australian breast care nurse as reported in the current literature?
2. What evidence is there to report on the role of the Australian breast care nurse and what are the gaps in the literature?

**Methodology**
A number of databases including CINAHL, Medline, The Cochrane Library, and Academic Search Complete were searched. Two major searches were conducted to extract specific information for this literature review. First, a search was completed
where the main search term used was ‘breast cancer’, combined with the term ‘breast care nurse’. Papers were limited to those published from 2006 to 2012 since papers published earlier than 2006 had been reviewed in a Cochrane Review (Cruickshank et al., 2008) and a systematic review (Eicher et al., 2006). Other limiters were added to extract only research papers written in the English language, with a geographical subset of Australia and New Zealand, simply to examine only research relating to the Australian context. This search revealed 71 articles. To check for any other relevant papers, the main search term ‘breast care nurse’ was combined with terms such as ‘supportive care’, ‘psychosocial care’ and ‘follow up care’. This search did not reveal any further relevant papers. The abstracts of 71 papers were read and papers not meeting the selection criteria were excluded, leaving a total of 9 papers to review. Reference lists of key articles were manually scanned and important papers identified were accessed for additional information. This literature review was limited to original research only. Table 1 details the inclusion and exclusion criteria.

**Table 1 Initial inclusion/exclusion criteria**

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
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<tbody>
<tr>
<td>Published 2006 or later</td>
<td>Published prior to 2006</td>
</tr>
<tr>
<td>Original research papers, focus on breast care nurse role in the provision of information and support to women with breast cancer</td>
<td>Letters to the editor</td>
</tr>
<tr>
<td>English language only</td>
<td>Editorials</td>
</tr>
<tr>
<td>Australian research only</td>
<td>Brief research summaries</td>
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<td>Languages other than English</td>
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<td>Literature reviews</td>
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<td>Research conducted in countries outside Australia</td>
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<td></td>
<td>Discussion papers, about information, support and the breast care nurse role</td>
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<td></td>
<td>Grey Literature such as Government reports</td>
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</table>
Results
The nine Australian published studies found since 2006 included one randomised control trial, five quantitative studies, two qualitative studies and one mixed method study. Four of the studies investigated the role of the breast care nurse and provided a list of roles undertaken by the BCN in their findings (Halkett et al., 2006; Jiwa et al., 2010; Jones et al., 2010; Watts et al., 2011). Two of the studies reported on the patient satisfaction of information and support received from BCNs (Eley & Rogers-Clark, 2012; Eley, Rogers-Clark, & Murray, 2008). One study explored the access to BCNs (Campbell, Khan, Rankin, Williams, & Redman, 2006), one explored patient preferences for follow-up care by a BCN (Jiwa et al., 2011) and the remainder examined the effectiveness of a brief nurse-led intervention to address the needs of women with advanced breast cancer (Aranda et al., 2006). Many of the studies were conducted using exploratory research based at a single site. Only one study attempted to explore the national perspective. Eight of the nine studies were conducted using participants from a single state, therefore not exploring the national perspective. The papers are summarised in Table 2.

Only one randomised control trial was identified (Aranda et al., 2006), where 105 participants at four large urban hospitals were given a baseline survey and then randomised into two groups. The control group received the standard care given at the treatment site. The intervention group received carefully structured and timed care with a BCN. All participants were surveyed again at one month and three months post intervention. The results indicate that there were no significant differences between the two groups in terms of changes in quality of life or unmet needs from baseline. The researchers identified three possible explanations. First, the sample size was not large enough to detect differences between the two groups. Second, the uptake of recommended strategies were not implemented sufficiently,
therefore negatively affecting the success of the intervention. Third, the intervention was not intense enough to achieve change, indicating the need for more intervention sessions. As well as these problem areas, the BCNs involved in conducting the intervention noted that the one week time frame between the two components of the intervention was too short.

Three quantitative studies using cross sectional survey methodology were identified (Campbell et al., 2006; Eley & Rogers-Clark, 2012; Eley et al., 2008). Campbell et al. (2006) surveyed 544 women with early breast cancer and produced a comparison between women who received systematic BCN care and those who had no contact with a BCN. The results demonstrated that the provision of service of BCNs in Australia has been slow to occur as less than half (48%) of the women surveyed recalled having contact with a breast care nurse. Furthermore, only 1 in 9 participants received systematic BCN care, where systematic care involved care at three points in time, preoperatively, postoperatively and at follow-up. Those who received systematic BCN care were better informed and reported feeling better supported than those who did not. The researchers claimed that they have provided evidence of benefit in the Australian context and their findings lend weight to the consumer demand for enhanced BCN access. Eley et al. (2008) surveyed women with breast cancer in a rural and remote area of Queensland (n=51) and staff from multidisciplinary teams and senior managers to explore the role of the BCN in the Queensland’s Supporting Rural Women with Breast Cancer Project. The findings demonstrate that BCNs were of great value to patients from regional, rural and remote areas. However, this study has two major limitations; first, the rural and remote area under study was serviced by only one BCN. Second, the study did not interview women who had not received support from a BCN.
In the third study of this type, Eley and Rogers-Clark (2012), aimed to provide quantitative and qualitative data useful for understanding the experience of those who have support from a BCN. This study used a before and after retrospective design in which some of the sample were surveyed between 1-3 years after having contact with the BCN. It is possible that surveying people three years later may lead to inaccurate information being provided. In addition, the differences reported over the three year period may be explained by other, unrecognised changes in health services over time. The authors also expressed concern about participants’ ability to distinguish and therefore report accurately on the role as opposed to personality of the BCN. Yet again, this study did not explore the national perspective recruiting participants from a single site/state. However, in their favour, the researchers used participants representing both those who do and don’t have access to a BCN. Additionally, participants were from a regional health service, therefore exploring the perspectives of women from regional, rural and remote areas.

One quantitative study used longitudinal surveys (Jiwa et al., 2011). This study aimed to explore women with breast cancers’ preferences for surveillance follow-up, surveying participants at two time points, follow-up and three months post follow-up. They found that not all women with breast cancer prefer to consult a GP following breast cancer treatment, and many women preferred to consult with a BCN. The study participants were limited to a group based at a single site.

Watts et al. (2011) conducted an intervention study whereby the development and evaluation of a specialist metastatic BCN role was implemented. This study aimed to address the gaps in service provision of BCNs for women with metastatic disease and the results of the study suggest strong support from both patients and health professionals for the continuation and expansion of the service. Like many of the
studies critiqued in this review, this study was limited to participants at a single site in a large metropolitan area.

The mixed methods study by Jones et al. (2010) aimed to describe the scope of practice of the BCN by conducting in-depth interviews (Study 1) and a survey (Study 2) gaining the perspectives of BCNs and other key health professionals about BCN scope of practice. The researchers found that provision of information and support to people with breast cancer and their families were central to the role of the BCN. They also concluded that the BCN scope of practice differed across practice contexts. A small sample size of BCNs (Study 1 n=11, Study 2 n=27) located in only one Australian state and the limited sample of health professionals (Study 1 n=7, Study 2 n=21) were recognised as limitations and the authors recommended that the survey be replicated with a larger sample of BCNs and a more diverse sample of health professionals.

One qualitative study used in-depth, semi structured interviews of women after treatment for breast cancer (Halkett et al., 2006). This study aimed to explore patient’s perspectives on the role of the breast care nurse. The authors state that their study builds on the knowledge that most women appreciated the support that BCNs provide and provided insight into women’s perceptions of the different roles that the BCN takes on. This study was conducted at a single site, comprising urban, English speaking women only. It can be argued that the information gained from this study supports the role of the BCNs, but does not add any new information.

Jiwa et al. (2010) undertook a qualitative study, taping BCN-led consultations with 21 women attending a hospital-based breast cancer follow up clinic in order to report a thematic analysis of the consultations between BCNs and patients. The researchers concluded that the BCN model of care evaluated in this study has the potential to
improve the follow-up experience of patients, while also reducing the clinical workloads for health practitioners in both tertiary and primary health care settings. Like many of the exploratory studies critiqued here, this study was limited to participants from a single site.
### Table 2 Summary of Review Articles

Key search terms – Breast care nurses and follow-up care or supportive care, published 2006 or after.

Australian papers only in chronological order.

<table>
<thead>
<tr>
<th>Authors and Year of Publication</th>
<th>Study Design</th>
<th>Sample Size</th>
<th>Population/Site Used</th>
<th>Summary of findings and recommendations</th>
<th>Limitations</th>
</tr>
</thead>
</table>
| (Aranda et al., 2006)           | Randomised controlled trial. | 105         | Four large urban hospitals in Melbourne, Australia. | • No significant differences between the two groups in terms of changes in quality of life or unmet needs.  
• Women with high psychological needs benefit.  
• BCNs should undertake a routine assessment of patient’s needs and psychological status.  
• BCNs need skills to respond to emotional concerns. | • Timeframe between intervention and follow-up too short.  
• More intervention sessions may have produced greater changes in outcomes.  
• A larger sample may have detected more significant differences.  
• Sample - urban, English speaking women only.  
• Low consent and retention rate.  
• Participants from a single state. |
| (Campbell et al., 2006)         | Quantitative study (cross-sectional survey design). | 544 (76% response rate) | Population based sample, randomly selected through state and territory cancer registries | • Slow uptake of BCN use in Australia; 48% recalled having contact with a BCN.  
• Only 1 in 9 received systematic BCN care.  
• Systematic BCN contact positively influenced women’s perceptions of care, particularly re provision of support. | • All states/territories represented, except Tasmania. |
| (Halkett et al., 2006)          | Qualitative, study (in-depth interviews). | 18          | One major hospital in South Australia | • Provided women’s perspectives on BCN role and recognised that BCNs are important to women with breast cancer. | • Single site study.  
• Sample - urban, English speaking women only. |
| (Eley et al., 2008)             | Quantitative study (2 cross sectional surveys) | 51 patients, 18 stakeholders | Patients from rural and remote locations in Queensland. Stakeholders; Qld Health Staff. | • First study reflecting current national information of breast cancer patients’ views of BCN.  
• BCN considered of great value to regional, rural and remote patients.  
• Continuation of BCN program recommended by consumers and stakeholders. | • The area under study was serviced by only one BCN.  
• No comparison group; interviews were not done with women receiving no BCN support. |
<table>
<thead>
<tr>
<th>Study Authors (Year)</th>
<th>Study Type</th>
<th>Participant Information</th>
<th>Key Findings</th>
<th>Limitations</th>
</tr>
</thead>
</table>
| Jones et al. (2010)  | Mixed Method Study (in-depth interviews & survey) | 18 (Study 1 In-depth interviews) 48 (Study 2 Survey) Queensland Health employees (nurses and medical staff, including BCNs) | • Results describe scope of practice of the BCN from the perspectives of the BCN and other key health professionals. | • Small sample size in one Australian state.  
• The health professional sample was limited to administrators, nurses and doctors. |
| Jiwa et al. (2010)   | Qualitative study (taping nurse-led consultations) | 21 patients under the care of 4 breast care nurses. Participants attended hospital-based breast cancer follow-up clinic in Western Australia. | • The specialist breast nurse led follow-up model has potential to improve patient follow-up and reduce clinical workloads in both tertiary and primary health care settings. | • Participants limited to one Australian state. |
| Watts et al. (2011)  | Quantitative, intervention study (Post-test only) | 31 patients 17 health professionals Metropolitan, major teaching hospital. | • Metastatic BCN provides the opportunity to tailor treatment and supportive care to the needs of the individual and addresses a significant gap in service provision. | • Single site study.  
• Limited to women with metastatic breast cancer. |
| Jiwa et al. (2011)   | Quantitative, study (longitudinal survey) | 101 (Survey 1, response rate 38%) 60 (Survey 2, response rate 59.4%) One hospital based clinic. | • Not all patients prefer to consult with a GP after treatment. Many in this study were observed to consult a BCN instead. | • Single site study.  
• The two services being compared were not equivalent service providers – one offered free of charge (hospital-led BCN clinic), the other was offered at a cost (GP). |
| Eley & Rogers-Clark (2012) | Qualitative and Quantitative data collected (cross sectional survey). | 28 (BCN care) 22 (no BCN care) Large Australian regional health service. | • The BCN model has been slow to be adopted in QLD and this study supports continuation of the program and the creation of additional positions. | • Author expressed concern about participants’ ability to evaluate the BCN role, and not the person.  
• Single site study.  
• Recall bias due to a reliance of memories from past events. |
Discussion
After reviewing the literature pertaining to breast care nurse practice in Australia, several themes have emerged which are worthy of discussion. First, despite the BCN being a part of the Australian health system for 20 years, women with breast cancer still have high unmet support needs. Second, BCNs are not regulated by a professional body, nor do they have a consistent structure to their practice. They practice in a variety of different settings, all of which have different roles and expectations of BCNs. Third, the research literature surrounding Australian BCNs has consisted of predominantly exploratory, single site studies many of which were conducted in metropolitan areas. There was only one RCT identified in this review, therefore a clear lack of level one or two evidence (National Health and Medical Research Council, 2009). Each of the three identified areas is discussed below in the context of the wider literature about the needs of women diagnosed with breast cancer.

Meeting the Needs of Women Diagnosed with Breast Cancer
Breast care nurses were introduced in Australia to help provide continuity of care to women with breast cancer, and most studies in this review report that the breast care nurse is highly valued by patients (Campbell et al., 2006; Eley & Rogers-Clark, 2012; Eley et al., 2008; Halkett et al., 2006; Jiwa et al., 2010; Watts et al., 2011). However, current literature reporting on the role of the breast care nurse and their ability to meet the information and support needs of women with breast cancer is sparse. Psychosocial and psychological information and support remain largely unmet for women with breast cancer even though health services such as that offered by the BCN are available in Australia. Research spanning the past decade provides evidence that women diagnosed with breast cancer need a high amount of
information and support especially in the psychosocial and psychological domains and many of these needs remain unmet (Beatty et al., 2008; Davis et al., 2004; Girgis et al., 2000; McGrath et al., 1999). Although women report high needs in the psychosocial and psychological support domains, follow-up care tends to focus on clinical aspects of the disease and treatment process (Brennan et al., 2008) and clinicians need to be more receptive to symptoms related to treatment morbidity and to the information needs of their patients (Roche, 2006). Further to this, Beatty et al. (2008) found that many patient education guides given to women with breast cancer address physical and medical concerns, but detailed information relating to psychological concerns were lacking.

When reading the wider literature about the unmet needs of women with breast cancer, it becomes clear that those living in rural and remote areas often have additional barriers to face. A number of studies reported that patients in rural and remote areas may experience lengthy travel distances for specialised treatment, the financial burdens of travel and accommodation, disruption to family lives, lack of treatment choice and lack of access to information (Bettencourt et al., 2007; Clavarino et al., 2002; Girgis et al., 2000; McGrath et al., 1999). Furthermore, these studies concluded that those in rural and remote areas also have higher unmet psychosocial needs. In particular, Bettencourt et al. (2007) argues that rural women have a unique set of needs such as feelings of isolation due to lack of psychosocial support, greater stress resulting from the higher demands of traditional gender roles in rural and remote areas, and feel a greater loss of privacy as a result of living in smaller communities. There is strong evidence reporting the additional barriers faced by those living in rural and remote areas even though models of care such as that of the BCN were introduced in Australia to help to address the urban and rural or remote divide.
The Role of the Breast Care Nurse
Since introduction to the Australian health system the number of BCNs has grown, however it is difficult to ascertain exact numbers of BCNs currently employed in Australia. In recent years, organisations such as the McGrath Foundation have helped to raise the profile of breast care nurses in Australia. The McGrath Foundation was established in 2002 to create more breast care nurse roles to support Australian families experiencing breast cancer, particularly those in rural and remote areas. The McGrath Foundation sourced additional funding from the Australian Government in 2008 to support breast care nurses in 44 communities nationwide over four years. The latest figures reveal that as at April 2013, the McGrath Foundation has placed 83 breast care nurses in Australian communities (McGrath Foundation, 2013). Further to this, the McGrath Foundation has received additional Government funding of $19.5 million to increase the number of breast care nurses working for the McGrath Foundation (Australian Bureau of Statistics, 2013b).

Although the BCN position has been operating in Australia for almost 20 years, there is some doubt about whether all women with breast cancer have adequate access to a BCN (Campbell et al., 2006; Eley & Rogers-Clark, 2012). Eley and Rogers-Clark, (2012) explain that at the time of their study in 2008, there were only 16 BCN positions for a population of four million in Queensland. In the past there has been some debate about the smaller caseload of BCNs in rural and remote areas, making the role of the BCN in these settings unsustainable (National Breast Cancer Centre and National Cancer Control Initiative, 2003). The overall number is estimated to be between 300 and 500 Australia wide, but exact numbers are unknown (Cancer Council Victoria, 2013). With the growing numbers of women being diagnosed with breast cancer, it is important that all of these women have adequate access to a BCN.
and little has been done to quantify the BCN access available to women with breast cancer.

Breast care nurses in Australia do not appear to be overseen by a professional body and although available since the mid 1990’s, the delivery of this health care service varies widely and is somewhat inconsistent, often dependent upon the practice context or geographical area in which they work. Past research of BCN practice in Australia suggests limited use by breast nurses of a structured clinical pathway, wide variation in clinical aspects of the role, and an inconsistent approach to providing continuity of care from diagnosis through to the end of treatment (Victorian Centre for Nursing Practice Research, 2001; K. White, Wilkes, & Campbell, 1997). The Specialist Breast Nurse Competency Standards were introduced in 2005 (National Breast Cancer Centre, 2005c), however, there is little current evidence to report on the validity and use of these standards. Currently, the McGrath Foundation is developing a National Breast Care Nurse Directory. Improved networking and collaboration between breast care nurses, and improved referral pathways between BCNs and from other healthcare professionals are two of the intended benefits of the Directory (McGrath Foundation, 2012). Four of the studies in this literature review focussed on describing the role of the breast care nurse (Halkett et al., 2006; Jiwa et al., 2010; Jones et al., 2010; Watts et al., 2011). The roles of the BCN common across each of these articles are shown in Table 3. The information provided in these studies is somewhat generic, and research about the how the role of the BCN differs according to different work contexts or geographical locations does not exist in the current literature.

Even though, the BCN has been a part of the Australian health care service for the past two decades, there is a lack of rigorous research evaluating BCN service
delivery in Australia and the information in the discussion below further illustrates this.

**Gaps in the Research**

Reviewing specific literature and reading the wider literature surrounding research based on breast care nurses, has revealed a number of gaps in the research. There are many studies where researchers conclude they have provided strong evidence of the positive impact that BCNs have on the quality of care of women with breast cancer (Amir, Scully, & Borrell, 2004; Eicher et al., 2006; Eley et al., 2008; Halkett et al., 2006; Jiwa et al., 2010; Liebert & Furber, 2004; Szwajcer, Hannan, Donoghue, & Mitten-Lewis, 2004). However, a Cochrane Review of five randomised controlled trials assessing the effects of interventions carried out by BCNs on quality of life outcomes for women with breast cancer between the years 1966 to 2006 found the evidence to be inconclusive. The Cochrane Review concluded that further research is required before the impact of BCNs on aspects of quality of life for women with breast cancer can be known (Cruickshank et al., 2008). Possibly, the reason for paucity of evidence in this area may be the lack of internationally established definition of roles and functions of BCNs and the lack of methodically high quality studies.
<table>
<thead>
<tr>
<th>Study</th>
<th>Provision of information and support to cater for individual needs of patients</th>
<th>Co-ordination of patient care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Developing therapeutic relationships with patients</td>
<td>Educate, encourage, and support patients to self-manage different aspects of their disease*</td>
</tr>
</tbody>
</table>

*Although these roles are highlighted in one paper only (Jiwa et al. 2010), the authors identified several themes relating to the self-management of disease.
Since the development of the role of the BCN both in Australia and internationally, clear definition of the BCN role has not been achieved (Amir et al., 2004; Yates et al., 2007). Breast care nurses may have a variety of training, education and experience and their roles have developed in a variety of settings (Eicher et al., 2012). A systematic review of the effectiveness of specialised nursing in breast cancer postulated that there is a need for a more specific definition of the role and required skills of specialised nurses in breast care (Eicher et al., 2006). Ten studies were included in this review; however the studies differed with respect to the roles of specialised nurses as well as the measured outcome variables, making the comparability and generalizability of results limited. The findings of this review called for a more uniform definition of models of specialised nursing in breast care, as well as rigorous studies to evaluate their practice. Yates et al., (2007) also highlighted the inconsistencies in BCN role definition and suggested that these are likely to cause varied outcomes for women with breast cancer.

Investigating the differences in the BCN service based on geographical location has been identified as an area in need of more research. Two Australian qualitative studies, established that more research is needed to evaluate the provision of BCNs and the role of BCNs in varying geographical areas and practice contexts (Halkett et al., 2006; Jones et al., 2010). This need is supported by (Minstrell et al., 2008; Vivar & McQueen, 2005) who suggested that investigating the ability of the BCN to address the unmet needs of women with breast cancer in rural areas is an area that is worthy of more research. Another area recognised as worthy of more research involves investigating the financial benefits gained by the health service using BCNs (Eley & Rogers-Clark, 2012; Eley et al., 2008).
Conclusion
The provision of information and support to all Australian women with breast cancer through the BCN service is an area that needs more research as evidenced by the information provided in this review. It is clear that studies conducted on a larger scale, using participants from diverse geographical areas are needed to gain more insight into the level of access to BCN care experienced by Australian women from both urban and rural and remote areas. Additionally, there is a need for further research to investigate the differing roles that BCNs are expected to take on in varying geographical and practice contexts. It is recommended that further research be undertaken in order to build up a body of quantitative data about the role of the Australian BCN in providing information and support to women. These quantitative data will provide evidence on which to base recommendations to assist the efficiency of this health service which will in turn provide better outcomes for women using this service. Further to this, research into the differences based on work context or geographic location may assist to inform policy surrounding the role and scope of the Australian breast care nurse. For example, there are Competency Standards for Specialist Breast Care Nurses (National Breast Cancer Centre, 2005c) but an exploration of the validity and use of these standards is not evident in the research literature. An evaluation of the usefulness of these competency standards is therefore needed.
Summary
This chapter presented a review of the academic literature focussed on the role of Australian BCNs, concluding that contemporary research about the role of the Australian BCN was limited to a number of small-scale, single-site studies. No authors embedded their research or findings within a conceptual or theoretical framework.

The findings of this review assisted in the conception and design of this doctoral research program comprising three studies, with the aim of undertaking a larger scale, national study investigating the information and support available to women with breast cancer, and particularly the role the BCN plays in supporting these women. As well as reviewing the Australian literature, wider reading of the international literature was undertaken. This revealed additional international concepts, namely, professional patient navigation and a theoretical framework guiding professional patient navigation, known as the Professional Navigation Framework. This theoretical framework was selected to underpin the doctoral research (See Chapter 1). Therefore, unique to the Australian research about BCNs, the research described in this thesis was underpinned by a theoretical framework.
Chapter 3a: Thesis Methodology Overview

Introduction
This chapter gives an overview of the methods used throughout the doctoral research. The design of each of the three studies was preceded by the construction of an overarching study aim and associated research questions for the doctoral program which are outlined in Chapter 1.

Survey Methodology
In each of the three studies undertaken throughout this doctoral program, online surveys were used to gather data. Qualtrics software (Qualtrics, 2013) was used to produce and disseminate the surveys. Care was taken to structure each survey with well-developed instructions, and where possible, using items that had been previously validated. Features of online surveys such as no progression without an answer, built in skips, validation, multiple choice and drop down menus were used. Online survey methodology was chosen particularly due to the ease of dissemination and the gathering of responses from participants. Due to the limited time constraints of a doctoral research program, the online survey was deemed to be the quickest method to receive data (de Leeuw, Hox, & Dillman, 2008). This method was also the most cost efficient method due to the ability for the data to be automatically collated/downloaded and therefore dealt with single-handedly, without the need for employment of additional personnel (de Leeuw et al., 2008).

Participants
There were 325 women diagnosed with breast cancer participating in Study One. Study Two involved the participation of 50 Australian BCNs and there were 902 women diagnosed with breast cancer participating in Study Three.
**Participant Recruitment**

Rather than survey the general population, a specific subgroup was chosen to meet the needs of this research, namely Australian women with breast cancer and Australian BCNs. To assist with the recruitment of women with breast cancer to participate in Survey One and Three, two targeted organisations were approached for access to their members: *Breast Cancer Network Australia (BCNA) Review and Survey Group and Register 4* (Breast Cancer Network Australia, 2013b; Register4, 2014). Both organisations have been established to assist researchers find suitable participants for their research, and both organisations are particularly interested in assisting with breast cancer research. Applications were made and reviews of the proposed research were undertaken by each organisation prior to agreeing to assist with recruitment for this research. Register4 disseminated research information via their website and called for interested participants to click a link to the online survey. The BCNA disseminated research information via an email which also provided a link to the online survey.

Membership to Register4 is open to all men and women over the age of 18. As at October 2013, there were approximately 34800 members, representing all Australian states and territories. Ninety-eight percent of members were female and a small percentage of members (9%) identified as Aboriginal or Torres Straight Islanders (Register4, 2015). Alternatively, the BCNA Review and Survey Group are comprised of 2500 members all of whom are women who have been diagnosed with breast cancer. These members represent all Australian states and territories (Breast Cancer Network Australia, 2013b). Members of both of these targeted organisations have joined either Register4 or the BCNA Review and Survey Group with the understanding of the importance of research and are committed to assisting by participating in research projects. Therefore, they are very familiar with completion of
surveys and particularly online surveys. To cater for those who prefer not to use
technology, participants could request a paper copy of the survey to be mailed to
them with a stamped self-addressed envelope. This option was only taken up by one
participant in Study One and two participants in Study Three.

**Limitations**
The method of participant recruitment was chosen particularly for its ability in
accessing large numbers of targeted participants, at low cost. The limitations of this
approach are that participants self-selected their participation based on the contact
made through the organisation, resulting in a convenience sample. There was also
no way to calculate response rates due to the total number of respondents not being
known and the population not well-defined.

The snowball recruitment method was used for Study 2 which involved disseminating
information to Australian BCNs and asking for expressions of interest. Expressions
of interest were sought from Australian BCNs by informing them of the study at a
National BCN conference (Ahern, 2013), through the McGrath Foundation as well as
two Australian nursing publications: Nursing Review and The Australian Nursing
Journal (Appendix D). BCNs who expressed an interest in the research were also
asked to forward information about the research to other BCNs. This resulted in a
database of 70 BCN expressions of interest. All of those on the database were
issued an email inviting them to participate in the online survey. Again, it is
acknowledged that the limitation of participant recruitment undertaken for Study Two
was that a convenience sample was used.

**Ethical Considerations**
The National Statement on Ethical Conduct in Human Research (Australian
Government, 2007) was used to inform the design, ethical review and conduct of
human research proposed in this doctoral program. Ethical approval for all three studies was granted through the Australian Catholic University Human Research Ethics Committee (Appendix C, D and E). Ethical issues for this research include informed consent, confidentiality and appropriate treatment of vulnerable groups.

**Informed Consent**
Participation was voluntary and prior to consent and survey completion, participants were supplied with an online version of the participant information letter supplying sufficient information to allow for an adequate understanding of both the proposed research and the implications of participation (Australian Government, 2007). Consent was expressed by submission of a completed survey and this was stated in the Participant Information Letter (Appendix C, D and E).

**Confidentiality**
Participants of any research study have the right to expect that any data they provide will be kept in the strictest confidence (Polit & Beck, 2008). All data collected were stored electronically and were password protected. In each of the three studies, detailed address data were collected to identify the geographic location of each participant; however, names of participants were not collected. Further, collection of Internet Protocol (IP) addresses of each participant was a default process of the online survey software. However, steps were taken to ensure that confidentiality and privacy were maintained by first deleting all IP addresses from the database and identifying each record by a unique number. Second, an Australian Bureau of Statistics (ABS) Remoteness Area (RA) code was manually allocated to the physical residential/workplace address of each participant to identify their geographical location (Australian Bureau of Statistics, 2013a). These RA codes were consistent with the latest available information from the ABS and were allocated using an
address coding tool on the ABS website (Australian Bureau of Statistics, 2013b). Once the RA code was allocated, all other information relating to place of residence was deleted from the database to protect the identity of participants.

**Treatment of Vulnerable Groups**
Study One and Three involved surveying women who had been diagnosed with breast cancer. Women with cancer are not specified as a vulnerable group in the National Statement on Ethical Conduct in Human Research (Australian Government, 2007). However, researchers need to estimate the risk of harm to the participant (Australian Government, 2007) and minimise risks to participants as far as possible. Study one and three were organised in such a way that the information gathering process would not take up too much of the participant’s time or compromise their health care or comfort in any way (30 minutes). However, reflecting on the breast cancer experience and answering questions about one’s health support systems for example, may in some cases affect the psychosocial well-being of a participant who is particularly vulnerable. Such risks were recognised and contact numbers for counselling services for women with cancer were provided to all participants in the Participant Information Letter (Appendix C, D and E).

**Data Collection, Management and Analysis**
Data collected were the completed survey instruments. The protocols implemented to maintain the integrity of data during collection, storage and retention are consistent with guidelines outlined in the National Statement on Ethical Conduct in Human Research (Australian Government 2007). Since the survey data were collected in an on-line format, data were password protected and only accessed by the student researcher and the principal supervisor.
SPSS Statistics Software, version 20.0 was used to manage and analyse the data in the form of closed items for all three studies (IBM Corp, 2011). The quantitative data analysed comprised nominal and ordinal data. Raw data were downloaded from the Qualtrics online survey software (Qualtrics, 2013). Data cleaning was then conducted primarily to delete responses that had not completed a significant portion of the survey, such as providing inadequate address information, or exiting the survey very early.

After data were cleaned, frequency tables were generated to allow a summary of the results at a glance. Further inspection of data in frequency tables often resulted in a number of fields being re-coded to combine categories. Statistical analysis was then undertaken and results were tabulated before being reported. There were very few open ended questions on the surveys and these were analysed to find recurring themes and add richness to the quantitative data. Specific details of statistical analysis performed are provided in chapters presenting the results of each of the three studies.

**Conclusion**
Chapter 3a provided a summary of methodology used throughout the doctoral research. Following, in Chapter 3b, is a detailed account of the methodology used in Study Two. Chapter 3b is presented in the form of a research publication.
Chapter 3b: Methodology for Study Two

This chapter is presented in the form of a research publication, in press, accepted 22 October 2015.

Reference:

Significance to the Overall Thesis
The literature review detailed in Chapter 2 highlighted a need for further research into the role of the BCN in the provision of information and support, particularly including participants Australia-wide and comparing any differences based on geographic location of work context.

There were no pre-existing instruments suitable to investigate the role of the BCN and hence a new instrument was formulated. The process of developing this new survey instrument was completed in a methodological way including item generation, item selection, testing for face validity and content validity, as well as pilot testing and reliability checks including internal consistency being undertaken (de Leeuw, Hox & Dillman, 2008). The final version of the survey was presented to participants as a self-report online survey as this was deemed to be the most effective and efficient way to survey participants on a national scale (de Leeuw, Hox & Dillman, 2008). A copy of the *Breast Care Nurse Survey* is provided in Appendix H.
Abstract
This paper reports the development of a survey instrument to explore the role of the breast care nurse (BCN) in the provision of information and support to Australian women with breast cancer, as well as the differences experienced by BCNs working in urban, rural and remote areas.

A comprehensive literature review and a panel of experts were used to inform the survey questions. The instrument was developed in an online format and pilot tested by a group of BCNs before being issued to participants.

The final version of the Breast Care Nurse Survey consists of 59 items organised into three sections. The survey was completed by 50 BCNs. Cronbach’s alpha for Section Three of the survey was .935 indicating strong internal reliability, however further validation of this instrument is recommended.

This is the first national survey to collect data about the role of the BCN in Australia, specifically related to the provision of education, information and support and the perceived barriers to undertaking the role.
**Introduction**
Breast cancer is the most common cancer among Australian women with 12,567 cases diagnosed in 2007 (Australian Institute of Health and Welfare (AIHW), 2012b). By 2015, the number of new breast cancer cases among women is projected to be 22% higher than in 2006, with the numbers of women diagnosed with breast cancer estimated to be around 15,409 (Australian Institute of Health and Welfare (AIHW), 2012b). There is evidence many women do not have adequate information about their disease and treatment, nor receive enough practical and emotional support from health professionals (Aranda et al., 2006; Davis et al., 2004; Girgis et al., 2000; Lawler et al., 2011; Raupach & Hiller, 2002). Addressing these needs for rural women can prove even more difficult with rural health service provision challenged by issues of equity, coverage and supply (National Breast Cancer Centre, 2001).

Specialist breast care nurses (BCNs) were formally introduced to the Australian health care system in the 1990s to facilitate better continuity of care and psychosocial support for people diagnosed with breast cancer (Jones et al., 2010). Evidence shows that BCNs are valued highly by their patients (Eicher et al., 2006; Jones et al., 2010; Reed et al., 2010), however, there has been little contemporary research conducted to investigate and report on the role of the Australian BCN (Halkett et al., 2006; Jones et al., 2010). This paper describes the development of a survey instrument to explore the role of the Australian BCN in the provision of information and support to women with breast cancer, with a particular focus on the differences between BCNs working in urban versus rural and remote Australia.

**Background**
In Australia, patients are treated in both public and private sectors and in urban, regional, rural and remote areas. Cancer care is delivered in a variety of settings with a wide range of services provided. In 2004, the Australian government
established a National Service Improvement Framework for Cancer which recommended a more coordinated approach to cancer care was required in which services be provided within a patient-centred and multidisciplinary framework (National Breast Cancer Centre, 2005a). The care of Australian women with breast cancer involves health professionals working collaboratively in multidisciplinary teams aiming to meet the multiple health needs of patients (National Breast Cancer Centre, 2005a, 2005b). As a member of the multidisciplinary team, the specialist breast care nurse was introduced in Australia in the mid 1990’s to assist women with breast cancer through all aspects of the cancer care continuum (National Breast Cancer Centre and National Cancer Control Initiative, 2003). A description of the evolution of the role of the Australian BCN follows.

**The Evolution of the Australian BCN**
Since the introduction of the BCN to the Australian health system the number of BCNs in Australia has grown, however the exact number of BCNs currently employed in Australia is not known as no database is maintained (Ahern & Gardner, 2015). In recent years, organisations such as the McGrath Foundation have helped to raise the profile of breast care nurses in Australia. Jane McGrath personally recognised the importance of having a breast care nurse during her treatment of breast cancer and as a result, the McGrath Foundation was established to fund more breast care nurse roles to support Australian families experiencing breast cancer, particularly those in rural and remote areas (McGrath Foundation, 2013). The McGrath Foundation sourced additional funding from the Australian Government Department of Health and Ageing in 2008 for funding of breast care nurse support in 44 communities nationwide over four years. As at April 2013, the McGrath Foundation had placed 83 breast care nurses in Australian communities (McGrath Foundation, 2013). Further to this, the McGrath Foundation received additional Government funding of $19.5
million to increase the number of breast care nurses working for the McGrath Foundation (Australian Bureau of Statistics, 2013b).

Although the BCN position has been operating in Australia for almost 20 years, there is some doubt about whether all women with breast cancer have adequate access to a BCN. Campbell, Khan, Rankin, Williams & Redman (2006) undertook a quantitative study (n=544) to explore access to BCNs by Australian women with breast cancer, with a focus on access to systematic BCN care. Systematic care was defined as having contact with a BCN at least three times; preoperatively, postoperatively and at follow-up. In this study, over half of the women surveyed had no BCN contact and only 11% received systematic BCN care (Campbell et al., 2006). Further, research conducted by Eley and Rogers-Clark (2012), found adoption of the BCN model to be slow, with only 16 BCN positions for a population of four million in Queensland, Australia. Historically, there has been debate about the smaller caseload of BCNs in rural and remote areas suggesting the role of the BCN in rural and remote settings is unsustainable (National Breast Cancer Centre and National Cancer Control Initiative, 2003).

Breast care nurses in Australia are employed in a variety of healthcare settings and delivery of this health care service varies widely. Research suggests there is disparity of clinical roles, use of structured clinical pathway and inconsistent provision of continuity of care between BCN practice in Australia (Victorian Centre for Nursing Practice Research, 2001; K. White et al., 1997). Currently, the McGrath Foundation is developing a National Breast Care Nurse Directory. Improved networking and collaboration between breast care nurses, and improved referral pathways between BCNs and from other healthcare professionals are two of the intended benefits of the Directory (McGrath Foundation, 2012). In Australia, the development of competency
standards and educational requirements was regarded as an important step in addressing issues of role variation amongst BCNs (Yates et al., 2007).

**Competency Standards**
In 2003, the National Breast Cancer Centre commissioned a project to define a set of Specialist Breast Nurse Competency Standards in an attempt to standardise the role of the BCN in terms of outcome measures, training and education (Yates et al., 2007). This project also noted the importance of the need to reflect the broad dimensions of specialist breast nurse practice (Yates et al., 2007). As a result, the Specialist Breast Nurse Competency Standards were developed in Australia in 2005 to inform policy and procedure development, assist the community’s understanding of the purpose of these nurses, provide a framework for curriculum development and evaluation and provide guidance for health workforce planning (National Breast Cancer Centre, 2005b). The Specialist Breast Nurse Competency Standards include five domains, each with associated competency standards, competency elements and performance criteria. These competency standards should be used in conjunction with other relevant competency standards for registered nurses and advanced practice nurses providing a framework that BCNs must meet to ensure that women with breast cancer are cared for by nurses who are well equipped to provide safe and effective nursing care (National Breast Cancer Centre, 2005c; Nursing and Midwifery Board of Australia, 2006, 2013).

There is a lack of rigorous research evaluating BCN service delivery in Australia as reported in a recently published literature review (Ahern & Gardner, 2015). This review revealed the provision of information and support to all Australian women with breast cancer through the BCN service is an area requiring more research. It was recommended that studies be conducted on a large scale, using participants from
diverse geographical areas to gain an insight into the level of access experienced by
Australian women from both urban and rural and remote areas. Additionally, a gap in
evidence on the differing roles of BCNs working in varying geographical and practice
contexts was identified (Ahern & Gardner, 2015).

Therefore, a study to address this gap was designed and a new survey instrument
developed. This paper describes the process followed to develop and test face
validity and reliability of a survey instrument to explore the role of the breast care
nurse in the provision of information and support to Australian women with breast
cancer in both urban areas and rural and remote areas.

Method
A literature review of published material (2006 to 2012) was completed to identify
current research and surveys developed in the area of BCN (Ahern & Gardner,
2015). The authors from three Australian studies and one United Kingdom study
were contacted to source pre-existing BCN survey instrument who then provided
copies of their surveys (Eley & Rogers-Clark, 2012; Fallowfield, 2012; Watts et al.,
2011). The surveys sourced were useful for item generation, however none could be
used in their entirety to address the research questions for this study. Therefore, a
new survey instrument was developed.

Item Generation Phase
Based on a review of published literature, the authors generated a pool of items
relevant to exploring the role of the BCN in different contexts and geographical
locations. As well, items were added to examine of the breadth of the BCN role in
the provision of education, information and support and perceived barriers to
undertaking their role. Two items collecting demographic detail (See Items 1 and 2 in
Table 1) were replicated from a pre-existing survey completed in the United Kingdom
Questions collecting specific geographical information were consistent with a previous survey conducted by the authors (Ahern, Gardner, & Courtney, 2014) and were based on the latest available information from the Australian Bureau of Statistics (Australian Bureau of Statistics, 2013a). This required allocation of an Australian Bureau of Statistics Remoteness Area (RA) code to each participant enabling comparisons between respondents working in urban areas with those working in rural and remote areas. Collection of geographical data in this way is useful for enabling direct comparison of results with other studies exploring geographical differences.

The performance criteria for Specialist Breast Nurse Competency Standards 1.1, 1.2, 1.3, 4.1 and 4.2 were used as a framework for generating items to explore the breadth of the BCN role in the provision of education, information and support and the regularity with which they undertake these activities that is, their perceived ability to undertake these activities (National Breast Cancer Centre, 2005b). Given the lack of consistency about the role in Australia in the published literature, the researchers considered that national competency standards were an appropriate source for description of the type of care that might be expected of BCNs. Frequency was explored as a way of providing baseline data about the potential for these competencies to be realised.

**Item Selection Phase**

**Content and Face Validity**
A panel of five experts was chosen to evaluate the draft survey for comprehensiveness, clarity and completeness. These experts included two research academics with extensive experience developing and testing survey instruments, one currently practicing breast care nurse, one representative from the McGrath
Foundation and one representative from the Breast Cancer Network Australia. This panel of experts was provided with a draft copy of the survey and an evaluation form which guided the panel to comment on the content and structure of the survey.

Completed evaluation forms from the expert panel were collated and feedback was discussed within the research team, resulting in substantial modification of the draft survey to reflect this feedback. A number of suggestions were made to refine terminology or vocabulary and these were followed. A question was added to determine how many of the participants were McGrath BCNs. Questions related to time frames were carefully considered and altered to demonstrate clarity of provision of care, eg per week/month. The relevance of two items were questioned and subsequently deleted. The questions exploring competency standards were restructured to eliminate ambiguity. Subsequently, the survey was transformed into an online format using Qualtrics software (Qualtrics, 2013). Five ‘test runs’ were completed to check flow and design resulting in minor alterations to improve text and structure.

**Pilot Testing**

Ethical approval was granted (2013 196N). Snowball sampling was used to generate a database of expressions of interest in this research from Australian BCNs (de Leeuw et al., 2008) resulting in a total of 70 expressions of interest. Three breast care nurses were randomly chosen from this database of 70 Australian BCNs to test the face validity of the online version. They were asked to complete the online survey as well as the evaluation form used by the panel of experts. The data collected in this evaluation was used solely for assessment and improvement of the survey design.
Internal Reliability
After item selection and pilot testing was finalised, the final version of the survey was distributed in August 2013 to all 70 BCNs to assess internal reliability. All data were analysed using SPSS Version 20.0 (IBM Corp, 2011). Cronbach’s Alpha, the most frequently used indicator of internal reliability, was used to test and report on internal reliability (McDowell, 2006).

Results

Survey Composition and Reliability
The final version of the survey consisted of three sections which comprised of a total of 59 structured items with 26 of these questions allowing for additional open ended responses. Section One (13 structured items) collected data about the education, experience and qualifications of each participant. Questions requesting the physical workplace address of the participant were required to accurately apply an Australian Bureau of Statistics RA code to each participant (Australian Bureau of Statistics, 2013a). These codes were allocated using an address coding tool on the ABS website (Australian Bureau of Statistics, 2013b). Once these codes were allocated, detailed address information was deleted from the database to protect the identity of participants.

Section Two (20 structured items) collected data about the work context and caseload of the BCN. Questions were asked to determine the average caseload of BCNs, the average consult times, methods of consult used, whether travel is involved as well as questions about clinical characteristics of patients.

Since there were no pre-existing instruments available to explore the kinds of care BCNs are expected to deliver, the Specialist Breast Nurse Competency Standards (National Breast Cancer Centre, 2005b), specifically those relating to the provision of
education, information and support were used as a framework for Section Three. Section Three comprised 26 structured items, with each item also allowing for an open ended response. In this section performance criteria for Competency 1.1, 1.2, 1.3, 4.1 and 4.2 were listed and respondents were asked about the regularity that each of these are undertaken during their work as a BCN using a four-point Likert scale (always, sometimes, rarely, never). Respondents were also asked to explain any perceived barriers to undertaking each of the competency performance criteria. A sample of survey questions is provided in Table 1.

Of the 60 participants who began the survey, 50 completed the survey, resulting in a completion rate of 83%. Accurate population data are not available because there are no national data specifying the number of BCNs working in Australia, however it is estimated that there could be up to 400 working in Australia (Paynter, 2013). The demographic and professional characteristics of respondents are summarised in Table 2. Cronbach’s alpha was calculated for Section Three only. The statistic was 0.935 indicating strong internal reliability.
### Table 1  Sample of survey questions in each section of the survey

#### Section 1  Your education, experience and qualifications

1. How many years have you been working as a breast care nurse?
   - [ ] Less than 1 year  
   - [ ] 1-2 years  
   - [ ] 3-5 years  
   - [ ] 6-10 years  
   - [ ] 11+ years

2. Are you employed?  
   - [ ] full time  
   - [ ] part-time

3. What is your highest qualification?
   - [ ] Hospital Trained Registered Nurse  
   - [ ] Bachelor of Nursing  
   - [ ] Graduate Certificate  
   - [ ] Graduate Diploma  
   - [ ] Master of Nursing  
   - [ ] PhD

4. Do you have a qualification in Breast Care Nursing?
   - [ ] Yes  
   - [ ] No

#### Section 2  Your work context

1. What is your CURRENT patient case-load?
   - [ ] 0-10 patients  
   - [ ] 11-20 patients  
   - [ ] 21-30 patients  
   - [ ] 31-40 patients  
   - [ ] 41-50 patients  
   - [ ] 50-100 patients  
   - [ ] 100+ patients

2. Approximately how many NEW breast cancer patients do you see each month?
   - [ ] None  
   - [ ] 1-5  
   - [ ] 6-10  
   - [ ] 11-20  
   - [ ] 21-30  
   - [ ] 31-40  
   - [ ] 40+

3. How soon after a patient is diagnosed with breast cancer do you consult with the patient?
   - [ ] At diagnosis  
   - [ ] Within one or two days  
   - [ ] Within one week  
   - [ ] More than a week

4. How regularly do you consult with patients within the first MONTH of diagnosis of breast cancer?
   - [ ] Never  
   - [ ] Daily  
   - [ ] 2 – 3 times per week  
   - [ ] Once a week  
   - [ ] Once a fortnight  
   - [ ] Once per month  
   - [ ] As needed basis
### Table 1 (Continued)

#### Section 3  Provision of education, information and support

When thinking about the education, information and support that you provide in your role as a BCN:

1. How regularly do you undertake any of the following activities? Please select one response from column 2*

2. Do you perceive there to be any barriers to you being able to fulfil each of these activities? Please explain your answer in column 3** and simply write an 'X' if you perceive there to be no barriers.


<table>
<thead>
<tr>
<th></th>
<th>*Regularity Undertaken</th>
<th>**Barriers Perceived</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Always</td>
<td>Sometimes</td>
</tr>
<tr>
<td>1.1a</td>
<td>Demonstrate comprehensive and advanced knowledge and appreciation of the experience and impact of breast cancer and its treatment on the physical, psychological, social, sexual and spiritual well-being of clients and their family/significant others</td>
<td></td>
</tr>
<tr>
<td>1.1b</td>
<td>Use contemporary standards and guidelines to inform comprehensive and timely assessment of current and potential support needs across the continuum of breast cancer care.</td>
<td></td>
</tr>
<tr>
<td>1.1c</td>
<td>Routinely assess all clients for psychosocial risk factors and distress at the time of diagnosis and on a regular basis using a systematic evidence-based approach.</td>
<td></td>
</tr>
</tbody>
</table>
### Table 2 Demographic and professional profile of breast care nurse respondents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total n=50</th>
<th>MajorCities n=20</th>
<th>InnerRegional n=21</th>
<th>Outer regional, remote or very remote n=9</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Years working as BCN</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>32 (64%)</td>
<td>13 (65%)</td>
<td>12 (57%)</td>
<td>7 (78%)</td>
</tr>
<tr>
<td>6-10 years</td>
<td>11 (22%)</td>
<td>2 (10%)</td>
<td>7 (33%)</td>
<td>2 (22%)</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>7 (14%)</td>
<td>5 (25%)</td>
<td>2 (10%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Employment basis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>20 (40%)</td>
<td>8 (40%)</td>
<td>9 (43%)</td>
<td>3 (33%)</td>
</tr>
<tr>
<td>Part time</td>
<td>30 (60%)</td>
<td>12 (60%)</td>
<td>12 (57%)</td>
<td>6 (67%)</td>
</tr>
<tr>
<td><strong>Highest Qualification</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital Trained or Bachelor of Nursing</td>
<td>5 (10%)</td>
<td>2 (10%)</td>
<td>0 (0%)</td>
<td>3 (33%)</td>
</tr>
<tr>
<td>Graduate Certificate or above</td>
<td>45 (90%)</td>
<td>18 (90%)</td>
<td>21 (100%)</td>
<td>6 (67%)</td>
</tr>
<tr>
<td><strong>Hold BCN Qualification</strong>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>42 (84%)</td>
<td>17 (85%)</td>
<td>18 (86%)</td>
<td>7 (78%)</td>
</tr>
<tr>
<td>No</td>
<td>8 (16%)</td>
<td>3 (15%)</td>
<td>3 (14%)</td>
<td>2 (22%)</td>
</tr>
</tbody>
</table>

*Not all of these qualifications are tertiary level*
Discussion
The Breast Care Nurse Survey has been used successfully to explore the role of the Australian breast care nurse in the provision of information and support to women with breast cancer (Ahern, Gardner, & Courtney, 2015). This has enabled researchers to report on the differences based on geographic location, a clear gap found in the literature. To our knowledge, this was the first survey to collect data about BCN perceived capacity to undertake the facets of the role related to provision of information, education and support and the barriers to undertaking their role.

The internal reliability of the BCN Survey as measured using Cronbach’s Alpha was found to be strong (.935). This high value may suggest that there is some item redundancy and the survey would benefit from further testing using factor analysis, for example. However, the items were closely aligned with competency statements (National Breast Cancer Centre, 2005c), suggesting that there may be redundancy in the standards.

The tool could also be extended to investigate other aspects of the role of BCNs described in the remaining competency standards and could be useful to identify educational support to assist BCNs to meet the competency standards associated with their role.

In the development of this survey, content validity was achieved using sources such as a literature review and consultation with experts. However, further content validity testing using the calculation of a content validity index would allow quantitative validation of the tool in terms of whether the items accurately measure all aspects of the construct.
Conclusion
There is limited evidence on the role of Australian breast care nurses in different contexts and geographical areas (Ahern & Gardner, 2015). Therefore a new survey instrument on the role of BCN was developed and tested for content validity and internal reliability. This instrument was used in a national study to explore the ways in which rural and remote BCN roles differ to urban BCN roles. It has enabled an investigation of the range of roles performed by a BCN in the provision of information and support and to what extent reported BCN roles are consistent with the Australian Specialist Breast Nurse Competency Standards. The structure of this instrument could be used to investigate further the kinds of care BCNs are expected to deliver. Using the instrument further would provide more information about the support required by BCNs and the effectiveness of current BCN educational programs. This instrument has been found to have strong content validity and high internal reliability, however, further use and testing of this instrument in different contexts is recommended.
Summary
This chapter outlined the methodology used throughout the doctoral research, indicating the many important considerations that informed the structure of this research program. Additionally, the second part of the chapter provided a detailed account of the development of a new survey instrument. The instrument described has been successfully used in a national study of Australian BCNs (Chapter 5). Specifically, through the use of this survey, problems faced by BCNs working in differing geographical locations have been recognised and recommendations made to inform education and practice.
Chapter 4: Results Study One

Aim 1: To investigate the information and support needs of women following primary treatment for breast cancer.

This chapter is presented in the form of a research publication, accepted on 26 June 2014 and published online.

Reference:

Significance to the Overall Thesis
The use of and satisfaction with information and support following primary treatment of breast cancer was the focus of research conducted by Raupach and Hiller over a decade ago (2002). As the first study in this doctoral research, the researchers replicated the earlier study by Raupach and Hiller. A major aim in doing this was to determine if there were significant differences in the information and support perceived by women with breast cancer since the 10 years had lapsed. Additionally, with a particular interest in national data, the current researchers extended the sample of this survey to women Australia-wide diagnosed with breast cancer. Therefore, the study by Raupach & Hiller (2002) was replicated, with two main differences:

1. Participants Australia-wide were included in the study to allow comparisons between those living in urban areas and those living in rural and remote areas.
2. The survey was offered in an online self-report format.
The development of geographical classifications in Australia that describe areas in terms of relative remoteness has provided an opportunity to compare a wide range of health and welfare indicators across Australia’s major cities, regional and remote areas (Australian Institute of Health and Welfare, 2004). In this study, to enable geographically comparable data, it was necessary to use the latest Australian Bureau of Statistics’ (ABS) geographical framework, the Australian Statistical Geography Standard (ASGS) which was established in 2011 (Australian Bureau of Statistics, 2013a). The ASGS provides a framework for the release of all geographically based statistics from the ABS. Therefore, an important element of the design of this study was to align with the ASGS and the advantage of doing so included access to a wider variety of geographically comparable statistics that enabled improved information for decision making.
Geographical comparisons of information and support needs of Australian women following the primary treatment of breast cancer: a 10 year replication study

Abstract
Background: In 2002, Raupach and Hiller examined the use of and satisfaction with information and support following treatment of breast cancer from a sample of participants in South Australia. In 2013 this study was replicated to include participants Australia wide and analyse comparisons based on geographical location. Statistical comparisons with the original study were also conducted.

Design: A 10 year replication study using a cross-sectional needs analysis survey.

Setting and participants: Women aged 18+ years diagnosed with breast cancer between six and 30 months ago were sourced from two national databases of women diagnosed with breast cancer.

Results: A total of 325 participants completed the survey. The Internet was the most commonly used source of information with 70% (n=229 of 325) of women using the internet for information, a statistically significantly higher percentage compared with the 2002 study. The study found the top four information issues rated as moderately/extremely important by women in 2013 were identical in 2002. A comparison of sources of support used showed that women in outer regional, remote and very remote areas were statistically more likely to use the breast care nurse (BCN) for support ($p= 0.044$).

Conclusions: The study provides useful, up-to-date data about the information and support services used by Australian women with breast cancer. Comparisons with
the earlier study show some of the needs of women have changed over time, but others have remained the same. Geographic comparisons overall, demonstrate many consistent findings regardless of location, however, the important work of the breast care nurse is an area in need of further research.
Introduction
In Australia in 2002, Raupach & Hiller (Raupach & Hiller, 2002) concluded women experience a heightened need for information concerning breast cancer related issues following primary treatment for breast cancer with many such needs largely unmet. Since then several studies continued to find women with breast cancer have high unmet needs (Aranda et al., 2005; Davis et al., 2004; Davis et al., 2002; Lawler et al., 2011; Minstrell et al., 2008; Roche, 2006; Sheppard, 2007; Vivar & McQueen, 2005).

In 2012, the Australian Institute of Health and Welfare (AIHW) reported breast cancer is the most common cancer among Australian women with 12,567 cases diagnosed in 2007 (AIHW 2012b). By 2015, the number of new breast cancer cases among women is projected to be 22% higher than in 2006, with numbers of women diagnosed estimated to be around 15,409 (AIHW 2012a). For women with a diagnosis of breast cancer, receiving adequate information is essential to make informed treatment decisions (Davis et al., 2002). Additionally, adequate support is required to help women cope with their diagnosis (Davis et al., 2002). There is evidence many Australian women do not have adequate information concerning their disease and treatment, nor do they receive sufficient practical and emotional support from health professionals (Aranda et al., 2006; Davis et al., 2004; Girgis et al., 2000; Lawler et al., 2011; McGrath et al., 1999; Raupach & Hiller, 2002).

Needs of women with breast cancer vary depending on their particular circumstances. For example, those with more advanced disease report higher levels of unmet needs in the psychological and physical and daily living domains (Aranda et al., 2005). On the other hand, young women with breast cancer report needing more age specific information and support (Connell et al., 2006).
Similarly, those living in rural and remote areas of Australia have needs specific to their situation and in fact there is great regional and remote disadvantage for Australians diagnosed with cancer. Addressing the needs of Australian women in rural and remote areas has proven difficult due to rural health service provision being challenged by issues of equity, coverage and supply (National Breast Cancer Centre, 2001). New figures reveal people in regional and remote Australia are much more likely to die from cancer than those in metropolitan areas (Coory et al., 2013). A study by Underhill, Bartel et al. (2009) highlighted marked cancer service deficiencies in rural and regional Australia, leading to poorer outcomes for cancer patients living in these areas. Many cancer patients are geographically isolated from care facilities and therefore do not experience the same access to specialists, GPs and allied health services as those in metropolitan areas (Sabesan & Piliouras, 2009).

Over the past decade, due to therapeutic advances and early detection initiatives such as the Breastscreen Australia Program, there have been reductions in morbidity and mortality from breast cancer in Australian women (Australian Government Department of Health, 2013). However, despite therapeutic advances, those living with and beyond a breast cancer diagnosis can still experience physical, functional and psychosocial morbidities impacting on their quality of life (Brennan et al., 2010; Harmer, 2012; Knobf, 2011; Thewes et al., 2004; Vivar & McQueen, 2005). The primary aim of this study is to replicate a previously validated needs analysis survey completed by Raupach & Hiller (2002) and to compare the findings with those of a decade ago, with the addition of making comparisons based on geographical location of participants.
Research Questions

1. What information is currently available to Australian women with breast cancer?
2. What is the level of satisfaction with information sources used by Australian women with breast cancer?
3. What sources of support are currently available to Australian women with breast cancer?
4. What is the level of satisfaction with sources of support used by Australian women with breast cancer?
5. What are the findings compared to a decade ago?
6. Are there geographic differences with information and support sources used by Australian women with breast cancer?

Methods

Design
A cross-sectional replication study was undertaken using a previously validated survey with both structured and semi-structured questions.

Survey Instrument
Permission to replicate was obtained from researchers conducting the original survey (Raupach & Hiller, 2002). The original survey was developed using interviews with women and service providers, a focus group with women with breast cancer, findings from a literature review and a report from a National Breast Cancer Conference for women. The original survey was evaluated by women and providers, before being formally pilot tested on a random sample of 25 women diagnosed with breast cancer (Raupach & Hiller, 2002). For the current study, six questions were added to determine the principal place of residence of each participant so geographical
differences could be analysed. A sample of survey questions are provided in the Appendix to the Publication (Page 119-120).

The original survey was paper based, however the replication survey was undertaken using an online format using Qualtrics survey software. The online format was tested by five people and minor modifications to layout completed. The self-report survey consisted of 150 items (142 closed questions and 8 open questions) and was distributed to women diagnosed with breast cancer belonging to two national databases. In the years since the original survey, general internet access across Australia has risen to 83% of households having access to the internet in the home (Australian Bureau of Statistics, 2014). This and the availability of women with breast cancer belonging to two national databases willing to participate in online research studies influenced the decision to use an online survey in this study.

Participants
Participant criteria for inclusion were replicated to match the original study, with women living in Australia aged 18 years and over who had been diagnosed with breast cancer between 6 and 30 months ago targeted. No other eligibility criteria were stipulated. The original study sourced participants from a single, urban hospital over a period of 25 months. However, due to a lack of national perspective of evidence on current unmet needs, participants from across Australia were targeted (Ahern & Gardner, 2015).

Participants were sourced from two national databases of women diagnosed with breast cancer that assist with recruitment of participants through online measures: Register4 has 34000 members Australia-wide and is open to people over 18 years old with and without cancer (National Breast Cancer Foundation, 2012; Register4, 2014) and the BCNA Review and Survey Group containing membership of 2500
women with breast cancer across Australia (Breast Cancer Network Australia, 2013b).

A total of 402 participants commenced the survey. Nineteen participants did not provide geographical information essential for allocating a geographical code enabling analysis of geographic differences and fifty-eight participants submitted an incomplete survey, and examination of incomplete surveys revealed random patterns of exit points in the survey. Therefore 325 responses or 81% were analysed.

Procedures
Following ethical approval from Australian Catholic University Human Research Ethics Committee, members of Register4 (National Breast Cancer Foundation, 2012) and the Breast Cancer Network Australia Review and Survey Group (Breast Cancer Network Australia, 2013b) were forwarded information about the study and directed to the online survey which included a participant information letter. Participants were given the option to receive a hard copy of the survey and a stamped, self-addressed envelope if they were unable to complete the online version of the survey. One participant chose to take this option. Voluntary participation was achieved by participants completing and submitting a survey.

An Australian Bureau of Statistics (ABS) Remoteness Area (RA) code was manually allocated to the physical residential address of each participant to identify their geographical location (Australian Bureau of Statistics, 2013a). These RA codes were consistent with the latest available information from the ABS and were allocated using an address coding tool on the ABS website (Australian Bureau of Statistics, 2013b). Once the RA codes were allocated, all other information relating to place of residence was deleted from the database to protect the identity of participants.
A de-identified summary of results was published on the Register4 website and sent via email to BCNA Review and Survey Group members.

**Data Analysis**

The data were analysed using IBM SPSS software, version 20.0. Descriptive statistics were calculated for all variables to determine missing and inappropriate (out of range) values. Frequency tables for each section of the survey were generated enabling a summary of results at a glance. After checking responses were consistent, some RA codes were combined resulting in the reduction of the number of categories from five to three. Major cities and inner regional categories remain unchanged, whereas the remaining three categories were combined; outer regional, remote and very remote. Variables measured on a four point Likert scale were collapsed into two categories. Responses in the ‘not’ or ‘slightly’ (important/useful/helpful) categories were combined and responses in the ‘moderately’ and ‘extremely’ (important/useful/helpful) categories were combined. This latter reduction of codes was a replication of recoding undertaken prior to reporting the original survey.

Open-ended questions were analysed using content analysis in order to identify common themes about women’s need or lack of need for information and support.

**Results**

Three hundred and twenty-five women completed the survey. Table 1 describes the demographic and treatment characteristics of respondents. Respondents from major Australian cities comprised 69% of the total sample. Nineteen percent resided in inner regional Australia, with the remaining 12% residing in outer regional, remote or very remote Australia. Age ranged from 27 to 81 years with a mean of 54 years. The number of women in outer regional, remote and very remote areas were significantly
more likely to be aged under 50 years \((n=18 \text{ of } 39, 45\%)\) than women in major cities \((n=74 \text{ of } 224, 33\%)\) compared to inner regional areas \((n=14 \text{ of } 62, 23\%)\), \((\chi^2 = 6.111, p \ 0.0047)\). Two hundred and sixty-nine participants \((83\%)\) were born in the continent of Australia and Oceania, with the remaining 17% \((n=56)\) being born in Europe, Asia, Africa or North America. Seventy-eight percent \((n=254)\) of women were married or committed. Just over half of respondents \((53\%, \ n=173)\) had completed a university education, however, the percentages of university graduates from major cities \((n=124 \text{ of } 224, 55\%)\) and inner regional areas \((n=33 \text{ of } 62, 53\%)\) were higher than those living in outer regional, remote or very remote areas \((n=16 \text{ of } 39, 41\%)\).

When analysing treatment characteristics, at least 98% of respondents had undergone surgery to treat their breast cancer. The percentage of respondents treated with chemotherapy \((62\%-66\%)\) or radiotherapy \((68\%-72\%)\) was comparable regardless of geographical residence. Respondents in outer regional, remote or very remote areas had much higher percentages of hormone therapy treatment \((n=31 \text{ of } 39, 80\%)\) compared to than those living in major cities \((n=161 \text{ of } 224, 72\%)\) and inner regional areas \((n=38 \text{ of } 62, 61\%)\). Breast reconstruction percentages were similar in all three geographical areas, with around one fifth of women choosing to have breast reconstruction.

Just under a quarter of respondents \((24\%, \ n=78)\) had an immediate family member diagnosed with breast cancer. However, percentages of an immediate family member being diagnosed with breast cancer were significantly higher in the outer regional, remote or very remote category 41% \((n=16 \text{ of } 39)\) compared to 22% \((n=49 \text{ of } 224)\) in the major cities and 21% \((n=13 \text{ of } 62)\) in inner regional areas \((\chi^2 = 14.329, p \ 0.006)\). Almost all \((97\%, \ n=315)\) of respondents had a regular general practitioner (GP).
Table 1 Demographic and treatment characteristics of respondents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total N=325</th>
<th>Major Cities n=224</th>
<th>Inner Regional n=62</th>
<th>Outer regional, remote or very remote n=39</th>
<th>Chi-squared</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than or equal to 50 years</td>
<td>106</td>
<td>33</td>
<td>74</td>
<td>33</td>
<td>14</td>
<td>23</td>
</tr>
<tr>
<td>More than 50 years</td>
<td>219</td>
<td>67</td>
<td>150</td>
<td>67</td>
<td>48</td>
<td>77</td>
</tr>
<tr>
<td><strong>Continent of Birth</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia and Oceania</td>
<td>269</td>
<td>83</td>
<td>180</td>
<td>80</td>
<td>55</td>
<td>89</td>
</tr>
<tr>
<td>All other continents</td>
<td>56</td>
<td>17</td>
<td>44</td>
<td>20</td>
<td>7</td>
<td>11</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single, separated, divorced or Widowed</td>
<td>71</td>
<td>22</td>
<td>49</td>
<td>22</td>
<td>11</td>
<td>18</td>
</tr>
<tr>
<td>Married or committed</td>
<td>254</td>
<td>78</td>
<td>175</td>
<td>78</td>
<td>51</td>
<td>82</td>
</tr>
<tr>
<td><strong>Education completed</strong>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary or Tertiary non-University</td>
<td>151</td>
<td>46</td>
<td>99</td>
<td>44</td>
<td>29</td>
<td>47</td>
</tr>
<tr>
<td>Tertiary University</td>
<td>173</td>
<td>53</td>
<td>124</td>
<td>55</td>
<td>33</td>
<td>53</td>
</tr>
<tr>
<td><strong>Immediate family diagnosed with breast cancer</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>78</td>
<td>24</td>
<td>49</td>
<td>22</td>
<td>13</td>
<td>21</td>
</tr>
<tr>
<td>No</td>
<td>239</td>
<td>74</td>
<td>170</td>
<td>76</td>
<td>49</td>
<td>79</td>
</tr>
<tr>
<td><strong>Has a usual GP</strong>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>315</td>
<td>97</td>
<td>216</td>
<td>96</td>
<td>62</td>
<td>100</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>3</td>
<td>8</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Treatment Undergone</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery (n=322) ***</td>
<td>320</td>
<td>98</td>
<td>219</td>
<td>98</td>
<td>62</td>
<td>100</td>
</tr>
<tr>
<td>Chemotherapy (n=321)</td>
<td>211</td>
<td>65</td>
<td>146</td>
<td>65</td>
<td>41</td>
<td>66</td>
</tr>
<tr>
<td>Radiotherapy (n=321)</td>
<td>231</td>
<td>71</td>
<td>161</td>
<td>72</td>
<td>42</td>
<td>68</td>
</tr>
<tr>
<td>Treatment completed (n=321) ***</td>
<td>299</td>
<td>92</td>
<td>205</td>
<td>92</td>
<td>57</td>
<td>92</td>
</tr>
<tr>
<td>Tamoxifen/Hormone Therapy (n=321)</td>
<td>230</td>
<td>71</td>
<td>161</td>
<td>72</td>
<td>38</td>
<td>61</td>
</tr>
<tr>
<td>Breast reconstruction (n=321)</td>
<td>75</td>
<td>23</td>
<td>52</td>
<td>23</td>
<td>15</td>
<td>24</td>
</tr>
</tbody>
</table>

* 1 missing (primary education only).

** The remainder said they ‘did not know’.

*** No statistic possible due to 0 values.

# statistically significant findings.
**Information about Specific Issues**

Table 2 shows the issues for which women rated a need for information was moderately or extremely important. The number of women receiving information about these issues in the last six months is also reported in the table.

In the current study for six out of the 13 issues presented to women 74% or more women rated the issue as moderately or extremely important to them. The three top issues were recognising a recurrence (n=304, 94%), chances of cure (n=274, 84%) and risk to family of breast cancer (n= 269, 83%). At least 50% of women rated 11 of the 13 issues as moderately or extremely important to them. The lowest need was expressed for information about breast reconstruction (n=125, 38%) and prostheses (n=98, 30%).

To enable comparisons, the results of the 2002 study are also provided in the table. The top four issues for women in 2002 are the same top four issues rated for women in the current study (recognising a recurrence, chances of cure, risk to family of breast cancer, Tamoxifen and other antioestrogen drugs). Ninety-five percent confidence intervals comparing the two studies reveal that women in the current study were statistically more likely to rate information about sexuality and relationships (n=171, 54%, 95% CI=48-58) as moderately or extremely important compared to the 2002 study (n=81, 39%, 95% CI=32-46).

Despite rating these issues as important, for many of the issues, information received in the past 6 months was reported on average by only 30% of women. In the current study, the three top issues that women received information about in the past 6 months included; Tamoxifen and other antioestrogen drugs (n=166, 51%), where to
go for more support (n=150, 46%) and chance of cure (n=121, 37%). It is important to note however, that the percentages of women actually receiving information in the previous six months is statistically significantly higher in the current study in ten out of the 13 information areas listed.
Table 2 Need for information and extent of information received
(listed in order of highest n to lowest n based on current results)

<table>
<thead>
<tr>
<th>Issue</th>
<th>Current Study n=325</th>
<th>2002 Study n=217*</th>
<th>Current Study n=325</th>
<th>2002 Study n=217*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rated Item as moderately/extremely important</td>
<td>Received information within the previous 6 months</td>
<td>Rated Item as moderately/extremely important</td>
<td>Received information within the previous 6 months</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>95% CI</td>
<td>n</td>
</tr>
<tr>
<td>Recognizing a recurrence</td>
<td>304</td>
<td>94</td>
<td>92-97</td>
<td>191</td>
</tr>
<tr>
<td>Chances of cure</td>
<td>274</td>
<td>84</td>
<td>80-88</td>
<td>167</td>
</tr>
<tr>
<td>Risk to family of breast cancer</td>
<td>269</td>
<td>83</td>
<td>79-87</td>
<td>167</td>
</tr>
<tr>
<td>Tamoxifen and other antioestrogen drugs</td>
<td>243</td>
<td>75</td>
<td>70-80</td>
<td>148</td>
</tr>
<tr>
<td>Where to go for more support</td>
<td>243</td>
<td>75</td>
<td>70-80</td>
<td>128</td>
</tr>
<tr>
<td>Effect on family of breast cancer</td>
<td>242</td>
<td>74</td>
<td>69-79</td>
<td>142</td>
</tr>
<tr>
<td>Physical appearance after surgery</td>
<td>186</td>
<td>57</td>
<td>52-62</td>
<td>121</td>
</tr>
<tr>
<td>Arm problems and lymphoedema</td>
<td>183</td>
<td>56</td>
<td>51-61</td>
<td>132</td>
</tr>
<tr>
<td>Sexuality and relationships</td>
<td>171</td>
<td>53</td>
<td>48-58#</td>
<td>81</td>
</tr>
<tr>
<td>Menopause and hormone replacement therapy</td>
<td>167</td>
<td>51</td>
<td>46-56</td>
<td>100</td>
</tr>
<tr>
<td>Complementary and alternative therapies</td>
<td>161</td>
<td>50</td>
<td>45-55</td>
<td>105</td>
</tr>
<tr>
<td>Breast reconstruction</td>
<td>125</td>
<td>38</td>
<td>33-43</td>
<td>74</td>
</tr>
<tr>
<td>Prostheses</td>
<td>98</td>
<td>30</td>
<td>25-35</td>
<td>82</td>
</tr>
</tbody>
</table>

*Varying levels of non-response in each category.
# Statistically significant findings.
**Sources of Information**

Women used a variety of sources of information and Table 3 shows the use of and extent of satisfaction with these sources of information. In the current study, the most frequently used source of information was the internet (70%, n=229). Other frequently used sources of information include the surgeon (58%, n=190), the cancer specialist (56%, n=181), and the television (53%, n=172).

A comparison with 2002 data revealed statistically significant differences for the receipt of information from the Internet (CI: 2013=65-75%, 2002=2-8%), the cancer specialist (CI: 2013=51-61%, 2002=19-32%), the breast cancer support group (CI: 2013=32-42%, 2002=2-9%), and the breast cancer support service volunteer (2013=14-21%, 2002=2-8%).

In the free text, many women indicated there were difficulties experienced in obtaining information such as having to self-source information, receiving too little information after completion of treatment or receiving confusing or conflicting information (Box 1).
Satisfaction with Information Sources
The highest levels of satisfaction with information sources were for information received from the Cancer Help Line (n=10 of 11, 91%), the breast care nurse (n=75 of 84, 89%), the surgeon (n=161 of 190, 85%), the complementary or alternative therapist (n=46 of 54, 85%) and cancer specialist (n=154 of 181, 85%). There were six other sources of information where at least 74% of women rated the information received as moderately or extremely useful. The lowest levels of satisfaction were for information received from television (n=65 of 172, 38%), newspapers (n=48 of 129, 37%) and magazines (n=30 of 90, 33%).


In the free text, many women indicated that the medical team (surgeon, oncologist, radiologist, BCN and GP) and cancer organisations and support groups were very useful sources of information. However, a strong theme emerged where women felt that if they needed additional information, they had to search for it themselves, usually turning to the internet. In terms of using the internet, women’s experiences were both negative and positive (Box 2).
Table 3 Sources of information used and satisfaction with those sources  
(ranked by frequency of use based on current results)

<table>
<thead>
<tr>
<th>Source of Information</th>
<th>Current Study n=325</th>
<th>2002 Study n=217</th>
<th>Current Study n=325</th>
<th>2002 Study n=217</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Received information within the previous 6 months</td>
<td>Satisfaction with information*</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>95% CI</td>
<td>n</td>
</tr>
<tr>
<td>Internet</td>
<td>229</td>
<td>70</td>
<td>65-75#</td>
<td>9</td>
</tr>
<tr>
<td>Surgeon</td>
<td>190</td>
<td>58</td>
<td>53-63</td>
<td>125</td>
</tr>
<tr>
<td>Cancer Specialist</td>
<td>181</td>
<td>56</td>
<td>51-61#</td>
<td>49</td>
</tr>
<tr>
<td>Television</td>
<td>172</td>
<td>53</td>
<td>48-58</td>
<td>114</td>
</tr>
<tr>
<td>Newspapers</td>
<td>129</td>
<td>40</td>
<td>35-45</td>
<td>66</td>
</tr>
<tr>
<td>General Practitioner</td>
<td>122</td>
<td>38</td>
<td>33-43</td>
<td>65</td>
</tr>
<tr>
<td>Breast Cancer Support Group</td>
<td>120</td>
<td>37</td>
<td>32-42#</td>
<td>10</td>
</tr>
<tr>
<td>Brochures</td>
<td>107</td>
<td>33</td>
<td>28-38</td>
<td>44</td>
</tr>
<tr>
<td>Books</td>
<td>97</td>
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<td>25-35</td>
<td>64</td>
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<td>Magazines</td>
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<td>28</td>
<td>23-33</td>
<td>91</td>
</tr>
<tr>
<td>Friends</td>
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<td>28</td>
<td>23-33</td>
<td>46</td>
</tr>
<tr>
<td>Breast Care Nurse</td>
<td>84</td>
<td>26</td>
<td>21-31</td>
<td>37</td>
</tr>
<tr>
<td>Breast Cancer Support Service Volunteer</td>
<td>57</td>
<td>18</td>
<td>14-21#</td>
<td>9</td>
</tr>
</tbody>
</table>
Table 3 Sources of information used and satisfaction with those sources  (Continued)

<table>
<thead>
<tr>
<th>Source of Information</th>
<th>Current Study n=325</th>
<th>2002 Study n=217</th>
<th>Current Study n=325</th>
<th>2002 Study n=217</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received information within the previous 6 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>%</td>
<td>95% CI</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Complementary or Alternative Practitioner</td>
<td>54</td>
<td>17</td>
<td>13-21</td>
<td>19</td>
</tr>
<tr>
<td>Radio</td>
<td>54</td>
<td>17</td>
<td>13-21</td>
<td>44</td>
</tr>
<tr>
<td>Family</td>
<td>28</td>
<td>9</td>
<td>6-12</td>
<td>24</td>
</tr>
<tr>
<td>Cancer Help Line</td>
<td>11</td>
<td>3</td>
<td>1-5</td>
<td>10</td>
</tr>
</tbody>
</table>

* Satisfaction = (number of women who rated information received from that source as moderately or extremely useful/total number of women who received information from that source) expressed as a percentage.

** One sided 97.5% CI.

# Statistically significant findings.
Difficult to obtain reliable, credible information.

After treatment is completed, not much information is available.

I am 20 months post breast cancer. I don’t receive any information.

I feel there is very little ongoing support.

I have had to source all information myself on anything I need.

Little support available outside the city.

Little information is offered unless specifically asked for.

Not given written information. Have found extra on www.

There is no central place to find good information.

Have not received any information and I have been discharged.

I have sourced all information myself.

Information has been confusing and contradictory.

Little information has been received.

Information is not always useful – vague at times.

Information is not easily available in my area.
Sources of Support
The frequency of use and extent of satisfaction with sources of support are reported in Table 4. The most frequently used sources of support in the past 6 months were friends (n=263, 81%) and family (n=261, 80%), followed by the GP and surgeon (both 61%). The least frequently used sources of support were the psychiatrist or psychologist (n=54, 17%), the breast cancer support service volunteer (n=31, 10%) and the Cancer Help Line (n=10, 3%).

Comparisons with 2002 data revealed significant differences were found in the support received with the previous 6 months from the cancer specialist (CI: 2013=54-
64%, 2002=23-36%), the Internet (CI: 2013=45-55%, 2002=1-6%), the breast cancer support group (CI: 2013=27-37%, 2002=2-9%), the psychiatrist or psychologist (CI: 2013=13-21%, 2002=3-10%) and the breast cancer support service volunteer (CI: 2013=7-13%, 2002=1-6%).

**Satisfaction with Support Sources**
In terms of satisfaction with support, women were generally very satisfied with the support they had received. All 12 sources of support were rated as moderately or extremely helpful by at least 76% of women (See Table 4). The highest levels of satisfaction were for the complementary or alternative therapist (n=63 of 71, 89%), the breast cancer support group (n=90 of 105, 86%), the psychiatrist or psychologist (n=46 of 54, 85%), and the breast care nurse (n=69 of 83, 83%). The lowest levels of satisfaction were reported for the support received from the internet (n=125 of 164, 76%).

Support from family (CI: 2013=78-86%, 2002=87-96%), the surgeon (CI: 2013=77-85%, 2002=87-96%) and the cancer specialist (CI: 2013=78-86%, 2002=90-100%) revealed significant differences in 2013 compared with 2002.

In the free text, women also regarded friends, family (including husband/partner), the oncologist, surgeon, GP and breast cancer organisations such as the Breast Cancer Network Australia (BCNA) and The Cancer Council highly in terms of being most helpful sources of support.
Table 4 Sources of support used and satisfaction with those sources (ranked by frequency of use based on current study)

<table>
<thead>
<tr>
<th>Source of support</th>
<th>Current Study n=325</th>
<th>2002 Study n=217</th>
<th>Current Study n=325</th>
<th>2002 Study n=217</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received support within previous 6 months</td>
<td>n % 95% CI</td>
<td>n % 95% CI</td>
<td>n % 95% CI</td>
<td>n % 95% CI</td>
</tr>
<tr>
<td>Friends</td>
<td>263 81 77-85</td>
<td>145 71 64-77</td>
<td>207 79 75-83</td>
<td>117 84 77-90</td>
</tr>
<tr>
<td>Family</td>
<td>261 80 76-84</td>
<td>164 81 75-86</td>
<td>215 82 78-86#</td>
<td>143 92 87-96</td>
</tr>
<tr>
<td>General Practitioner</td>
<td>198 61 56-66</td>
<td>107 52 45-59</td>
<td>162 82 78-86</td>
<td>94 91 84-96</td>
</tr>
<tr>
<td>Surgeon</td>
<td>197 61 56-66</td>
<td>145 70 63-76</td>
<td>160 81 77-85#</td>
<td>128 93 87-96</td>
</tr>
<tr>
<td>Cancer Specialist</td>
<td>191 59 54-64#</td>
<td>57 29 23-36</td>
<td>157 82 78-86#</td>
<td>52 98 90-100</td>
</tr>
<tr>
<td>Internet</td>
<td>164 50 45-55#</td>
<td>5 2 1-6</td>
<td>125 76 71-81</td>
<td>4 80 28-100</td>
</tr>
<tr>
<td>Breast Cancer Support Group</td>
<td>105 32 27-37#</td>
<td>9 5 2-9</td>
<td>90 86 82-90</td>
<td>7 70 35-93</td>
</tr>
<tr>
<td>Breast Care Nurse</td>
<td>83 26 21-31</td>
<td>47 24 18-30</td>
<td>69 83 79-87</td>
<td>40 87 74-95</td>
</tr>
<tr>
<td>Complementary or Alternative Practitioner</td>
<td>71 22 17-21</td>
<td>29 14 10-20</td>
<td>63 89 86-92</td>
<td>26 90 73-98</td>
</tr>
<tr>
<td>Psychiatrist or Psychologist</td>
<td>54 17 13-21#</td>
<td>9 5 3-10</td>
<td>46 85 81-89</td>
<td>10 91 59-100</td>
</tr>
<tr>
<td>Breast Cancer Support Service Volunteer</td>
<td>31 10 7-13#</td>
<td>6 3 1-6</td>
<td>24 77 72-82</td>
<td>5 83 36-100</td>
</tr>
<tr>
<td>Cancer Help Line</td>
<td>10 3 1-5</td>
<td>9 4 2-8</td>
<td>8 80 76-84</td>
<td>6 67 30-93</td>
</tr>
</tbody>
</table>

* Satisfaction = (number of women who rated support received from that source as moderately or extremely helpful/number of women who received support from that source) expressed as a percentage.

# Statistically significant findings.
Comparisons by Geographical Location
Table 5 shows percentages of women in each of the geographical areas reporting having received information or support about specific issues or from specific sources within the previous six months. The table also reports the satisfaction with information and support sources in each of the geographical areas. There were a number of items measured in each of the categories, however, only the top four issues in each of the three categories measured is displayed in this table. Statistically significant findings for each of the categories are also displayed.

Information Issues Received
Of the 13 issues where information had been received by women in the previous six months (see Table 2), only one issue recorded a percentage above 50% (Tamoxifen and other antioestrogen drugs, n=166, 51%). In the remaining 12 information areas, a range of between 21% and 46% of women reported receiving information about these issues in the previous six months. There are no statistically significant differences found based on geographic location (see Table 4 for a summary of these). However, there were lower percentages of women receiving information in outer regional, remote and very remote areas in seven out of the 13 information areas measured (see Table 2).

Sources of Information Used
Percentages across all geographic areas were consistent for the top four sources of information. However, percentages of women using the newspaper as an information source is statistically significantly lower (χ² =8.033, p 0.018) in outer regional, remote and very remote areas (n=8, 21%) compared with major cities (n=91, 41%) and inner regional areas (n=30, 48%).
Satisfaction with Information Received
The percentage of women in outer regional, remote and very remote areas satisfied with the information they received from the complementary or alternative practitioner (n=3, 50%) was much lower compared with women in major cities (n=34, 87%) and inner regional areas (n=9, 100%). Furthermore, the percentages of women in major cities who were satisfied with information received from breast cancer support groups (n=69, 85%) outweighed women in inner regional (n=16, 67%) and outer regional, remote and very remote areas (n=9, 60%). The remainder of information areas assessed for satisfaction revealed no major differences based on geographical location.

Sources of Support Used
Percentages across all geographical areas were consistent for the top four sources of support. However, notable is the statistically significant difference found with the breast care nurse as a source of support ($\chi^2=6.253$, $p=0.044$) at a much higher percentage in the outer regional, remote and very remote areas (n=16 out of 39, 41%) compared to the major cities (n=50 out of 224, 22%) and inner regional areas (n=17 out of 62, 27%).

Satisfaction with Sources of Support Received
The percentage of women in outer regional, remote and very remote areas satisfied with the support received from the psychiatrist or psychologist (n=2, 40%), as well as the cancer specialist (n=16, 64%), were much lower than that reported by women in major cities (n=37, 90% and n=108, 83% respectively) and inner regional areas (n=7, 88% and n=33, 92% respectively). The percentage of women from inner regional areas satisfied with support received from a complementary or alternative practitioner (n=12 100%) outweighed the satisfaction reported by women in major cities (n=44, 86%) and outer regional, remote and very remote areas (n=7, 88%). No
other major differences were found, however in 8 out of the 12 sources of support measured, women from outer regional, remote and very remote areas were less satisfied than women in the major cities and inner regional areas.
Table 5 Comparisons based on geographical location

<table>
<thead>
<tr>
<th>Information or support received/used within the previous six months</th>
<th>Total n=325</th>
<th>Major Cities n=224</th>
<th>Inner Regional n=62</th>
<th>Outer Regional, Remote and Very Remote n=39</th>
<th>chi-square</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information issues received</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tamoxifen and other antioestrogen drugs</td>
<td>166 51</td>
<td>122 54</td>
<td>28 45</td>
<td>16 41</td>
<td>3.474</td>
<td>0.176</td>
</tr>
<tr>
<td>Where to go for more support</td>
<td>150 46</td>
<td>106 47</td>
<td>26 42</td>
<td>18 46</td>
<td>0.567</td>
<td>0.753</td>
</tr>
<tr>
<td>Chances of cure</td>
<td>121 37</td>
<td>86 38</td>
<td>24 39</td>
<td>11 28</td>
<td>1.547</td>
<td>0.461</td>
</tr>
<tr>
<td>Arm problems and lymphoedema</td>
<td>114 35</td>
<td>77 34</td>
<td>24 39</td>
<td>18 33</td>
<td>0.46</td>
<td>0.795</td>
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<td>Sources of information used</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internet</td>
<td>229 70</td>
<td>158 71</td>
<td>44 71</td>
<td>27 69</td>
<td>0.037</td>
<td>0.982</td>
</tr>
<tr>
<td>Surgeon</td>
<td>190 58</td>
<td>132 59</td>
<td>39 63</td>
<td>19 49</td>
<td>2.049</td>
<td>0.359</td>
</tr>
<tr>
<td>Cancer Specialist</td>
<td>181 56</td>
<td>128 57</td>
<td>32 52</td>
<td>21 54</td>
<td>0.663</td>
<td>0.718</td>
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<tr>
<td>Television</td>
<td>172 53</td>
<td>118 53</td>
<td>30 48</td>
<td>24 62</td>
<td>1.679</td>
<td>0.432</td>
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<tr>
<td>Newspapers</td>
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<td>91 41</td>
<td>30 48</td>
<td>8 21</td>
<td>8.033</td>
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<td>Satisfaction with information received</td>
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<td></td>
<td></td>
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<tr>
<td>Cancer Help Line (n=11)</td>
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<td>9 90</td>
<td>1 100</td>
<td>0 0</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Breast Care Nurse (n=84)</td>
<td>75 89</td>
<td>46 90</td>
<td>17 90</td>
<td>12 86</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Surgeon (n=190)</td>
<td>161 85</td>
<td>112 85</td>
<td>32 82</td>
<td>17 90</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Cancer Specialist (n=181)</td>
<td>154 85</td>
<td>112 85</td>
<td>25 78</td>
<td>17 81</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Complementary or Alternative Practitioner (n=54)</td>
<td>46 85</td>
<td>34 87</td>
<td>9 100</td>
<td>3 50</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Breast Cancer Support Group (n=120)</td>
<td>94 78</td>
<td>69 85</td>
<td>16 67</td>
<td>9 60</td>
<td>*</td>
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</table>
Table 5 Comparisons based on geographical location *(Continued)*

<table>
<thead>
<tr>
<th>Information or support received/used within the previous six months</th>
<th>Total n=325</th>
<th>Major Cities n=224</th>
<th>Inner Regional n=62</th>
<th>Outer Regional, Remote and Very Remote n=39</th>
<th>chi-square</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sources of support used</td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Friends</td>
<td>263</td>
<td>81</td>
<td>175</td>
<td>78</td>
<td>54</td>
<td>87</td>
</tr>
<tr>
<td>Family</td>
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<td>80</td>
<td>174</td>
<td>78</td>
<td>56</td>
<td>90</td>
</tr>
<tr>
<td>General Practitioner</td>
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<td>140</td>
<td>63</td>
<td>36</td>
<td>58</td>
</tr>
<tr>
<td>Surgeon</td>
<td>197</td>
<td>61</td>
<td>135</td>
<td>60</td>
<td>36</td>
<td>58</td>
</tr>
<tr>
<td>Breast Care Nurse</td>
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<td>27</td>
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<td>89</td>
<td>44</td>
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<td>Breast Cancer Support Group (n=105)</td>
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<td>86</td>
<td>63</td>
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<td>84</td>
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<tr>
<td>Psychiatrist or Psychologist (n=54)</td>
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<td>85</td>
<td>37</td>
<td>90</td>
<td>7</td>
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<tr>
<td>Breast Care Nurse (n=83)</td>
<td>69</td>
<td>83</td>
<td>44</td>
<td>88</td>
<td>13</td>
<td>77</td>
</tr>
<tr>
<td>Cancer Specialist (n=191)</td>
<td>157</td>
<td>82</td>
<td>108</td>
<td>83</td>
<td>33</td>
<td>92</td>
</tr>
</tbody>
</table>

Although many items were measured, only the top four results in each category are listed, as well as statistically significant results found for each category.

# Statistically significant finding.

* No statistic possible due to 0 values.
Discussion
Women facing a diagnosis of breast cancer need information and support to help them make informed treatment decisions and cope with their diagnosis. Over a decade ago, Raupach and Hiller (2002) identified the lack of information and support available to women following treatment for breast cancer. Replicating this study enabled comparisons over time. The study findings overall reveal that some of the needs of women with breast cancer have changed, but many have remained the same.

Information Issues Important to Women
Raupach and Hiller (2002) found issues such as recognising a recurrence, chances of cure, risk to family of breast cancer and tamoxifen and other antioestrogen drugs were the most important information issues for women. The current study found these four issues were also the most important issues proving women diagnosed with breast cancer have some of the same information needs as ten years ago. Furthermore, the study shows in most cases, only one-third of women are receiving information that report is important to them and therefore the majority have unmet information needs. Therefore, the findings add to the volume of Australian and international literature reporting that despite advances in cancer care, women continue to have high unmet information and support needs (Ankem, 2005; Aranda et al., 2005; Beatty et al., 2008; Cowan & Hoskins, 2007; Davis et al., 2002; Minstrell et al., 2008; Raupach & Hiller, 2002; Vivar & McQueen, 2005).

Internet Information Sources Versus Face-to-face Information Sources
Perhaps, not surprisingly, this study confirms the internet as an information source has become more popular. Having access to information and support when the need arises, despite location, is important for patients (Smith-McLallen, Fishbein, & Hornik,
Significantly however, both qualitative and quantitative findings demonstrated satisfaction with information retrieved from the internet is not as high as information received through face-to-face delivery. As was found in previous studies (Cowan & Hoskins, 2007; Raupach & Hiller, 2002), women were most satisfied with the information they received from members of the healthcare team, including the surgeon, the cancer specialist, the breast care nurse and the complementary or alternative therapist, confirming that delivery of information through face-to-face sources continues to be highly valued.

Although satisfaction was rated highest from face-to-face medical sources, patients in the present day rely heavily on non-medical information sources such as the Internet. The information presented via the Internet is under no guidance or regulation, and therefore can be of questionable reliability and quality (Cowan & Hoskins, 2007). O’Grady (2006) explains despite calls for research into the credibility of health care web sites for a number of years, little has been undertaken. Consistent with other research, our study found the Internet to be widely used as a health information source, highlighting a need for providing patients with the details of high-quality websites to access for information (Cowan & Hoskins, 2007).

**Sources of Support for Women**
The findings also reveal the highest sources of support came from friends and family, with the general practitioner and the surgeon also offering high levels of support. Interestingly, these top four sources of support were also the top four sources of support in the original study. These findings once again highlight the importance that women place on receiving information in a supportive and caring context where information and support can be tailored to meet individual needs (Raupach & Hiller, 2002).
A new finding was that women in outer regional, remote and very remote areas were more likely to use a breast care nurse as a source of support. It is not clear why this is so, but it may be that BCNs are more accessible to those in rural and remote areas, however, no national comparative data exist about the geographical distribution of BCNs. It is well publicised that patients in rural and remote Australia experience limited access to health professionals including cancer specialists, GPs or allied health services (Clinical Oncological Society of Australia & Medical Oncology Group of Australia, 2010; Grimison et al., 2013; Redman et al., 2003; Sabesan & Piliouras, 2009) and perhaps BCNs are more accessible. The value of BCNs has been reported in several Australian and international studies (Carnwell & Baker, 2003; Cruickshank et al., 2008; Eicher et al., 2012; Eicher et al., 2006; Eley & Rogers-Clark, 2012; Eley et al., 2008; Jiwa et al., 2010; Jones et al., 2010; Minstrell et al., 2008; Paynter et al., 2013). However, a review of contemporary Australian literature has revealed little is known about the role of the Australian BCN (Ahern & Gardner, 2015) indicating a need for more research in this area.

Importantly, our study revealed overall women in outer regional, remote and very remote areas have lower levels of satisfaction with sources of support they receive, compared to women in major cities and inner regional areas. This adds to the volume of evidence reporting on the geographical disadvantage that exists in healthcare services and support available in Australia.

**Policy and Research Implications**

Since the internet is so widely used, the opportunity exists for health professionals when interacting face-to-face to educate women on the appropriate use of only reputable and credible internet sites. Research in the United States has revealed when using the Internet, patients have trouble knowing what information is relevant
and what is reliable and it is the health care provider that patients turn to for consistent, reliable information and answers (Seigel et al., 2006). Australian BCNs could take on the role of educating women about the appropriate use of the Internet for attaining health information and provide a list of appropriate Internet sites. BCNs in Australia may already do this, however since limited research exists about the BCN role, this is not known.

Previous research suggests increasing health literacy and access to good targeted information can improve patient compliance and satisfaction with treatment options (Helft, 2008). Prolific use of the Internet to access health information is irreversible and therefore there is a high need for further research to investigate the characteristics of reputable and informative breast cancer internet sites and inform policy makers about the potential regulation of such internet sites.

The study found that patients value the information and support they receive from their BCN. Perhaps, BCNs could be further utilised to improve patient education and care through the use of e-health solutions. The use of such initiatives has the potential to not only improve health outcomes for patients, but save time and resources for health professionals and patients alike. Therefore, further research is recommended to investigate interventions whereby additional BCNs could be employed to specialise in offering e-health solutions enabling the delivery of health services to all women with breast cancer, but particularly those in rural and medically underserved populations on a more regular basis, eg video-linked appointments. Such services enable health care providers to educate their patients within the confines and time constraints of today’s medical system (Harless et al., 2009) and these targeted services may also address the levels of low satisfaction experienced by women in outer regional, remote and very remote Australia.
Strengths and Limitations
A particular strength of this study were that comparisons of the demographic data with Australian Bureau of Statistics demographic data indicated that in terms of numbers, the sample was representative of women living in metropolitan, regional and rural and remote areas. Furthermore, the sample size was adequate to provide ample data about the information and support needs of women in each of the geographical areas and perform comparisons between the different geographical areas.

There are a number of limitations of this study. First, we did not know exactly where women were in the participant treatment trajectory and therefore could not report on differences experienced due to time since diagnosis. Second, participants in this study belonged to one of two national databases of women diagnosed with cancer and participants self-selected their involvement in the study. Using a convenience sample such as this meant it was not possible to clearly identify the population from which the sample was derived. Third, it is also recognised that using online recruiting methods may potentially exclude those who do not have internet access. Finally, non-completion of surveys may have been due to respondent burden.

Conclusion
This study has provided quantitative findings about the information and support services that are currently available to and used by women with breast cancer. Importantly, the respondents were a geographically representative sample enabling comparison of those living in metropolitan areas, with those living in inner regional, outer regional, remote and very remote areas. The methods provide a platform which further studies can emulate in order to attain data based on a national
perspective. It is suggested that the findings from this study be used to drive further targeted research to improve information and support services available to women with breast cancer, thereby improving outcomes for the many Australian women diagnosed with cancer each year.
Appendix to the Publication

Sample Survey Questions

Section A – This section was comprised of demographic questions.

Section B – As a woman who has been diagnosed and treated for breast cancer, you may want information about the following issues. Please consider whether you want information, now, on these issues:

Tick one box for each statement.

1 Arm problems such as pain, numbness, or swelling (lymphoedema)
   a) It is important for me to receive information about arm problems.
      □ Not important
      □ Slightly important
      □ Moderately important
      □ Extremely important

   b) In the past six months I have received information about arm problems.
      □ Yes
      □ No

Section C – These questions ask about places where you have looked for and found information about breast cancer in the past six months. Tick one box for each statement.

3 Breast Care Nurse
   a) In the past six months I have received information about breast cancer from the breast care nurse.
      □ Yes
      □ No ⇒ Go to Question 4

   b) This information was:
      □ Not useful at all
      □ Slightly useful
      □ Moderately useful
      □ Extremely useful

   c) The amount of information I received was:
      □ Too much
      □ Just right
      □ Not enough

Section D – Support involves spending time with another person, listening and talking about problems and concerns in a way that is helpful and reassuring. These questions ask about places where you have looked for and found support in the past six months. Tick one box for each statement.

1. Family
   a) In the past six months I have received support from my family.
      □ Yes
      □ No ⇒ Go to Question 2
b) This support was:
   □ Not helpful at all
   □ Slightly helpful
   □ Moderately helpful
   □ Extremely helpful

c) I wish I had received:
   □ More
   □ Less
   □ About the same amount of support from my family

Section E – These questions ask about how the information and support that you have received in the last six months has helped you. Tick one box for each statement.

As a result of the information and support that I have received in the past six months I feel:

1. Able to cope with life
   □ Not at all able
   □ Somewhat able
   □ Moderately able
   □ Very able

2. Able to understand about breast cancer
   □ Not at all able
   □ Somewhat able
   □ Moderately able
   □ Very able

Section F – These questions are about your treatment. Tick one box for each statement.

5. Have you had chemotherapy to treat the breast cancer?
   □ Yes
   □ No

6. Have you had x-ray treatment to the breast cancer (radiotherapy)?
   □ Yes
   □ No

Sample free text questions:
What is the most important area of information for you at the moment?
What has been the most helpful source of information about breast cancer, for you, in the last six months?
Who has been the most helpful source of support, for you, in the last six months?

This information has been provided with permission from the original authors:
**Summary**
This study explored the information and support services used by women with breast cancer in different geographical locations of Australia. Research consisting of geographical comparisons such as those presented in this chapter are an important consideration in a country that covers such a large land mass. The vast distances within the country mean that people live in urban, regional, remote and very remote areas and not all of these people have equal access to services, including healthcare services. Through this research, exploring the differences between those living in major cities and those living in regional and remote areas provided a clearer picture of the breast cancer information and support services that are most useful to women in Australia.

The findings presented in this chapter also provide insight into the information and support available to women with breast cancer in Australia at the present time compared to over a decade ago. Data such as this enables researchers to see where improvements have been made over time, as well as indicate where further improvement is necessary. Contributions to the evidence base provided in this chapter are intended to inform policy and drive further research in the area of breast cancer care.
Chapter 5: Results Study Two

Aim 2: To explore the role of the BCN in supporting women with breast cancer in different geographical locations.

This chapter is presented in the form of a research publication, accepted on 13 April 2015 and published online.

Reference:

Significance to the Overall Thesis
Central to the work of this doctoral research is the exploration of the breast care nurse role in the provision of information and support to Australian women with breast cancer. Another clear focus of the research is the comparisons between services provided to women after breast cancer treatment in urban areas with those in rural and remote Australia. Study Two involved surveying BCNs Australia-wide to gather data about their role in the provision of information and support using a newly developed survey instrument (as described in Chapter 3b and Appendix H).
Importantly, this was the first national study of BCNs undertaken in Australia and findings have resulted in a number of recommendations being made to improve the education and support provided to Australian BCNs.
A survey of the breast care nurse role in the provision of information and supportive care to Australian women diagnosed with breast cancer.

Abstract

Aim: To explore the role of the Australian breast care nurse (BCN) in the provision of information and support to women with breast cancer, with a focus on the differences experienced depending on geographic work context.

Design: A cross-sectional study.

Methods: This study conducted in 2013, involved surveying BCNs currently working in Australia, using a newly developed self-report online survey.

Results: Fifty breast care nurses completed the survey, 40% from major cities, 42% from inner regional Australia and 18% from outer regional, remote and very remote Australia. Patterns of service indicated higher caseloads in urban areas, with fewer kilometres served. Breast care nurses in outer regional, remote and very remote areas were less likely to work in multi-disciplinary teams and more likely to spend longer consulting with patients. Breast care nurses reported they undertook roles matching the competency standards related to the provision of education, information and support however there were barriers to fulfilling competencies including knowledge based limitations, time constraints and servicing large geographical areas.

Conclusions: This was the first Australian study to describe the role of the breast care nurse nationally and the first study to investigate breast care nurses perceived ability to meet a selection of the Australian Specialist Breast Nurse Competency Standards. Important differences were found according to the geographical location of breast care nurses.
Introduction
Breast cancer is the second most common cancer in the world and the most frequent cancer among women worldwide (Ferlay et al., 2013). Consistent with worldwide prevalence, breast cancer is the most common cancer amongst Australian women with incidence continuing to increase (Australian Institute of Health and Welfare (AIHW), 2012b). Best practice for care of Australians with breast cancer involves health professionals working collaboratively in multidisciplinary teams aiming to meet the multiple health needs of patients (National Breast Cancer Centre, 2005a, 2005c; 2003). As a member of the multidisciplinary team, the specialist breast care nurse (BCN) was introduced in Australia in the mid-1990s to facilitate better continuity of care and psychosocial support (Jones et al., 2010) for people undergoing treatment for breast cancer. Specialist breast care nursing has evolved over the past twenty years not only in Australia, but in Canada, Europe, the UK and the US (Eicher et al., 2012).

In the Australian context, the BCN role involves assisting people with breast cancer across all stages of the continuum of care, including diagnosis, treatment, rehabilitation and palliative care by providing clinical care, information, education, psychological and emotional support, as well as taking an active role in the coordination of care (National Breast Cancer Centre, 2005c). Further, the BCN model of practice is defined as a specialist practice, therefore requiring a higher level of knowledge and skill in the care of women with breast cancer (National Breast Cancer Centre, 2005c). Usual requirements include experience in oncology nursing as well as the recommended minimum education such as a Bachelor of Nursing and a Post Graduate Diploma of Breast Care Nursing (Yates et al., 2007). The scope of specialist breast nursing practice is defined as occurring in the context of a model of care that enables the nurse to work collaboratively with patients contributing to
patient-centred care, while also working collaboratively within the multi-disciplinary team (National Breast Cancer Centre, 2005c).

The consensus view is that BCNs are valued highly by their patients (Eicher et al., 2006; Halkett et al., 2006; Jones et al., 2010; Reed et al., 2010). However, despite advances in healthcare initiatives including the introduction of BCNs, women with breast cancer still have high unmet support needs. Several studies have found that many women do not have adequate information about their disease and treatment, nor receive enough practical and emotional support from health professionals (Aranda et al., 2006; Davis et al., 2004; Girgis et al., 2000; Lawler et al., 2011; McGrath et al., 1999; Raupach & Hiller, 2002; Vivar & McQueen, 2005). Historically, addressing these needs for rural or remote Australian women has proven more difficult because cancer service capabilities in Australia are restricted by many factors including challenges in attracting and retaining a sufficiently skilled workforce and servicing large geographical areas (Health Workforce Australia, 2013; National Breast Cancer Centre, 2001). For example, in Australia, the large geographical mass means that a woman living in the rural town of Richmond, Queensland, would need to travel 500 kilometres to reach the closest regional hospital offering cancer treatment services. Further, to have their treatment in the closest metropolitan city, they would need to travel 1584 kilometres to Brisbane, Queensland.

**Background**

In Australia, BCNs are either employed by the McGrath Foundation or by public or private healthcare providers. In 2013, at the time of this study there were no existing statistics on BCNs working in Australia, however it was estimated that there were around 400, with 84 of these being employed by the McGrath Foundation (McGrath Foundation, 2013; Paynter, 2013).
Like many nurses who work in advanced practice roles or specialised practice areas, Australian BCNs practice in a variety settings (Yates et al., 2007), with a range of expectations for the role, leading to lack of role clarity (Eicher et al., 2006; Lowe, Plummer, O'Brien, & Boyd, 2011). Previous research shows there is some doubt about whether all Australian women with breast cancer have adequate access to a BCN (Campbell et al., 2006; Eley & Rogers-Clark, 2012). Furthermore, there has been debate about the smaller caseload of BCNs in rural and remote areas, suggesting the role of the BCN in these settings is unsustainable (National Breast Cancer Centre and National Cancer Control Initiative, 2003).

The research literature about Australian BCNs consists of predominantly exploratory, single site studies conducted primarily in metropolitan areas (Ahern & Gardner, 2015) indicating a need for further research to investigate differing BCN roles in varying geographical and practice contexts. This study was designed in response to this finding and therefore explores the role of the Australian BCN in providing information and support to women diagnosed with breast cancer, with a particular focus on reporting the differences experienced in varying geographic work contexts. The research questions addressed are:

1. What role differences occur between rural/remote and urban BCNs in Australia?
2. How does the self-report role of an Australian BCN compare with Australian Specialist Breast Care Nurse Competency Standards relating to the provision of education, information and support?
The Study
An online survey, known as the Breast Care Nurse Survey was developed for this study and issued using a cross-sectional design. Ethical approval was granted by the Australian Catholic University Human Research Ethics Committee (approval number 2013 196N). Participants were BCNs currently working in Australia recruited using snowball sampling. Of the 60 participants who began the survey, 50 completed it, giving a completion rate of 83%. Consent was indicated by submission of a completed survey and this was explained in the participant information.

A literature search revealed no suitable pre-existing survey instrument. Therefore, a new survey instrument was developed, consisting of 59 structured items and allowance for 26 open ended responses, divided into three sections. Section One (13 items) collected demographic information about participants. Section Two (20 items) collected primarily interval and ratio data about caseloads, consults, and multi-disciplinary team involvement. Section Three (26 structured items with Likert scales and allowance for additional free text) was based on the Specialist Breast Nurse Competency Standards. In this section, the performance criteria for Specialist Breast Nurse Competency Standards 1.1, 1.2, 1.3, 4.1 and 4.2 (see Figure 1) were used as a framework for generating items to explore the breadth of the BCN role in the provision of education, information and support, as well as the perceived barriers to undertaking each of the performance criteria. Details of development, face validity and reliability of the survey are being prepared for publication separately.
Figure 1  Specialist breast nurse competency standards used to guide Section Three of the Breast Care Nurse Survey

**Domain: Supportive Care**

*Competency Element 1.1*
Identifies, validates and prioritises potential and actual physical, psychological, social, sexual and spiritual health and support needs of clients across the continuum of breast cancer.

*Competency Element 1.2*
Develops collaborative therapeutic relationships with clients and their families/significant others to anticipate and meet their multiple care needs across the continuum of breast cancer care.

*Competency Element 1.3*
Demonstrates a high level of proficiency in integrating competency knowledge and evidence about breast cancer and its impact to effectively provide a range of supportive care interventions to meet the multiple health needs of clients with breast cancer, in the context of a multidisciplinary approach to care.

**Domain: Information Provision and Education**

*Competency Element 4.1*
Provides comprehensive and specialised information to assist clients and their family and/or significant others to achieve optimal health outcomes, reduce distress and make informed decisions about treatment options and supports available within the community.

*Competency Element 4.2*
Provides education to clients with breast cancer to enable clients to be active participants in their care and engage in self-management of health-related problems where appropriate to achieve optimal health outcomes across the continuum of breast cancer.

This information was extracted from the Specialist Breast Nurse Competency Standards and Associated Educational Requirements (National Breast Cancer Centre, 2005c).

All data were stored electronically in password protected files. Detailed address data were collected to identify the geographic location of each participant; however, names of participants were not collected. Collection of Internet Protocol (IP) address of each participant was a default process of the online survey software. However, steps were taken to ensure that confidentiality and privacy were maintained by first deleting all IP addresses from the database and identifying each record by a unique number. Second, an Australian Bureau of Statistics (ABS) Remoteness Area (RA) code was manually allocated to the physical residential/workplace address of each participant to identify their geographical location (Australian Bureau of Statistics, 2013a). These RA codes were consistent with the latest available information from the ABS and were allocated using an address coding tool on the ABS website.
(Australian Bureau of Statistics, 2013c). Once the RA code was allocated, all other information relating to place of residence was deleted from the database to protect the identity of participants.

Structured items collected both nominal and ordinal data and were analysed using descriptive statistics with SPSS Statistics software, version 20.0 (IBM Corp, 2011). Categories where cell numbers were small were combined. For example, number of years working as a BCN were collapsed from five categories down to three. Thematic analysis was applied to open-ended questions, where responses were used to add richness to the quantitative data.

**Results**

Fifty BCNs completed the survey. Respondents working in major Australian cities comprised 40% (n=20) of the total sample. Forty-two percent (n=21) worked in inner regional Australia, with the remaining 18% (n=9) working in outer regional, remote or very remote Australia. Respondents worked in a variety of health care settings.

Figure 2 shows kilometres served by BCNs working in different geographic areas.

**Kilometres served by Australian BCNs working in different geographical areas**

![Bar chart showing kilometres served by Australian BCNs working in different geographical areas.](image)

**Figure 2**

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Breast Care Nurse Education, Experience and Qualifications
The majority of respondents had worked less than 6 years as a BCN (64%, n=32) and this pattern was consistent regardless of geographic location (Table 1). Forty percent of respondents were employed full time. Most BCNs employed in major cities worked between 3 and 5 days per week (80%, n=16) in contrast to less than half of those employed in outer regional, remote or very remote areas. Overall, BCNs in outer regional, remote and very remote areas also reported being less highly qualified.

Current Patient and Consult Characteristics
Higher caseloads and higher percentages of patients newly diagnosed with breast cancer were seen in major cities and inner regional areas (Table 2). Results indicate that BCNs in outer regional, remote and very remote areas were more likely to continue to follow patients from diagnosis through to and after completion of adjuvant treatment, than BCNs in major cities. Ninety percent of all BCNs reported seeing patients within one week of diagnosis, with 64% reporting consulting patients at least weekly within the first month of diagnosis. No BCNs reported spending less than 20 minutes each consult with breast cancer patients and BCNs in outer regional, remote and very remote areas were more likely to spend an hour or more consulting with patients.

Consult Methods and Multi-disciplinary Team Involvement
Regardless of geographic location, BCNs mostly used face-to-face and telephone consultations, only spending 10% of their working week using electronic consultations. Those working in geographically distant areas report less likelihood of involvement in multidisciplinary teams (MDTs). Overall, the majority of BCNs reported spending up to 30% of their working week in MDT meetings and most of these reported feeling encouraged to share their views in MDT meetings (Table 3).
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total n=50</th>
<th>Major Cities n=20</th>
<th>Inner Regional n=21</th>
<th>Outer regional, remote or very remote n=9</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Years working as BCN</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>32</td>
<td>64</td>
<td>13</td>
<td>65</td>
</tr>
<tr>
<td>6-10 years</td>
<td>11</td>
<td>22</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>7</td>
<td>14</td>
<td>5</td>
<td>25</td>
</tr>
<tr>
<td>Employment basis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>20</td>
<td>40</td>
<td>8</td>
<td>40</td>
</tr>
<tr>
<td>Part time</td>
<td>30</td>
<td>60</td>
<td>12</td>
<td>60</td>
</tr>
<tr>
<td>Percentage of work week as BCN</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.5 to 2.5 days per week</td>
<td>16</td>
<td>32</td>
<td>4</td>
<td>20</td>
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<tr>
<td>3 to 5 days per week</td>
<td>34</td>
<td>68</td>
<td>16</td>
<td>80</td>
</tr>
<tr>
<td>Highest Qualification</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital Trained, Bachelor of Nursing</td>
<td>5</td>
<td>10</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Graduate Certificate, Graduate Diploma, Master of Nursing, PhD</td>
<td>45</td>
<td>90</td>
<td>18</td>
<td>90</td>
</tr>
<tr>
<td>Hold BCN Qualification*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>42</td>
<td>84</td>
<td>17</td>
<td>85</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>16</td>
<td>3</td>
<td>15</td>
</tr>
</tbody>
</table>

*Not all of these qualifications are tertiary level
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total n=50</th>
<th>Major Cities n=20</th>
<th>Inner Regional n=21</th>
<th>Outer Regional, remote and very remote n=9</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td><strong>Case load</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-50 patients</td>
<td>26</td>
<td>52</td>
<td>11</td>
<td>55</td>
</tr>
<tr>
<td>51 - 100 patients</td>
<td>12</td>
<td>24</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>More than 100 patients</td>
<td>12</td>
<td>24</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td><strong>Newly diagnosed breast cancer patients per month</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-10 patients</td>
<td>35</td>
<td>70</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>11-20 patients</td>
<td>11</td>
<td>22</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td>More than 20 patients</td>
<td>4</td>
<td>8</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td><strong>When patients are seen</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At diagnosis</td>
<td>44</td>
<td>88</td>
<td>18</td>
<td>90</td>
</tr>
<tr>
<td>Pre-operatively</td>
<td>45</td>
<td>90</td>
<td>16</td>
<td>80</td>
</tr>
<tr>
<td>Post-operatively</td>
<td>46</td>
<td>92</td>
<td>17</td>
<td>85</td>
</tr>
<tr>
<td>During adjuvant chemotherapy/radiotherapy</td>
<td>43</td>
<td>86</td>
<td>15</td>
<td>75</td>
</tr>
<tr>
<td>After completion of adjuvant treatment</td>
<td>43</td>
<td>86</td>
<td>14</td>
<td>70</td>
</tr>
<tr>
<td><strong>How soon consults occur after diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At diagnosis</td>
<td>14</td>
<td>28</td>
<td>9</td>
<td>45</td>
</tr>
<tr>
<td>Within one or two days</td>
<td>14</td>
<td>28</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Within one week</td>
<td>17</td>
<td>34</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td>More than a week</td>
<td>5</td>
<td>10</td>
<td>2</td>
<td>10</td>
</tr>
</tbody>
</table>
Table 2  Current patient and consult characteristics *(Continued)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total n=50</th>
<th>Major Cities n=20</th>
<th>Inner Regional n=21</th>
<th>Outer Regional, remote and very remote n=9</th>
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<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Regularity of consults within the first month of diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Daily</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>At least once per week</td>
<td>32</td>
<td>64</td>
<td>11</td>
<td>55</td>
</tr>
<tr>
<td>Once a fortnight</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Once per month</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>As needed</td>
<td>17</td>
<td>34</td>
<td>8</td>
<td>40</td>
</tr>
<tr>
<td>Time allocated to a consult</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Up to 20 minutes</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>21-30 minutes</td>
<td>21</td>
<td>42</td>
<td>13</td>
<td>65</td>
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<tr>
<td>Up to 1 hour</td>
<td>25</td>
<td>50</td>
<td>6</td>
<td>30</td>
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<td>More than one hour</td>
<td>4</td>
<td>8</td>
<td>1</td>
<td>5</td>
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</table>
### Table 3 Consult methods and multi-disciplinary team involvement

<table>
<thead>
<tr>
<th>Characteristic Measured</th>
<th>Total n=50</th>
<th>Major cities n=20</th>
<th>Inner regional n=21</th>
<th>Outer regional, remote and very remote n=9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face-to-face consults (n=50)</td>
<td>Up to 50%</td>
<td>31 (62%)</td>
<td>7 (35%)</td>
<td>16 (76%)</td>
</tr>
<tr>
<td></td>
<td>More than 50%</td>
<td>19 (38%)</td>
<td>13 (65%)</td>
<td>5 (24%)</td>
</tr>
<tr>
<td>Telephone consults (n=50)</td>
<td>Up to 50%</td>
<td>33 (66%)</td>
<td>17 (85%)</td>
<td>12 (57%)</td>
</tr>
<tr>
<td></td>
<td>More than 50%</td>
<td>17 (34%)</td>
<td>3 (15%)</td>
<td>9 (43%)</td>
</tr>
<tr>
<td>Electronic communication consults (n=50)</td>
<td>Up to 10%</td>
<td>47 (94%)</td>
<td>19 (95%)</td>
<td>21 (100%)</td>
</tr>
<tr>
<td></td>
<td>More than 10%</td>
<td>3 (6%)</td>
<td>1 (5%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Do you work in a MDT? (n=50)</td>
<td>Yes</td>
<td>44 (88%)</td>
<td>19 (95%)</td>
<td>19 (91%)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>6 (12%)</td>
<td>1 (5%)</td>
<td>1 (9%)</td>
</tr>
<tr>
<td>If yes:</td>
<td>What percentage of your week is spent in MDTMs? (n=44)</td>
<td>Up to 30%</td>
<td>32 (73%)</td>
<td>11 (58%)</td>
</tr>
<tr>
<td></td>
<td>31-60%</td>
<td>9 (20%)</td>
<td>6 (32%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td></td>
<td>More than 60%</td>
<td>3 (7%)</td>
<td>2 (11%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Are you encouraged to share your view in MDTs about patient care? (n=43)</td>
<td>Yes, always</td>
<td>23 (53%)</td>
<td>11 (58%)</td>
<td>10 (56%)</td>
</tr>
<tr>
<td></td>
<td>Yes, but only if I have been working with the patient</td>
<td>10 (23%)</td>
<td>5 (26%)</td>
<td>3 (17%)</td>
</tr>
<tr>
<td></td>
<td>No, but I feel free to share my view</td>
<td>10 (23%)</td>
<td>3 (16%)</td>
<td>5 (28%)</td>
</tr>
</tbody>
</table>
Perceived Ability to Undertaking Competencies Related to Provision of Information and Support
Respondents reported regularly undertaking the performance criteria embedded in competency standards 1.1, 1.2, 1.3, 4.1 and 4.2 (National Breast Cancer Centre, 2005c). Analysis of relationships using cross tabulation between responses and years’ experience revealed those with more than 5 years’ experience were more likely to reporting to ‘always’ undertake performance criteria in 22 out of the 26 criteria listed. Relationships between responses and level of education revealed those with post-graduate education were more likely to report ‘always’ undertaking performance criteria in 19 out of the 26 criteria listed. Notably, much lower percentages of BCNs perceived an ability to ‘always’ undertake performance criteria 1.1c, than was reported in any of the other performance criteria listed and these percentages were equivalent regardless of levels of experience and education.

Barriers to Undertaking Competencies Related to Provision of Information and Support
Free text information revealed the most common barriers to undertaking performance criteria were large patient loads, limited time constraints and knowledge base limitations. In the supportive care domain, BCNs working in rural or remote centres reported limited resources and limited access to other health care workers and identified geographical distances to main treatment centres as barriers to fulfilling competencies. The existence of ethnic and cultural barriers was also acknowledged, especially by those working in remote and very remote settings.

In the domain of information provision and education, a number of BCNs reported lack of private spaces to address matters needing discretion. Some reported they lacked experience, knowledge, skills and confidence dealing with sensitive matters,
but many explained they were increasing their skill and knowledge base through education. Those in geographically isolated areas reported that although ongoing education was available, access was difficult due to factors such as distance, cost and time away from work. Free text responses also revealed the difficulties experienced accessing the MDT due to geographical distance. Additionally, some BCNs reported MDT meetings were held infrequently, leading to barriers in provision of timely advice.

Discussion
Current evidence about the role of the Australian BCN providing information in support to women with breast cancer is lacking (Ahern & Gardner, 2015). This study provides insights into the role of the Australian breast care nurse particularly in the context of different geographical locations.

A Comparison of BCNs Based on Geographical Location
Since the majority of respondents had less than 6 years’ experience in their position, assessing the educational needs of this group and providing additional educational support may be required. Access to additional education through continued professional development (CPD) is an important factor regardless of geographical location and ensures that nursing practice is evidence-based, maintains best-practice standards and meets the current needs of communities (Black & Farmer, 2013).

Although the ratios of full-time to part-time BCNs were consistent across the three geographical areas, there were major differences in total working hours. Perhaps, like many other rural nursing roles, BCNs working in outer regional, remote and very
remote areas may be predominantly part-time in this role and combine the BCN role with other nursing roles, increasing role diversity (Francis & Mills, 2011).

The higher caseloads experienced by those working in major cities and inner regional areas may contribute to reduced regularity and duration of consult time. These results support findings of Jones et al., (2010) who noted BCNs in metropolitan areas had a wider range of responsibilities, higher caseloads with the potential for more limited care being provided to patients.

Findings related to length of consultations and regularity with which BCNs see their patients throughout the cancer trajectory suggest that women in outer regional, remote and very remote areas may have higher levels of access to their BCNs and therefore more time and opportunity to receive information and support from their BCN. This reinforces findings from a previous study that found a statistically significantly higher percentage of women in outer regional, remote and very remote areas reported using the BCN for support than women in major cities and inner regional areas (Ahern et al., 2014). An increase in the number of BCNs available to meet the needs of women in major cities and inner regional areas would decrease caseloads, enabling BCNs in these areas to increase regularity and duration of consultations, potentially improving the levels of BCN support experienced by these women.

Limited use of electronic consultations were surprising considering that internet-based telemedicine is readily available and regularly used by many health professionals (Fatehi, Martin-Khan, Gray, & Russell, 2014). Increased uptake of the telemedicine model would provide advantages for BCNs and patients alike saving
BCN travel time, whilst allowing patients the convenience of consulting from the privacy of their own home (Sabesan & Piliouras, 2009).

**BCN Perceived Ability to Undertake Competencies Consistent with their Role**

Perceptions of BCNs with more experience and/or higher qualifications associated with higher levels of ability to undertake competencies related to the provision of information and support reinforce once again the benefit of continued professional development, training or education relevant to BCN roles. Importantly, BCN perceptions highlighted a specific area of need to enable them to more confidently meet performance criteria 1.1c. This performance criterion indicates that BCNs are required to routinely assess all clients for psychosocial risk factors and distress at the time of diagnosis and on a regular basis using a systematic evidence-based approach (National Breast Cancer Centre, 2005c). Therefore, BCNs may need further education and access to appropriate evidence-based screening tools to assist them to become more confident and competent in addressing psychosocial and psychological needs of patients.

Online courses are one way of delivering CPD to rural and remote nurses through organisations such as CRANAplus and EdCaN (Australian Government, 2010; CRANAplus Incorporated, 2014). Each offer web-based learning resources useful to rural nurses and within cancer control, but more specific resources for BCNs could be developed. However, through an open forum discussion at a national cancer nurses conference, the point was made that often BCNs fail to take up online education that is offered (Ahern, 2014), although the reason behind the lack of uptake are unknown.
Reported barriers to undertaking the selected competencies included a lack of culturally appropriate resources available to meet the multiple care needs of women with breast cancer. While there are now resources available through the Breast Cancer Network Australia and Cancer Australia, at the time this study was conducted these resources may not have been readily available (Breast Cancer Network Australia, 2013a; Cancer Australia, 2012c).

**Policy and Research Implications**
Continued professional development (CPD), training and support are recommended for all BCNs (Yates et al., 2007). It is well documented that continued professional development and education of nurses in the rural setting is difficult due to limited resources (Fahey & Monoghan, 2005; Health Workforce Australia, 2013; McCoy, 2009), however, these are critical elements supporting the role and professional practice of BCNs (Black & Farmer, 2013; Francis & Mills, 2011). Therefore, individual BCNs should commit to CPD offered and employers need to support and fund nurses to undertake CPD through post-graduate study and clinical learning opportunities (Black & Farmer, 2013). Ongoing assessment of gaps in the education and training provided to BCNs is recommended for educating bodies, and additionally, the reasons for failure to take up online CPD is an area worthy of further investigation.

The lack of access to and participation for BCNs in outer regional, remote and very remote areas to multi-disciplinary teams compared with their peers in major cities and inner regional areas is consistent with a recent study evaluating the McGrath BCN service which found 47% of rural BCNs participated in MDT meetings (Paynter et al., 2013). Multidisciplinary care benefits both clinicians and patients and it is well recognised that cancer care is most effectively delivered by MDTs (Catt, Fallowfield,
Jenkins, Langridge, & Cox, 2005; Health Workforce Australia, 2013; National Breast Cancer Centre, 2005a). The BCN is positioned between cancer specialists and patients enabling the nurse to advocate for patients and assist in their medical management (Amir et al., 2004), thus the importance of BCN involvement in MDT meetings conducted by the cancer treatment team. Diverse geographical locations make it difficult for face-to-face MDT meetings. However, Internet and videoconferencing software can be used not only for outpatient consultations, but also case discussions between health professionals (Doolittle & Spaulding, 2006; Sabesan et al., 2012). Therefore, it is recommended that clinicians seek opportunities to use videoconferencing technologies enabling inclusion of BCNs from all geographical areas in regular MDT meetings. Current availability of and use of videoconferencing technologies by MDTs is an area in need of more research.

**Strengths and Limitations**

Importantly, this is the first study to describe the Australian BCN role nationally and to investigate BCNs’ perceived ability to meet the Specialist Breast Nurse Competency Standards relating to the provision of education, information and support (National Breast Cancer Centre, 2005c). Limitations include using a newly developed self-report survey tool and a small convenience sample. Further validation of the instrument would be beneficial before it is used in other contexts.

**Conclusion**

This study reports the differences in characteristics and practice of BCNs working in urban areas and those working in regional, rural and remote areas. Findings suggest BCNs in outer regional, remote and very remote areas require improved support through better access to continued professional development and training,
as well as better inclusion in MDT meetings. Innovative use of web-based resources such as online training and videoconferencing should be investigated and used to achieve improved access to CPD and MDTs for BCNs working in outer regional, remote and very remote areas. For BCNs working in major cities and inner regional areas, an increase in numbers of employed BCNs may decrease caseloads and increase patient contact time. All recommendations have the capacity to improve the professional practice of Australian BCNs and outcomes for women with breast cancer.
Summary
The findings resulting from Study Two, presented in this chapter offer insight into the differences experienced by BCNs working in different geographical areas. This is the first national study of Australian BCNs with a focus on the differences due to geographic work context. The study has enabled a number of areas of need to be highlighted to improve the professional development and professional support offered to BCNs, particularly in rural and remote areas. The study also highlighted a gap in the knowledge regarding the quantifying of workable caseloads for specialised nurses such as BCNs. The recommendations resulting from this study have the potential to enhance working conditions for BCNs potentially leading to improved job satisfaction and improved outcomes for their patients.
Chapter 6: Results Study Three

Aim 3: To examine the unmet needs and self-efficacy of women diagnosed with breast cancer with and without the support of a breast care nurse.

This chapter is presented in the form of a research publication which has been peer reviewed and is currently being amended ready for resubmission.

Reference:


Significance to the Overall Thesis

Study Three was conducted as the final phase of this thesis. Guided by work undertaken previously, and the theoretical framework underpinning the research, a central focus of Study Three was the unmet needs and self-efficacy of women with breast cancer under the care of a BCN. The findings from Study One and Two gave an insight into the information and support used by Australian women with breast cancer and the role of the BCN in providing such information and support, aligning with Dimension 1 of the *Professional Development Framework*, ‘continuity of care’ (Fillion et al., 2012). However, more research was necessary to explore further the perceived areas of need for women with breast cancer, as well as the concepts of active-coping and cancer self-management as described in Dimension 2 of the *Professional Navigation Framework* (Fillion et al., 2012). Of particular interest were the differences in perceptions of women with and without the support of a BCN.
Furthermore, like Studies One and Two, the gathering of data on a national scale was also an important feature of Study Three.

For this study, two well validated survey instruments were chosen and permission to use these was granted by the original authors. Both instruments chosen were identified in the *Professional Navigation Framework* (Fillion et al., 2012) as useful instruments for assessing outcomes related to the concepts of active coping, cancer self-management and supportive care.
A survey of unmet needs and self-efficacy in women diagnosed with breast cancer with and without the support of a breast care nurse.

Abstract

Introduction: Research surrounding BCNs in the Australian context is limited and no existing published research has explored the differences in unmet need or self-efficacy of women and the role of the BCN.

Aim: To compare the unmet needs and self-efficacy of women diagnosed with breast cancer who have the support of a BCN with those who do not have BCN support.

Method: Participants were Australian women who had completed treatment for breast cancer between 6 months and 5 years 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. Statistical data were analysed using SPSS software, with chi-square being 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 with a BCN were significantly less likely to report unmet needs in eleven of the 34 areas measured. Scores of self-efficacy showed women with a BCN had significantly higher self-efficacy when seeking and obtaining information (p=>0.001) and understanding and participating in care (p=0.032).
Conclusions: This large Australian study has provided useful baseline information supporting the role of the BCN in addressing unmet needs and increasing self-efficacy of women with breast cancer. There is an association between decreased levels of unmet need and increased levels of self-efficacy for women with a BCN. However, further research is needed to determine if there are factors other than the existence of BCN supports influencing these findings.
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, Darshini Devi, Wong, & Koh, 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 & Fenlon, 2010).

Predictions of the number of Australians diagnosed with breast cancer in 2015 equate to approximately 15000 (Cancer Australia, 2012a). This population live in a variety of geographical areas and receive 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 health care, social support and information (Palesh et al., 2006; Sabesan & Piliouras, 2009), sometimes resulting in high levels of psychosocial unmet need (Butow et al., 2012; Harrison, Young, Price, Butow, & Solomon, 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.,
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 & 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, Chang, Davis, & Makoul, 2005) which may result in successful outcomes being achieved (Lev & Owen, 2001). Previous research has indicated the existence of unmet needs to be strongly associated with psychological distress and/or 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, Dalton, Christensen, Frederiksen, & Johansen, 2010). Importantly, high self-efficacy
achieved early in the disease trajectory is predictive of positive long-term adaption (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 & Bitzer, 2003; Collie et al., 2005).

The breast care nurse 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 breast care nurse 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 breast care nurses and those in the more regional or remote areas were statistically significantly more likely to report the breast care nurse 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 breast care nurse to enable enhanced continuity of care and psychosocial support (Jones et al., 2010; National Breast Cancer Centre, 2005c). However, studies have shown that not all women have access to such services (Campbell et al., 2006; Eley & Rogers-Clark, 2012).

In earlier work, researchers “explored the role of the Australian breast care nurse in the provision of information and support to women with breast cancer” (Ahern et al., 2014, 2015). To explore this further, in this study it was hypothesized that Australian
women with breast cancer under the care of a breast care nurse 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.

**Purpose and Specific Aims**
The purpose of this study was to compare the unmet needs and perceived self-efficacy of women with and without the support of a BCN.

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 under the care of a BCN compared to those who do not have BCN care?
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 access to BCNs reported by women with breast cancer living in urban areas compared to women with breast cancer living in regional, rural or remote areas?

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

**Methodology**

**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) (Boytes, Girgis, & Lecathelinais, 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 (Boytes 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 need to (5) high need (Boytes et al., 2009). Previous validation studies have shown that the Cronbach alpha for SCNS-SF34 ranged from 0.88-0.96 (Boytes et al., 2009).

The CASE-cancer is a 12-item self-efficacy measure comprising three domains: (1) understanding and participating in care; (2) maintaining a positive attitude; and (3) seeking and obtaining information (Wolf et al., 2005). Scores for the CASE-cancer are on a four-point Likert scale where higher scores indicate higher self-efficacy (Wolf et al., 2005). Previous validation studies have shown that the Cronbach alpha for CASE-cancer ranged from 0.75 to 0.76 (Wolf et al., 2005).

Permission to use both instruments was granted by the original authors. The instruments were then structured as a self-report online survey using Qualtrics survey software (Qualtrics, 2013).

Participants
Participants were women over 18 years of age with breast cancer who had completed active treatment at least 6 months ago, but not more than five years ago.
Ethical approval (No. 201461N) was granted and following this, recruitment was undertaken using two national databases of women diagnosed with breast cancer: Register4 and the BCNA Review and Survey Group (Breast Cancer Network Australia, 2013b; National Breast Cancer Foundation, 2012). Participation was voluntary and all participants were fully informed of the purpose and procedures of the study. Consent was assumed through submission of a completed survey which was explained in the Participant Information Letter provided. Although issued in an online format, the option to request a paper-based survey was offered in the initial recruitment information.

Confidentiality of participants was achieved through the allocation of identification numbers to replace IP addresses and Australian Bureau of Statistics (ABS) Remoteness Area (RA) codes to replace address details (Ahern et al., 2014; Australian Bureau of Statistics, 2013a). At the completion of the study, a de-identified summary of results was issued to members of both databases.

**Data Analysis**
The data were analysed using IBM SPSS software, version 20.0 (IBM Corp, 2011). Soon after the survey had been issued, a participant provided feedback about clarity of one survey question and a minor amendment was made in Section One. Statistical analyses of responses before and after the amendment were performed and no significant difference in responses was identified.

Similar to methods followed in a previous study (Ahern et al., 2014), descriptive statistics were calculated for all variables to determine missing and out of range values. Then, frequency tables for each section of the survey were generated so a summary of results could be analysed. After checking that responses were
consistent, some RA codes were combined reducing the number of categories from five to three (Ahern et al., 2014). Major cities and inner regional categories remained unchanged, whereas the remaining three categories were combined; outer regional, remote and very remote (Ahern et al., 2014). For statistical analysis of unmet needs measured by the SCNS-34 by BCN access or geographical location, the 5 point Likert scale was reduced to two categories: ‘satisfied need’ and ‘unmet need’.

Composite scores for each of the CASE-cancer subscales were calculated to analyse the perceived self-efficacy of participants. Analysis of initial frequencies and bar charts showed clearly that responses for each of the subscales were strongly positively skewed, with most participants responding that they ‘strongly agree’ to each of the items in the subscale. There was however, a bi-modal data distribution so findings were recoded into two categories, those scoring a composite score of 0-12 and those scoring a composite score of 13-16. The latter category indicated participants with a higher self-efficacy in each subscales. Throughout the analysis of data, chi-square was used to report statistically significant findings.

**Results**
Nine hundred and two women completed the survey. Table 1 presents the respondent demographics and treatment characteristics, whereby information reported follows a similar format to a previous study by the researchers (Ahern et al., 2014). Respondents from major cities comprised 67% of the total sample. Twenty three percent lived in inner regional Australia, with the remaining 10% living in outer regional, remote or very remote Australia. Age ranged from 28 to 82 years with a mean of 56 years. Seven hundred and twenty-two respondents (80%) were born in Australia and Oceania, with the remaining 20% (n=180) being born Europe, Asia,
Africa or North America. Seventy-eight percent (n=703) of women were married or committed. Just under half of participants (47%, n=420) had a university education, however a statistically significant difference was found when comparing those in major cities (51%, n=305) and inner regional areas (43%, n=88) with those in outer regional, remote and very remote areas (30%, n=27) with a university education ($\chi^2=15.558, \rho=<0.001$).

When analysing frequency of access to BCNs, 68% (n=616) reported that they did have access to a BCN at some stage during their treatment of breast cancer. The highest reported access to BCNs was by women in inner regional areas (74%, n=154; see Table 1) although the difference was not statistically significant. An analysis of treatment characteristics showed that 99.7% of respondents had undergone surgery to treat breast cancer. The percentage treated with chemotherapy (62-67%) or radiotherapy (69-71%) was similar regardless of geographical residence (see Table 1). The number of respondents treated with hormone therapy was lowest in inner regional areas (67%, n=138). Reported incidence of breast reconstruction was lowest in outer regional, remote and very remote areas (18%, n=16).

**Perceived Unmet Needs**

Of the 902 participants completing the survey, 93% completed the SCNS-34 measuring unmet needs. The top 15 unmet needs that were rated as moderate to high are shown in Table 2. Among the highest unmet needs items, eight items were in the psychological domain, three were in the physical and daily living domain, two
were in the health systems domain and two were in the sexuality domain. The most common unmet needs were “fears about the cancer spreading” (22.1%) followed by “uncertainty about the future” (17.7%) and “changes in sexual feelings” (17.3%).
Table 1  Demographic and treatment characteristics of respondents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total N=902</th>
<th>Major Cities n=604</th>
<th>Inner Regional n=207</th>
<th>Outer regional, remote or very remote n=91</th>
<th>Chi-square</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2.124</td>
<td>0.346</td>
</tr>
<tr>
<td>Less than or equal to 50 years</td>
<td>272 30.2</td>
<td>189 31.3</td>
<td>54 26.1</td>
<td>29 31.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 50 years</td>
<td>630 69.8</td>
<td>415 68.7</td>
<td>153 73.9</td>
<td>62 68.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continent of Birth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.109</td>
<td>0.211</td>
</tr>
<tr>
<td>Australia and Oceania</td>
<td>722 80.0</td>
<td>474 78.5</td>
<td>174 84.1</td>
<td>74 81.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All other continents</td>
<td>180 20.0</td>
<td>130 21.5</td>
<td>33 15.9</td>
<td>17 18.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.369</td>
<td>0.186</td>
</tr>
<tr>
<td>Single, separated, divorced or widowed</td>
<td>199 22.1</td>
<td>144 23.8</td>
<td>38 18.4</td>
<td>17 18.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or committed</td>
<td>703 77.9</td>
<td>460 76.2</td>
<td>169 81.6</td>
<td>74 81.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education completed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>15.558</td>
<td>&lt;0.001#</td>
</tr>
<tr>
<td>Primary, Secondary or Tertiary non-University</td>
<td>482 53.4</td>
<td>299 49.5</td>
<td>119 57.5</td>
<td>64 70.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tertiary University</td>
<td>420 46.6</td>
<td>305 50.5</td>
<td>88 42.5</td>
<td>27 29.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had BCN care during treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4.989</td>
<td>0.083</td>
</tr>
<tr>
<td>Yes</td>
<td>616 68.3</td>
<td>399 66.1</td>
<td>154 74.4</td>
<td>63 69.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>286 31.7</td>
<td>205 33.9</td>
<td>53 25.6</td>
<td>28 30.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment Undergone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.485</td>
<td>0.476</td>
</tr>
<tr>
<td>Surgery</td>
<td>899 99.7</td>
<td>601 99.5</td>
<td>207 100.0</td>
<td>91 100.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>570 63.2</td>
<td>381 63.1</td>
<td>128 61.8</td>
<td>61 67.0</td>
<td>0.744</td>
<td>0.689</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>643 71.3</td>
<td>427 70.7</td>
<td>143 69.1</td>
<td>64 70.3</td>
<td>0.192</td>
<td>0.908</td>
</tr>
<tr>
<td>Treatment completed*</td>
<td>852 94.5</td>
<td>573 94.9</td>
<td>194 93.7</td>
<td>85 93.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tamoxifen/Hormone Therapy*</td>
<td>644 71.4</td>
<td>438 72.5</td>
<td>138 66.7</td>
<td>68 74.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast reconstruction*</td>
<td>215 23.8</td>
<td>143 23.7</td>
<td>56 27.1</td>
<td>16 17.6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* No statistic possible due to 0 values.
# Statistically significant finding
### Table 2  Top 15 unmet needs by percentage rating with moderate or high need n=839

<table>
<thead>
<tr>
<th>Unmet needs item</th>
<th>n</th>
<th>% of sample reporting needs</th>
<th>Needs domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Fears about the cancer spreading</td>
<td>199</td>
<td>22.1</td>
<td>Psychological</td>
</tr>
<tr>
<td>2 Uncertainty about the future</td>
<td>160</td>
<td>17.7</td>
<td>Psychological</td>
</tr>
<tr>
<td>3 Changes in sexual feelings</td>
<td>156</td>
<td>17.3</td>
<td>Sexuality</td>
</tr>
<tr>
<td>4 Having access to professional counselling if you, family or friends need it</td>
<td>148</td>
<td>16.4</td>
<td>Health systems and information</td>
</tr>
<tr>
<td>5 Anxiety</td>
<td>147</td>
<td>16.3</td>
<td>Psychological</td>
</tr>
<tr>
<td>6 Concerns about the worries of those close to you</td>
<td>144</td>
<td>16.0</td>
<td>Psychological</td>
</tr>
<tr>
<td>7 Changes in sexual relationships</td>
<td>144</td>
<td>16.0</td>
<td>Sexuality</td>
</tr>
<tr>
<td>8 Having one member of medical staff with whom you can talk to about aspects of</td>
<td>137</td>
<td>15.2</td>
<td>Health systems and information</td>
</tr>
<tr>
<td>your condition, treatment and follow-up</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 Feeling down or depressed</td>
<td>134</td>
<td>14.9</td>
<td>Psychological</td>
</tr>
<tr>
<td>10 Lack of energy/tiredness</td>
<td>130</td>
<td>14.4</td>
<td>Physical and daily living</td>
</tr>
<tr>
<td>11 Feelings of sadness</td>
<td>125</td>
<td>13.9</td>
<td>Psychological</td>
</tr>
<tr>
<td>12 Worry that the results of treatment are beyond your control</td>
<td>124</td>
<td>13.7</td>
<td>Psychological</td>
</tr>
<tr>
<td>13 Not being about to do the things you used to do</td>
<td>113</td>
<td>12.5</td>
<td>Physical and daily living</td>
</tr>
<tr>
<td>14 Learning to feel in control of your situation</td>
<td>106</td>
<td>11.8</td>
<td>Psychological</td>
</tr>
<tr>
<td>15 Pain</td>
<td>104</td>
<td>11.5</td>
<td>Physical and daily living</td>
</tr>
</tbody>
</table>
Unmet Needs in the First Year of Diagnosis Compared with Unmet Needs 5 or More Years After Diagnosis

The top 10 unmet needs reported as moderate to high in the first year of diagnosis and reported as moderate to high five or more years after diagnosis are listed in Table 3. In the first year of diagnosis, four items were in the psychological domain, three were in the physical and daily living domain, two were in the health systems and information domain and one item each were from the sexuality domain and the patient care and support domain. The most common unmet need in the first year of diagnosis was “lack of energy/tiredness” (25.0%), followed by “not being able to do the things you used to do” (24.0%), and “having one member of medical staff with whom you can talk to about all aspects of your condition, treatment and follow-up” (22.9%).

Five or more years after diagnosis, women reported some different unmet needs to those reported by women in the first year of diagnosis, however, four of the unmet needs remained the same. “Fears about the cancer spreading”, “changes in sexual feelings”, “anxiety” and “feeling down or depressed” were reported as moderate or high unmet needs by both groups. Five or more years after diagnosis, seven unmet needs items were in the psychological domain, three were in the sexuality domain and one where in the health systems and information domain. The most common unmet needs reported by this group were “fears about the cancer spreading” and “changes in sexual feelings” (both 26.8%) and “changes in sexual relationships” (25.6%).
Table 3 Top 10 unmet needs in first year of diagnosis compared with five or more years after diagnosis

<table>
<thead>
<tr>
<th>Unmet Needs Item</th>
<th>n</th>
<th>%**</th>
<th>Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unmet needs in the first year since diagnosis n=96</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 Lack of energy/tiredness</td>
<td>24</td>
<td>25.0</td>
<td>Physical and daily living</td>
</tr>
<tr>
<td>2 Not being able to do the things you used to do</td>
<td>23</td>
<td>24.0</td>
<td>Physical and daily living</td>
</tr>
<tr>
<td>3 Having one member of medical staff with whom you can talk to about all aspects of your condition, treatment and follow-up</td>
<td>22</td>
<td>22.9</td>
<td>Health systems and information</td>
</tr>
<tr>
<td>4 Anxiety</td>
<td>20</td>
<td>20.8</td>
<td>Psychological</td>
</tr>
<tr>
<td>5 Fears about the cancer spreading</td>
<td>19</td>
<td>19.8</td>
<td>Psychological</td>
</tr>
<tr>
<td>Having access to professional counselling if you, family or friends need it</td>
<td>19</td>
<td>19.8</td>
<td>Health systems and information</td>
</tr>
<tr>
<td>7 Concerns about the worries of those close to you</td>
<td>18</td>
<td>18.8</td>
<td>Psychological</td>
</tr>
<tr>
<td>8 Feeling down or depressed</td>
<td>17</td>
<td>17.7</td>
<td>Psychological</td>
</tr>
<tr>
<td>9 Work around the home</td>
<td>16</td>
<td>16.7</td>
<td>Physical and daily living</td>
</tr>
<tr>
<td>Changes in sexual feelings</td>
<td>16</td>
<td>16.7</td>
<td>Sexuality</td>
</tr>
<tr>
<td>Reassurance by medical staff that the way you feel is normal*</td>
<td>16</td>
<td>16.7</td>
<td>Patient care and support</td>
</tr>
<tr>
<td><strong>Unmet needs five or more years after diagnosis n=82</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 Fears about the cancer spreading</td>
<td>22</td>
<td>26.8</td>
<td>Psychological</td>
</tr>
<tr>
<td>Changes in sexual feelings</td>
<td>22</td>
<td>26.8</td>
<td>Sexuality</td>
</tr>
<tr>
<td>3 Changes in your sexual relationships</td>
<td>21</td>
<td>25.6</td>
<td>Sexuality</td>
</tr>
<tr>
<td>4 Concerns about the worries of those close to you</td>
<td>20</td>
<td>24.4</td>
<td>Psychological</td>
</tr>
<tr>
<td>5 Anxiety</td>
<td>18</td>
<td>22.0</td>
<td>Psychological</td>
</tr>
<tr>
<td>6 Feeling down or depressed</td>
<td>16</td>
<td>19.5</td>
<td>Psychological</td>
</tr>
<tr>
<td>Uncertainty about the future</td>
<td>16</td>
<td>19.5</td>
<td>Psychological</td>
</tr>
<tr>
<td>Being given info about sexual relationships</td>
<td>16</td>
<td>19.5</td>
<td>Sexuality</td>
</tr>
<tr>
<td>9 Having access to professional counselling if you, family or friends need it</td>
<td>15</td>
<td>18.3</td>
<td>Health systems and information</td>
</tr>
<tr>
<td>10 Learning to feel in control of your situation</td>
<td>14</td>
<td>17.1</td>
<td>Psychological</td>
</tr>
<tr>
<td>Feelings of sadness*</td>
<td>14</td>
<td>17.1</td>
<td>Psychological</td>
</tr>
</tbody>
</table>

* There are 11 items listed due to some items rating an equal percentage

** Percentages are based on ratings of high or moderate need
**Unmet Needs by BCN Access**
Of the 34 unmet needs measured in this survey, eleven statistically significant differences were found when comparing the unmet needs of participants with and without the support of a BCN (Table 4). Five of these were in the psychological domain, three in the domain of health systems and information, two in the domain of patient care and support and the remaining one in the physical and daily living domain.

**Unmet Needs by Geographical Residence**
The analysis of unmet needs by geographical residence revealed only two statistically significant findings. First, those in outer regional, remote and very remote areas were significantly more likely to report unmet need in the choice about which healthcare service/hospital they attended ($\chi^2=8.780$, $p=0.012$). Second, those in major cities were significantly more likely to report unmet need being treated in a hospital or clinic that was as physically pleasant as possible ($\chi^2=6.151$, $p=0.046$).

**Perceived Self-efficacy**
Of the 902 participants completing the survey, only 833 participants completed the CASE-cancer scale measuring perceived self-efficacy. Table 5 shows a comparison of perceived self-efficacy scores of participants with and without the support of a BCN. Those with a BCN reported higher self-efficacy in all three subscales. Respondents with a BCN reported significantly higher self-efficacy in both ability to “seek and obtain information” ($\chi^2=14.9114$, $p=>0.001$) and “understand and participate in care” ($\chi^2=4.6267$, $p=0.032$). There was no difference in reported self-efficacy scores across geographical areas.
<table>
<thead>
<tr>
<th>Unmet needs Item</th>
<th>Needs Domain</th>
<th>BCN Care</th>
<th>Satisfied Need</th>
<th>Unmet Need</th>
<th>Chi-square</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of energy/tiredness (n=481)</td>
<td>Physical and daily living</td>
<td>Yes</td>
<td>104</td>
<td>31.7</td>
<td>224</td>
<td>68.3</td>
</tr>
<tr>
<td>No</td>
<td>32</td>
<td>20.9</td>
<td>121</td>
<td>79.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety (n=453)</td>
<td>Psychological</td>
<td>Yes</td>
<td>96</td>
<td>31.7</td>
<td>207</td>
<td>68.3</td>
</tr>
<tr>
<td>No</td>
<td>34</td>
<td>22.7</td>
<td>116</td>
<td>77.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uncertainty about the future (n=502)</td>
<td>Psychological</td>
<td>Yes</td>
<td>112</td>
<td>33.5</td>
<td>222</td>
<td>66.5</td>
</tr>
<tr>
<td>No</td>
<td>39</td>
<td>23.2</td>
<td>129</td>
<td>76.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning to feel in control of your situation (n=428)</td>
<td>Psychological</td>
<td>Yes</td>
<td>122</td>
<td>43</td>
<td>162</td>
<td>57</td>
</tr>
<tr>
<td>No</td>
<td>42</td>
<td>29.2</td>
<td>102</td>
<td>70.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keeping a positive outlook (n=394)</td>
<td>Psychological</td>
<td>Yes</td>
<td>131</td>
<td>50</td>
<td>131</td>
<td>50</td>
</tr>
<tr>
<td>No</td>
<td>40</td>
<td>30.3</td>
<td>92</td>
<td>69.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings about death and dying (n=381)</td>
<td>Psychological</td>
<td>Yes</td>
<td>108</td>
<td>43</td>
<td>143</td>
<td>57</td>
</tr>
<tr>
<td>No</td>
<td>34</td>
<td>26.2</td>
<td>96</td>
<td>73.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reassurance by medical staff that the way you feel is normal (n=440)</td>
<td>Patient care and support</td>
<td>Yes</td>
<td>166</td>
<td>56.8</td>
<td>126</td>
<td>43.2</td>
</tr>
<tr>
<td>No</td>
<td>69</td>
<td>46.6</td>
<td>79</td>
<td>53.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical staff acknowledging, and showing sensitivity to your feelings and emotional needs (n=431)</td>
<td>Patient care and support</td>
<td>Yes</td>
<td>170</td>
<td>61.6</td>
<td>106</td>
<td>38.4</td>
</tr>
<tr>
<td>No</td>
<td>78</td>
<td>50.3</td>
<td>77</td>
<td>49.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being treated like a person not just another case (n=333)</td>
<td>Health systems and information</td>
<td>Yes</td>
<td>142</td>
<td>66</td>
<td>73</td>
<td>34</td>
</tr>
<tr>
<td>No</td>
<td>58</td>
<td>38.4</td>
<td>93</td>
<td>61.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being treated in a hospital or clinic that is as physically pleasant as possible (n=312)</td>
<td>Health systems and information</td>
<td>Yes</td>
<td>152</td>
<td>72.0</td>
<td>59</td>
<td>28.0</td>
</tr>
<tr>
<td>No</td>
<td>61</td>
<td>60.4</td>
<td>40</td>
<td>39.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having one member of medical staff whom you can talk to about all aspects of your condition, treatment and follow-up (n=449)</td>
<td>Health systems and information</td>
<td>Yes</td>
<td>159</td>
<td>53.4</td>
<td>139</td>
<td>46.6</td>
</tr>
<tr>
<td>No</td>
<td>58</td>
<td>38.4</td>
<td>93</td>
<td>61.6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: Only statistically significant results were tabulated*
Table 5 Self-efficacy of participants with and without a Breast Care Nurse using CASE-C (n=833)

<table>
<thead>
<tr>
<th>CASE-c Subscale</th>
<th>BCN Care (Yes n=576, No n=257)</th>
<th>Case-C Score*</th>
<th>Chi-square</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>0-12 n</td>
<td>13-16 n</td>
<td></td>
</tr>
<tr>
<td>Seek and obtain information</td>
<td>Yes</td>
<td>115</td>
<td>461  80.0</td>
<td>14.991</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>83</td>
<td>174   67.7</td>
<td></td>
</tr>
<tr>
<td>Understand and participate in care</td>
<td>Yes</td>
<td>114</td>
<td>462  80.2</td>
<td>4.626</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>68</td>
<td>189   73.5</td>
<td></td>
</tr>
<tr>
<td>Maintain positive attitude</td>
<td>Yes</td>
<td>199</td>
<td>377   65.5</td>
<td>0.320</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>94</td>
<td>163   63.4</td>
<td></td>
</tr>
</tbody>
</table>

*Higher score means higher self-efficacy
# Statistically significant findings

Discussion
This large Australian study investigated the unmet needs and self-efficacy of women with breast cancer producing findings consistent with international literature. Uniquely though, this study reports differences in unmet needs and self-efficacy of women who have had a BCN at any time during their cancer treatment compared with those who do not have did not. A positive finding based on comparisons made according to geographical residence of participants, suggest that unmet needs and perceived self-efficacy were not influenced by rurality or remoteness.

Prominent Unmet Needs Reported
International literature reporting unmet needs of women with breast cancer demonstrate that women perceive having unmet needs throughout the cancer trajectory (Boynes et al., 2012; Park & Hwang, 2012; von Heymann-Horan et al., 2013). Congruent with international literature, this Australian study found that psychological unmet needs were the most prevalent (Akechi et al., 2011; Fiszer et al., 2014; Knobf, 2011; Minstrell et al., 2008; Schmid-Büchi, Halfens, Müller, Dassen,
This was true regardless of whether women were in their first year since diagnosis or five or more years after diagnosis. Furthermore, consistent with international research, the longer a respondent was from diagnosis, the more likely they were to report unmet psychological needs. A possible explanation for this is the lack of support felt by women who are no longer receiving active treatment and the associated regular interactions with healthcare staff (Foster & Fenlon, 2011).

The fear of progression or fear of recurrence reported in this study confirms that Australian women are similar to those in many other countries with this as the most common unmet need amongst breast cancer patients (Akechi et al., 2011; Fiszer et al., 2014; Harrison et al., 2009; Mehnert, Berg, Henrich, & Herschbach, 2009; van den Beuken-van Everdingen et al., 2008). Research investigating the association between time since diagnosis and fear of progression varies widely in timing of data collection (Ziner et al., 2012). Some studies investigated survivors at diagnosis or a few months post-treatment (Minstrell et al., 2008), while this study explored women from 6 months to 5 years post treatment. Fear of progression was more commonly reported as an unmet need by respondents who were five or more years after diagnosis, however similar results from comparable studies could not be found in the international literature.

**Differences Based on the Presence of a BCN**

Another key finding was that the presence of a BCN for women with breast cancer was associated with significantly lower levels in almost 1/3 of unmet needs measured, especially in the psychological domain. This is not surprising given that one of the key functions of the BCN is to identify psychological needs of patients throughout the continuum of breast cancer care and implement evidence-based
supportive care interventions to promote optimal health of their patients (National Breast Cancer Centre, 2005c). Significantly, we could find no studies of a similar nature in the published literature and therefore these results provide baseline data about the possible impact Australian BCNs have on reducing unmet needs. This finding contributes a better understanding of the level of support that BCNs provide to women with breast cancer and also supports studies both nationally and internationally demonstrating the role of the BCN in the multidisciplinary team (Cruickshank et al., 2008; European Society of Breast Cancer Specialists, 2010; Fillion et al., 2012; Jones et al., 2010; Voigt et al., 2011).

Participant access to a BCN was associated with significantly higher levels of communication and attitudinal self-efficacy, particularly in ability to “understand and participate in care”, as well as “seek and obtain information”. To our knowledge, research investigating the impact of the presence of a BCN on patient self-efficacy has not been undertaken. Consequently, these findings provide additional baseline data about the impact of the BCN on patient self-efficacy.

**Differences Based on Geographic Residence**
Very few significant differences in unmet needs were reported by those living in urban areas compared to those living in inner regional areas or outer regional, remote or very remote areas. This is in contrast to an earlier Australian study which indicated significant levels of unmet need particularly for those living in rural areas (Girgis et al., 2000). However, our findings are consistent with a more recent study by Minstrell et al. (2008) finding that unmet needs of rural women with breast cancer are lower than previously reported. Possible explanations for this change in Australia include improvements of cancer care and support over time and the enhanced cancer services to regional areas, including the increased presence of BCNs to
regional and rural areas through initiatives such as the McGrath Foundation (Paynter et al., 2013; Shepherd et al., 2008). The breast care nurse has been reported to be of particular benefit to women in outer regional, remote and very remote Australia in terms of providing supportive care (Ahern et al., 2014). Furthermore, novel telehealth initiatives in cancer care have recently helped to close the gap between urban and rural and remote dwellers (Sabesan et al., 2012). These improvements to services for women with breast cancer also provide a possible explanation for the finding of no differences in perceived self-efficacy when comparing geographical residence.

**Frequency of Access to BCN Support**
Notably, one-third of respondents reported no access to a BCN, consistent regardless of geographical location. This finding supports earlier Australian research suggesting that access to BCNs, although highly recommended, is not available to all women undergoing breast cancer treatment (Campbell et al., 2006; Eley et al., 2008; Watts et al., 2011). This is disappointing given the BCN service was introduced in Australia over 20 years ago and BCNs are recommended as an integral member of the multidisciplinary breast cancer team (National Breast Cancer Centre, 2005c).

**Policy and Research Implications**
In essence, this study has provided important baseline information about the unmet needs and self-efficacy of Australian women with breast cancer, with and without the support of a breast care nurse. This baseline information can be used to guide future planning and intervention research in the Australian context. Regardless of time since diagnosis, Australian women with breast cancer reported numerous unmet needs, particularly psychological needs. Development of high self-efficacy early in the cancer trajectory reduces psychological distress (Philip et al., 2013; Rottmann et
al., 2010) so treatment of women with breast cancer should include targeted interventions enhancing this personal resource. Furthermore, it is important such interventions are used in the initial stages of care and treatment for women with breast cancer, because enhancing this personal resource early can result in continued benefit for women through their diagnosis, treatment and into survivorship (Rottmann et al., 2010).

Worldwide, best practice treatment and support of women with breast cancer indicates that all women should have access to BCN support and that BCNs are core members of the cancer care multidisciplinary team (Lux et al., 2013; Voigt et al., 2011; Wilson et al., 2013). Contrary to this, evidence in this and other studies has demonstrated both BCN access and BCN involvement in multidisciplinary teams is inadequate (Ahern et al., 2015; Paynter et al., 2013). The European literature describes emerging fully accredited specialist Breast Centres where health care professionals and specialists form a multidisciplinary approach to breast cancer care providing services beginning at breast diagnosis, throughout treatment and including long-term care (Lux et al., 2013; Wilson et al., 2013). Adopting models of care offered similar to those reported in the United Kingdom and Europe may be appropriate in terms of ensuring BCN access to all women with breast cancer in Australia and other countries. Importantly, in these specialist Breast Centres, at least two full time BCNs are included as core team members. These BCNs must be present at multidisciplinary case management meetings and therefore are continually involved in the management of all patients attending the Breast Centre (Wilson et al., 2013). Although setting up such centres are initially costly, the available data show improved quality in processes and results (Lux et al., 2013) and therefore these centres are worthy of investigation in the Australian context, despite differing healthcare funding structures.
These results support our hypothesis that women with BCN support would experience decreased unmet needs and increased self-efficacy. However, further research is recommended to investigate other factors influencing unmet needs and self-efficacy in order to quantify this finding. Additional research could also be undertaken to investigate exactly how the BCN contributes to a reduction of psychological unmet needs. Given widespread international implementation of similar roles, replicating this study in other countries with similar healthcare structures and funding would also contribute to our understanding of the BCN role and women’s health outcomes after breast cancer.

**Strengths and Limitations**

When comparing with Australian Bureau of Statistics demographic data, the study sample was proportionally representative of the numbers of women residing in metropolitan, regional and rural and remote areas. In addition, the large sample size contributed to the statistical power of the study. Importantly, this is the first Australian-wide study to compare unmet needs and self-efficacy of women with breast cancer with and without BCN support. Therefore, the results contribute to the understanding of the value of the BCN role. Furthermore, the survey comprised previously used demographic questions as well as two very well validated measures of unmet needs and perceived self-efficacy amongst cancer patients.

Limitations of the study include using a convenience sample; however this was necessary due to no availability of national comprehensive databases from which representative samples could be derived. Second, using online recruiting methods may have excluded those without Internet access, however household internet access is increasing: 83% of Australian households had access in 2012-2013 (Australian Bureau of Statistics, 2014). Finally, the study was also limited to women
and not men with breast cancer. The cancer trajectory and perceived needs and self-efficacy of men with breast cancer differ markedly from that experienced by women and should be studied separately.

**Conclusion**
To our knowledge this is the first Australian study to compare the perceived self-efficacy of women with and without the support of a BCN. The results of this large study provide baseline information useful to guide future planning and intervention research surrounding the role of the Australian BCN and reinforce international findings. Overall, it is clear that Australian women with breast cancer have unmet needs, particularly psychological and regardless of time since diagnosis. The positive association between BCN support and lower levels of unmet need and higher levels of self-efficacy is promising. However, further research is needed to determine if there are factors other than the existence of BCN support influencing these findings.
Summary
This chapter gave an account of the findings of the third and final study in this doctoral research. Importantly, the study included a large number of participants who resided in all areas of Australia. The study compared the unmet needs and self-efficacy of women who had a BCN to women who did not have a BCN. Notably, research such as this cannot be found in the literature. The findings provide meaningful baseline data showing an association between the presence of a BCN and decreased unmet needs and increased self-efficacy adding to the evidence base surrounding the role that BCNs play in the care of women with breast cancer. Therefore, this research paves the way toward further investigation of the BCN and the influence they have in improving the QOL of their patients.
Chapter 7: Development of a New Conceptual Model

Aim 4: To develop a patient-centred BCN supportive care conceptual model relevant to the Australian context.

The Breast Care Nurse Supportive Care Model

Introduction
This chapter reports the development of a patient-centred nursing model to guide the BCN role in providing information and support to women with breast cancer. The model builds on the work of Fillion et al. (2012) who developed the Professional Navigation Framework for use in the care of women with breast cancer in the Canadian context. Furthermore, the model, known as the BCN Supportive Care Model, has been developed at the culmination of a three phase research project presented in this thesis exploring the role of the Australian BCN in the provision of information and supportive care. In addition to the research by Fillion et al. (2012), important findings from the research presented in this thesis have influenced the design and development of the BCN Supportive Care Model.

Theoretical Underpinnings
As was described in Chapter 1, Fillion et al. (2009) found there was no generally accepted definition of the role of the PPN and sought to explore the concept of patient navigation within the theoretical concepts of continuity of care and patient empowerment, with the goal of ascertaining the organisational and clinical nature of the role. This exploration led to the development and validation of a theoretical definition of the bi-dimensional nature of the role of the PPN: the Professional Navigation Framework (Fillion et al., 2012). The Professional Navigation Framework consists of two dimensions; facilitating continuity of care and promoting patient and family empowerment, each with three important concepts.
This framework was chosen to underpin the doctoral research due to the similarities recognised between the responsibilities of PPNs and BCNs, as well as the desire to evaluate the applicability of this framework in the Australian context (See Chapter 1). At the completion of the doctoral research, findings have enabled utilising the original framework and developing a model applicable to Australian BCN practice. Following is a comprehensive explanation of the *BCN Supportive Care Model*, which builds upon the underpinning framework.
Figure 1: The Breast Care Nurse Supportive Care Model

The BCN Supportive Care Model
The diagram representing the BCN Supportive Care Model situates the patient and family at the centre of care (See Figure 1). Patient-centred or person-centred care is widely accepted as the philosophy and practice that underpins quality health care (Pulvirenti, McMillan, & Lawn, 2011). The bi-dimensional model acknowledged by the Professional Navigation Framework recognises the patient at the centre of care, whilst recognising that the role of PPNs is also healthcare system orientated (Fillion et al., 2012).

In the new model, circling the patient and family is the role of the BCN. Here, the two dimensions and six concepts identified in the Professional Navigation Framework are evident; each with arrows directed towards the patient/family suggesting that the role of the BCN encompasses each of the six concepts and uses these concepts to inform the BCN role in the provision of patient-centred care.

Pictured on the outer-most circle, surrounding the BCN, are the essential elements for supporting the professional practice of BCNs which have been identified from the research presented throughout this thesis. There are seven elements essential to supporting the professional practice of BCNs; clinical education, clinical experience, communication, collaboration, professional development, professional support and workable caseloads. These essential elements surround the BCN indicating that BCNs need these elements in order to provide continuity of care and patient and family empowerment. Overall, the findings demonstrate that all elements within the outer ring are essential to the practice of the BCN. If any of these elements are not present, this has the potential to negatively impact on the BCNs ability to provide high levels of patient-centred supportive care.
In the next part of the chapter, each concept represented in the *BCN Supportive Care Model* is related to the findings of the research reported in this thesis.

**Facilitating Continuity of Care**
This section considers the three concepts within Fillion’s dimension of ‘facilitating continuity of care’ in relation to the findings of this doctoral research. Important links are made, where possible, to the essential elements supporting BCN professional practice which have been derived directly from the three studies undertaken in this doctoral research.

**Informational Continuity**
In Chapter 6 the issue is raised about BCNs being considered mandatory members of the multidisciplinary cancer care team in countries such as Europe and the United Kingdom. In the Australian context, the findings presented in Chapter 5 demonstrate that breast care nurses in outer regional, remote and very remote areas were less likely to collaborate in MDTs and therefore may not have access to the high levels of information about their patients which is required to enable the provision of timely and tailored information and advice. Without BCN inclusion in MDT meetings, the concept of informational continuity may not be maintained to a high standard, thereby affecting the experience of care for breast cancer patients. Therefore essential elements influencing the ability of the BCN to facilitate continuity of care, through information continuity are collaboration and communication.

Fillion et al. (2012) found that PPNs need access to, and understanding of, high levels of information about the patient with cancer and their care. When such patient-centred information is acquired, PPNs are more able to provide information and advice that is timely and tailored to both the patient and the MDT, assisting them to make appropriate referrals. Fillion et al. (2012) suggests further that PPNs need to
work closely with MDTs in order to improve the continuity of the information and knowledge of patients’/families’ needs. In doing this, communication tools and strategies become important to the work of the PPN.

**Management Continuity**
The findings presented in Chapter 4 show that satisfaction with the information and support provided face-to-face by healthcare professionals’ outweighed information and support gained through sources such as the Internet. Moreover, the findings in Chapter 6 demonstrate that Australian women with breast cancer continue to have unmet needs, particularly psychological. Breast care nurses contribute to improved outcomes for women with breast cancer through an advanced practice that is performed in close collaboration with the patient/family. These specialised nurses are well placed to improve the information and support provided to women with breast cancer through continual assessment of the needs of their patients enabling them to identify resources lacking as well as, find solutions and report system gaps.

Breast care nurse initiated screening for unmet needs and matching of unmet needs with appropriate services and resources can only be achieved if BCNs have the knowledge required, can communicate and collaborate (National Breast Cancer Centre, 2000) between the MDT and the patient/family and have manageable caseloads with which to work. Therefore, through this research, it has been deduced that the essential elements of clinical education, clinical experience, communication, collaboration and workable caseloads pictured in the conceptual model, impact on the ability of the BCN to provide management continuity.

Within the concept of management continuity, Fillion et al. (2012) found that PPNs see themselves as essential to the MDT, and in collaboration with the team, can make changes in coordination of care of patients. Once again, this reinforces the
fact that without regular inclusion in MDT meetings, Australian BCNs would have less opportunity to advocate on behalf of their patients and collaborate in the coordination of care, impacting negatively on management continuity. Fillion et al. (2012) explained that efficient and timely matching of unmet needs with services, resources and support systems within the cancer care organisation and the community can be achieved through PPNs conducting comprehensive screening and assessment of needs and resources, both initially and throughout the cancer continuum. Examples of instruments useful for conducting these assessments are provided within the original framework (Appendix F).

**Relational Continuity**

The sustained presence and continued personal contact with the PPN decreases patient distress levels and increases confidence (Fillion et al., 2012). In the first study of this thesis, presented in Chapter 4 the findings show that patients in outer regional, remote and very remote areas were statistically significantly more likely to use the BCN as a source of support ($\rho =0.044$) (Ahern et al., 2014). In the second study of this thesis, presented in Chapter 5, findings reveal that BCNs in outer regional, remote and very remote areas were more likely to continue to see their patients through all stages of the cancer trajectory and spent more time in consultation with their patients (Ahern et al., 2015). It may be that the smaller caseloads experienced by BCNs in these areas enable BCNs to see their patients more regularly and spend more time in consultation with their patients, contributing to the higher levels of BCN support reported by patients in these areas. There is little evidence however about the caseloads of BCNs currently working in Australia and how this may impact on the professional practice of BCNs, but the findings suggest that quantifying workable caseloads is an area worthy of research (Ahern et al., 2015).
Within the concept of relational continuity, PPNs are seen to build a positive and therapeutic relationship with their patient that continues throughout several stages of the cancer trajectory (Fillion et al., 2012). Effective *communication* can assist in building positive relationships and is therefore recognised as an essential element to facilitating continuity of care through relational continuity within the *BCN Supportive Care Model*.

**Facilitating Patient and Family Empowerment**

This section considers the three concepts within Fillion’s dimension of ‘facilitating patient and family empowerment’ in relation to the findings of this doctoral research. Important links are made, where possible, to the **essential elements supporting BCN professional practice** which have been derived directly from the three studies undertaken in this doctoral research.

**Active Coping**

In Study Three, presented in Chapter 6, findings indicate that BCN support has a positive impact on two of the three areas of self-efficacy measured. Both of these areas of self-efficacy can contribute to higher levels of active coping. Hence, active coping, included in the conceptual model, is likely to be enhanced for Australian women who have access to a BCN throughout the breast cancer trajectory.

Fillion et al. (2012) reported that PPNs assist patients and family to actively attain information, support and referrals needed and this promoted active coping. Professional patient navigators also have a role to play in educating and supporting patients to maintain their sense of control and quality of life through enhancing patients’/family members’ senses of autonomy and self-determination. They do this by identifying distress and providing education and information on coping with health
changes, as well as facilitating problem solving and decision making around those changes. Active coping corresponds with the concept of self-efficacy (investigated in Chapter 6) which has been associated with a wide range of cancer-related outcomes including improved adjustment to disease, better management and improved QOL (Bandura, 1997; Philip et al., 2013; Rottmann et al., 2010). Enhanced active coping can be achieved through increasing self-efficacy of women with breast cancer. Therefore, continued professional development educating BCNs about strategies used for enhancing self-efficacy for their patients is recommended.

Cancer Self-management
The findings of Study Three, presented in Chapter 6 indicate that many women facing diagnosis and treatment of breast cancer had unmet needs and many of these were in the psychological domain. In addition, women reported unmet needs regardless of the time since diagnosis, and although these needs may change over time, needs in the psychological domain were dominant. An important finding presented in Chapter 6 is the association between BCN support and decreased unmet needs. Further to this, those with a BCN were significantly more likely to score higher in their ability to participate in care. Therefore, the ongoing presence of a BCN is pivotal in assessing and addressing unmet needs and enhancing patients’ abilities to participate in care and self-manage their altered health states proactively.

Fillion’s Patient Navigation Framework points out that a key role of the professional navigation is to support the patient and family and assist them in the adjustment of managing their health, through provision of timely and tailored information and self-care strategies (Fillion et al., 2012). Australian guidelines also emphasise promoting the patients’ ability to participate in care decisions and self-management of health needs as important in the work of a BCN (National Breast Cancer Centre, 2005c).
Central to the idea of promoting cancer self-management is the BCN’s ability to continually assess for unmet needs and work with the patient to address these unmet needs. In order to gain these skills, BCNs need to keep up to date with resources available to address unmet needs and this can be achieved through communication and collaboration with peers and members of the MDT, participation in professional development and by engaging in professional support available.

**Supportive Care**

Chapters 4, 5 and 6 provide a number of findings to demonstrate the value of the Australian BCN in the provision of supportive care. Findings such as their availability to perform longer consultations, as well as a continued presence throughout the cancer trajectory and the association with improved patient outcomes including decreased unmet needs and increased self-efficacy demonstrate some of the benefits of the support offered by BCNs in the Australian context.

One of the most recognised roles of PPNs or BCNs is the provision of supportive care in a patient-centred environment. A diagnosis of breast cancer can be extremely difficult and have a high psychological impact, as evidenced in the findings presented in Chapter 6 particularly. Many of the needs of women with breast cancer can be addressed by providing the necessary services to meet physical, informational, practical, emotional, psychological, social and spiritual needs (Fitch, 2008). Both PPNs and BCNs are required to screen for distress and regularly conduct assessments for supportive care needs and other resource needs (Fillion et al., 2012; National Breast Cancer Centre, 2000). Assessment of unmet needs enables the BCN to provide supportive care that is timely and suited to the individual patient/family. BCN knowledge and understanding of needs assessment tools are essential and therefore need to be included in clinical education and professional
development programs. A broad knowledge of supportive care resources available within individual communities is another important consideration for BCNs meeting the supportive care needs of their patients. Continual collaboration with key members of the healthcare community as well as the wider community is a recommendation towards enhancing the variety of appropriate supportive care resources provided to women with breast cancer.

Essential elements for supporting BCN professional practice
In this section, the essential elements for supporting the professional practice of BCNs which were derived from the doctoral research are validated in more detail.

Clinical Education and Clinical Experience
Breast care nurse practice is a specialty practice involving advanced specialised knowledge and skills in the care of women across the cancer continuum and therefore clinical education and clinical experience are critical to the role. For the Australian BCN, an advanced level of clinical education and clinical experience within oncology and breast cancer is a role requirement (National Breast Cancer Centre, 2005c). The Specialist Breast Nurse Competency Standards and Associated Educational Requirements, issued in 2005 identify competency standards and associated knowledge, skills and abilities of nurses who practice as BCNs in Australia (National Breast Cancer Centre, 2005c). Earlier Australian guidelines recommended that the minimum education level for BCNs be a Graduate Diploma in the specialty of cancer nursing (or equivalent) (National Breast Cancer Centre, 2000, 2005c). Current thought however is that BCN education programs should also include both theoretical and clinical learning experiences and reflect content addressing the BCN Competency Standards (National Breast Cancer Centre, 2005c; Yates et al., 2007).
There has been little research conducted to evaluate the current validity of the BCN competency standards. However, the survey conducted in Study Two (Chapter 3b) used a selection of the Australian competency standards to investigate the breadth of the BCN role in the provision of education, information and support to women with breast cancer. The regularity with which BCNs undertook these activities and the perceived barriers in undertaking these activities were investigated. Breast care nurses with higher levels of educational qualifications who completed the survey in Study Two were more likely to report to ‘always’ undertake performance criteria embedded in competencies as part of their work. Results also showed that BCNs having more years’ experience in their role were more likely to report ‘always’ undertaking performance criteria embedded in competencies as part of their work. Therefore findings herein suggest there is an association between having higher qualifications/experience and perceptions about undertaking competencies.

**Collaboration**
A collaborative approach to cancer care can improve quality of life and survival for the patient (National Breast Cancer Centre, 2005a; Taylor et al., 2013) and therefore multidisciplinary input should be considered for all patients with cancer. Within breast cancer care, it is well documented that the presence of a BCN nurse in a MDT is beneficial to both the women and the clinicians (Amir et al., 2004; Eicher et al., 2012). Therefore, inclusion of a supportive care provider such as a nurse specialist or BCN is recommended as a core team member in Australia (National Breast Cancer Centre, 2005a) and as a mandatory member of the MDT in the UK (Taylor et al., 2013).

Despite this, there has been evidence to suggest that Australian BCNs may have limited participation in MDT meetings (Paynter et al., 2013; Taylor et al., 2013). This
evidence is further supported by the results of Study Two, presented in Chapter 5, which found a disparity between MDT involvement of BCNs in outer regional, remote and very remote areas compared with their peers in other geographic areas. This is disappointing given that the Specialist Breast Nurse Competency Standards developed in Australia almost a decade ago clearly stipulate that BCNs demonstrate advanced skills in facilitating a coordinated, collaborative, multidisciplinary approach to health care planning, implementation and evaluation (National Breast Cancer Centre, 2005c). Furthermore, geographical remoteness and/or small size of the institution delivering care should not impede the delivery of MDT care, nor access to services (National Breast Cancer Centre, 2005a).

Inclusion in the MDT and collaboration with the MDT are fundamental to the work of the BCN. Breast care nurses play a central role in ensuring holistic care of patients and are often the key point of contact for women with breast cancer, enabling timely identification of needs and concerns and appropriate referrals (Taylor et al., 2013). Without such inclusion, the BCN may not receive the benefits of MDT involvement such as problem sharing, joint decision making, education and peer interaction which often results in the use of up-to-date evidence based treatment plans suited to individual patients’ needs (National Breast Cancer Centre, 2005a).

**Communication**

Alongside collaboration within the MDT is collaboration with service providers in various care contexts and as well with patients and family enabling a care that is coordinated, consistent and timely. For this to take place, the skill of communication is pivotal. Efficacious MDTs require all members to communicate effectively with one another. Failure to do so can lead to confusion for patients about diagnosis, prognosis and treatment plans (National Breast Cancer Centre, 2003). Further,
liaising with various service providers in co-ordinating care planning requires nurses to possess effective communication skills, as does working with the patient/family to provide patient-centred care. Skills such as having a sympathetic presence, providing engagement, sharing decision-making, providing for physical needs and working with the patient's beliefs and values all add to formation of a therapeutic relationship and influence the provision of patient-centred care (McCormack & McCance, 2006). Patient satisfaction with care is well documented in the literature as an indicator of quality care and is closely linked with patient-centred communication (McCormack & McCance, 2006). Planning and implementing care to meet the multiple needs of patients over the cancer trajectory requires effective collaboration and communication and are therefore recognised in the conceptual model as essential elements supporting the professional practice of BCNs.

**Professional Development**
Recommendations made in Chapter 6 called for BCNs to demonstrate a commitment to maintaining competence through participation in professional development activities relevant to cancer care (Aranda & Yates, 2009) enabling them to meet the complex needs of their patients. As well, recommendations were made for employers to support and fund BCNs to undertake professional development opportunities. In 2009, a National Professional Development Framework for Cancer Nursing was published guiding the support of nurses' professional development in cancer control (Aranda & Yates, 2009), emphasising the importance of ongoing professional development of cancer nurses and thus enabling the provision of high-quality services that meet the needs of all people affected by cancer. Specialised nurses, such as the BCN require formal support in order to ensure professional development and skill maintenance. Continued professional development, training and support are critical to the role of the BCN (Yates et al., 2007). In an area such
as breast cancer care, where treatments are improving and constantly evolving, the provision of continuing professional education is critical in facilitating effective performance (Watts et al., 2011). Continuing professional education also supports evidence-based nursing practice, enables best-practice standards to be met as well as matching services with the needs of the community (Black & Farmer, 2013).

**Professional Support**
Alongside professional development, comes professional support. Such support helps to prevent emotional burnout, leading to retention of nurses (Black & Farmer, 2013; Watts et al., 2011). Professional support can be accessed through mentoring programs, professional networking and peer support with other BCNs. Mentoring is more likely to be career rather than clinically focused (Heartfield & Gibson, 2005) and therefore complements the clinical focus of ongoing professional education for BCNs. Mentoring provides guidance and support, promotes confidence and can lead to professional and personal growth (Heartfield & Gibson, 2005). Mentoring can be achieved through one-on-one mentoring, group mentoring or by distance mentoring and therefore can be accessed by all BCNs, including those separated by geographical distance. However, distance mentoring through electronic communication methods has been found difficult to maintain and should be used in conjunction with other networking methods such as conferences (Heartfield & Gibson, 2005).

Professional networking and peer support has been recognised as a valuable method of support for BCNs (National Breast Cancer Centre, 2005c; Yates et al., 2007) and is of particular benefit to those working in rural and remote areas (Black & Farmer, 2013). Professional networking in Australia is provided by a variety of Australia-wide organisations and associations such as the Cancer Nurses Society of
Australia and the McGrath Foundation, as well as state based and/or regional based groups (Black & Farmer, 2013; McGrath Foundation, 2014). Peer support networks are valuable in preventing stress and burnout for oncology health professionals such as cancer nurses (Girgis, Hansen, & Goldstein, 2009). It is evident that both professional development and professional support contribute towards professional competence, confidence and job satisfaction and are critical to the practice of BCNs.

**Workable Caseloads**
Staff shortages and high workloads are barriers to patient-centred care observed in the practice setting (Pelzang, Wood, & Black, 2010). Australian literature about BCN caseloads is limited. However, it has been found that large caseloads result in more time being spent on administrative work, organising referrals and liaising with other health professionals therefore reducing time spent with patients and their families (Jones et al., 2010). The evidence reported in Chapter 5 of the thesis demonstrates that BCNs in major cities and inner regional areas have high caseloads compared with BCNs in outer regional areas. These BCNs also have higher percentages of new patients compared with BCNs in outer regional areas. Numerous BCNs in this study reported that ‘limited time available’ was a barrier to undertaking competency standards relating to the provision of education, information and support. Further, women in outer regional, remote and very remote areas were more likely to report their BCN as a source of support (Ahern et al., 2014). Breast care nurses in these areas spend more time with their patients in consultation and are more likely to see their patients through all stages of the cancer trajectory (Chapter 5). Therefore, this evidence suggests that those with high caseloads experienced an increased workload, impacting negatively on the time available to spend with their patients and it is recommended that restricting caseloads will allow BCNs more time to deliver appropriate care to their patients.
Early research conducted in the UK found that many BCNs are concerned about how best to cope in the face of increasing demands on their time. The study also suggested that new responsibilities of BCNs, combined with an increasing number of patients and the complexity of treatment, make it increasingly difficult for BCNs to devote time to their patients ensuring they have adequate information and support (Wood, 2004). Additionally, nurses reported not having time to dedicate towards developing and improving services and that the time spent on administrative duties could be better spent on patient care (Wood, 2004). This research called for the establishment of a recruitment and retention strategy and an increased investment in sufficient numbers of BCNs to deal with demand. Additionally, in meeting the recommendation that every women diagnosed with breast cancer have access to a BCN, guidelines about the maximum caseload for BCNs were deemed necessary as well as the establishment of adequate numbers of BCNs needed in a breast care unit (Wood, 2004). Providing administrative support is also recommended as a way of enabling more time to be spent with patients (Wood, 2004).

More recently, in the UK a study surrounding lung cancer specialist nursing, found that factors such as caseload size and workload resulted in work being left undone in the areas of proactive management, undertaking holistic needs assessments, and provision of psychological support and information (Leary, J., & Yarnell, 2014). In essence, evidence suggests that best practice standards are more likely to be achieved if the nurse specialist roles are supported by organisations with regard to appropriate staffing levels, calculating optimum caseloads and maintaining managerial and secretarial support (Leary et al., 2014). Therefore, enabling BCNs to work within workable caseloads has been recommended as an essential element supporting the professional practice of BCNs.
Implications for Research, Education and Practice

The conceptual model presented contributes to our understanding of the role of the BCN and the essential elements required supporting BCNs in undertaking their role in the Australian context. In the Australian context, there are other similar specialised nursing roles including prostate cancer nurses and chronic disease nurses. This conceptual model could be applied to further research of other such models of nursing, to establish its applicability to nursing practice on a wider scale.

In addition to this, the conceptual model offers conceptual underpinning useful to guide decision making about education programs and professional development provided to Australian BCNs. Both the tertiary sector and individual organisations such as the McGrath Foundation have the potential to benefit from the use of an evidence-based conceptual model guiding areas where education and professional development ought to be concentrated.

For BCN practice, this conceptual model provides a platform on which to guide areas for improvement in the professional practice of the individual. For example, it was clearly identified that those working in rural and remote areas need to investigate ways to achieve improved access to MDT involvement. Furthermore, for those in urban areas where caseloads are high, there may be a need to advocate for workable caseloads to improve in areas such as job satisfaction and enhanced outcomes for patients. Both BCNs and employing bodies can contribute to enhancing the professional practice of BCNs through a commitment to following the evidence-based guidelines presented in the conceptual model.
**Conclusion**
Overall, the BCN Supportive Care Model provides educators, employing organisations and individual BCNs with a conceptual model illustrating elements essential to supporting BCN professional practice, namely in facilitating continuity of care and promoting patient and family empowerment within a patient-centred approach to nursing care. Development of this new conceptual model involved building upon the *Professional Navigation Framework* by using findings from the research and exploring their application within the Australian context. The evidence-based *BCN Supportive Care Model* can be used in conjunction with the *Australian Specialist Breast Nurse Competency Standards* as a guide to inform professional practice. Further research assessing the applicability of this model to other speciality areas of nursing is recommended.
Summary
Drawing on all the evidence captured in the doctoral research, this chapter proposed an evidence-based conceptual model to underpin curriculum decision-making undertaken by educating bodies and employment organisations within the realm of the BCN role in the provision of informative and supportive care. Not to be overlooked is the potential for the conceptual model to be applied to other nursing models of care, such as chronic disease nurses, prostate cancer nurses or palliative care nurses. Further research investigating the applicability of this conceptual model to other areas of nursing is proposed.
Chapter 8: Conclusion

Introduction
One of the most important features of this research is the capturing of national data about the role of the BCN in the provision of information and support to women with breast cancer. Similar studies cannot be found in the literature and therefore this research offers meaningful evidence to increase the body of knowledge surrounding the role of the BCN from the perspective of both women with breast cancer and BCNs. The contribution to knowledge resulting from this doctoral research includes both recommendations for research and practice with variation across the three studies. This chapter presents a brief overview and conclusion of the thesis. Research aims and results are recapped, while implications of the research, as well as strengths and limitations are detailed.

Research Aims and Results
Study One of this thesis aimed to investigate the information and support needs of women following primary treatment for breast cancer (Ahern et al., 2014). The results of this study, detailed in Chapter 4, highlight that some needs of women with breast cancer have changed over time, but others have remained the same. Analysis of survey results indicate specific, up to date information about issues important to women should be provided. Since much of this information is sourced via the Internet, women must be educated about the use of credible internet sites. Breast care nurses have an opportunity to provide the information and education necessary to enable women to meet their information and support needs using technology such as the Internet. The study provided a new perspective about support used by women with breast cancer in rural and remote areas, finding that these women were significantly more likely to use the BCN as a source of support.
Overall, the study provided information that can be used to inform targeted research to improve information and support services available to women with breast cancer.

Study Two was devised to explore the role of the BCN in supporting women with breast cancer in different geographical locations around Australia (Chapter 5). A new survey instrument was developed and tested for face validity and reliability before being used to survey BCNs (Chapter 3b). This was the first Australian study to describe the role of the BCN nationally and the first study to investigate BCNs’ perceived ability to meet a selection of the Australian Specialist Breast Nurse Competency Standards. Important differences were found according to the geographical location of BCNs and recommendations were made to support the professional practice of Australian BCNs, hence potentially improving outcomes for women with breast cancer.

Study Three examined the unmet needs and self-efficacy perceptions of women diagnosed with breast cancer who are with or without the support of a BCN (Chapter 6). This study was designed to explore the underpinning theoretical framework (Appendix F) further and determine if BCN support enhanced the concepts of active coping and cancer self-management within their patients. Psychological unmet needs were prominent amongst women with breast cancer, regardless of time since diagnosis. However, those with BCN support had significantly lower levels of unmet need and significantly higher levels of communication and attitudinal self-efficacy, potentially leading to improved active coping and cancer self-management. There are no other studies of this type in the literature and therefore the findings provide important baseline data about the association between BCN support and unmet needs and self-efficacy.
Implications of the Research

Clinical Practice
The final aim of the research involved development of a conceptual model, applicable to the Australian context informing BCN professional practice, BCN employing bodies and policy makers (Chapter 7). Known as the BCN Supportive Care Model, this model compliments an already existing Australian BCN framework; the Specialised Breast Nurse Competency Standards and Associated Educational Requirements (National Breast Cancer Centre, 2005c).

I further propose that the BCN Supportive Care Model (Chapter 7, p170) is considered for expanded use in other Australian contexts, enabling people with other forms of cancer to have their care co-ordinated in a similar way to the co-ordination provided by BCNs to women with breast cancer, thus extending the idea of professional cancer navigation. The model should be explored to assess its applicability to different areas of nursing such as prostate cancer nurses or chronic disease nurses.

Education
The BCN Supportive Care Model emphasises the provision of patient-centred care as imperative to the role of the BCN. Assessing and addressing unmet needs continually throughout the cancer trajectory can highlight specific patient needs enabling the provision of care to be patient-centred. Therefore, it is recommended that education and ongoing professional development provided to BCNs be reviewed, planned and co-ordinated to encompass the principles of patient-centred care as a core element of the education. Furthermore, provision of education surrounding standardised assessment of unmet needs should also be an educational priority for all BCNs.
Exploring the use of videoconferencing and telehealth methods of communication are worthy of inclusion in BCN education. The knowledge and use of such methods would more easily enable geographically distant BCNs to be involved in MDT discussions. Consulting with patients using telehealth methods where appropriate would also enable more efficient use of time for BCNs in both urban and rural or remote areas. Such methods are now being embraced widely by health professionals within cancer care management in regional and rural areas.

Breast care nurse education programs should enhance knowledge and understanding of patient self-efficacy. Implementing interventions for enhancing self-efficacy amongst patients early in their diagnosis and treatment is an important consideration for role extension for BCNs. Higher levels of self-efficacy are associated with decreased psychological distress and increased QOL. Promoting and enhancing self-efficacy early in the cancer trajectory is an important aspect of promoting patient and family empowerment and may well lead to positive long term adaption to altered health states.

**Research**
Prior to this research, what was known about the role of the BCN is that the role varies according to different settings, and that the role of the BCN is of high value to patients. Nevertheless, with very few studies being undertaken surrounding the role of the Australian BCN, it was clear that many aspects of the role were not well understood. This research has added to the body of literature surrounding the role of BCNs, but there remain a number of questions unanswered. The results presented in Chapter 6 clearly illustrate that women continue to experience unmet needs regardless of time since diagnosis. Not enough is known about the complexities of unmet needs amongst this population and how these needs could be better
addressed. It would be useful to further investigate factors contributing to needs remaining unmet and understanding further what would be considered a ‘normal’ range of unmet needs amongst this population. Furthermore, the research highlighted that those who had the support of a BCN had decreased unmet needs and increased self-efficacy, however it is unclear exactly what interventions BCNs use in their practice to achieve such improved outcomes. Another area worthy of more investigation is in gaining a better understanding of the variations in BCN practice in different settings and thus variations in expected outcomes.

Additionally, since BCNs in outer regional, remote and very remote areas are less likely to be involved in MDT meetings, more research is recommended to investigate the reasons for this. Implementing interventions involving the use of videoconferencing and conducting research on the effectiveness of such methods to improve MDT involvement are also worthy of more research. During the research process, feedback was received through personal communication at a national cancer nurses’ conference that BCNs in geographically distant areas do not take up online training offered to increase their professional development. Therefore, more research is recommended to investigate the barriers to uptake of online training and professional development as well as formulate ways to meet the ongoing professional development needs of BCNs in geographically distant areas.

Finally, one of the essential elements supporting the role of the BCN as illustrated in the BCN Supportive Care Model is workable caseloads. Little is known about what constitutes a workable caseload for a BCN and more research is needed to quantify optimal caseloads for BCNs.
**Strengths**  
The research undertaken has produced important findings which contribute to our understanding of the role of the Australian BCN in the provision of information and support to women with breast cancer. The research was conducted nationally and has made important comparisons between patients and breast care nurses in urban areas and those located in rural and remote areas. These comparisons represent a unique contribution to knowledge in this area. Overall, the findings have been drawn together to produce a conceptual model useful for guiding the professional practice of Australian BCNs in the provision of informative and supportive patient-centred care.

**Limitations**  
There were a number of limitations of the study. First, the scope of the study was descriptive. To answer the research questions posed for this doctoral program, a descriptive study was deemed to be the best method due to the lack of any baseline national data. Second, in all three studies a convenience sample was used because there were no national comprehensive databases from which representative samples could be derived. Therefore, caution should be exercised when generalising from the results. Third, a single method of data collection was used throughout the study; self-report surveys. This was deemed to be the most efficient and cost effective method of gathering data for the purposes of this doctoral research program. The fourth limitation was that the research focussed on women only. Men with breast cancer have very different needs, for example, in relation to sexuality and breast cancer, and this population should be studied separately. Finally, few risk factors were controlled for in analysis; such analysis was beyond the scope of this research.
Conclusion
Overall, the findings presented in this thesis provide insight into the role of the Australian BCN in the provision of information and support to women. This research has contributed to the body of knowledge about the role of the Australian BCN, an important health service provided to breast cancer patients. Additionally, the research has resulted in development of a conceptual model to inform professional BCN practice. However, to understand more fully the role of the Australian BCN in different geographical contexts, clinical studies using a variety of data collection methods investigating the role and how it contributes to Australian women with breast cancer are recommended.
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Appendix A Research Portfolio

A) Actual and Potential Publications


B) Statement of Contributions

Chapter 2 – Literature Review


Tracey Ahern
Conception and design of the literature review
Performed search of literature and data extraction
Analysis and interpretation of data
Wrote the manuscript and revised it critically for important intellectual content

Anne Gardner
Input into the conception and design
Revision of data analysis
Made critical revisions to the draft version of the manuscript for important intellectual content

Mrs Tracey Ahern  Prof Anne Gardner
Chapter 3 – Methodology

**Tracey Ahern**
Led the conception and design of study
Responsible for data collection and analysis
Wrote the manuscript and revised it critically for important intellectual content

**Anne Gardner**
Advised on conception and design of study
Made critical revisions to the draft version of the manuscript for important intellectual content
Principal supervisor of research project

**Mary Courtney**
Advised on conception and design of study
Made critical revisions to the draft version of the manuscript for important intellectual content
Co-supervisor of research project

Mrs Tracey Ahern
Prof Anne Gardner

Prof Mary Courtney
Chapter 4 – Results Study One


Tracey Ahern
Led the conception and design of study
Responsible for data collection and analysis
Wrote the manuscript and revised it critically for important intellectual content

Anne Gardner
Advised on conception and design of study
Made critical revisions to the draft version of the manuscript for important intellectual content
Principal supervisor of research project

Mary Courtney
Advised on conception and design of study
Made critical revisions to the draft version of the manuscript for important intellectual content
Co-supervisor of research project

Mrs Tracey Ahern

Prof Anne Gardner

Prof Mary Courtney
Chapter 5 – Results Study Two


**Tracey Ahern**

Led the conception and design of study

Responsible for data collection and analysis

Wrote the manuscript and revised it critically for important intellectual content

**Anne Gardner**

Advised on conception and design of study

Made critical revisions to the draft version of the manuscript for important intellectual content

Principal supervisor of research project

**Mary Courtney**

Advised on conception and design of study

Made critical revisions to the draft version of the manuscript for important intellectual content

Co-supervisor of research project

__________________________  __________________________
Mrs Tracey Ahern    Prof Anne Gardner

__________________________
Prof Mary Courtney
Chapter 6 – Results Study Three

**Tracey Ahern**
Led the conception and design of study
Responsible for data collection and analysis
Wrote the manuscript and revised it critically for important intellectual content

**Anne Gardner**
Advised on conception and design of study
Made critical revisions to the draft version of the manuscript for important intellectual content
Principal supervisor of research project

**Mary Courtney**
Advised on conception and design of study
Made critical revisions to the draft version of the manuscript for important intellectual content
Co-supervisor of research project

__________________________  __________________________
Mrs Tracey Ahern    Prof Anne Gardner

__________________________
Prof Mary Courtney
C) Conference Presentations


D) Other Media Coverage and Research Disseminations


*(Please Note: Copies of media coverage in print are presented on the following pages)*
Central to the task

Breast care nurses help guide cancer patients in the right direction throughout their continuum.

By Amie Larter

About 113 out of every 100,000 Australian females will be diagnosed with breast cancer each year, a figure set to remain constant until at least 2020.

However, with the expected rise in population, prevalence is projected to jump from an estimated 14,290 cases in 2011 to a predicted 17,210 nine years later.

Breast care nurses (BCNs) have played a large role in the effective treatment and care of women and men diagnosed with the disease since the inception of the role nearly 20 years ago.

PhD candidate Tracey Aherin at the Australian Catholic University is conducting new research consisting of three studies, which will be used to gain a national perspective on both patients and BCNs.

She will compare BCNs working in metropolitan areas with those in rural or remote settings, and hopes results of the surveys will provide up-to-date information about the role to help inform policy and further research. The study opened in late August and will conclude in October this year.

In 2008, I was a Cancer Council Queensland Nurse of the Year entrant and during this time I had the opportunity to hear professor Jeff Dunn (CEO of Cancer Council Queensland) speak about initiatives of Cancer Council Queensland.

“One statement that he made resonated with me and I have never forgotten it. He said the statistics show that the further (people) live from a metropolitan area, the more likely they are to die from cancer.

“Having always lived in rural Australia and having worked as a registered nurse in a rural area, 2000km from the nearest metropolitan city, I was appalled by this statistic.”

The current BCN workforce is estimated at about 350 strong. The McGrath Foundation now provides funding for 85 of those throughout Australia. Through this unique care model, BCNs are funded for a minimum of three years and act as patient advocates that coordinate the care for women with cancer.
Traditionally, McGrath BCNs have been placed in the areas of greatest need, which up until now has been predominantly on the eastern seaboard of Australia. However, having secured an extra $5.5 million in funding earlier this year, the not-for-profit foundation is now looking to extend its footprint in South Australia and Western Australia.

The organisation is seeking funds to raise its total to about 150 nurses.

McGrath programme director Helen Paynter confirms the foundation will also look at extending its work with the Royal Flying Doctor Service, which had one nurse working out of its Broken Hill Branch.

Paynter says a recent study – the Breast Cancers Nurses Initiative – funded by the Commonwealth of Australia and conducted by HealthConsult, evaluated the organisation’s nurse program. Results showed that those who had access to a BCN felt well-supported throughout their cancer treatment.

This was compared with patients from areas with no BCN available, who said they had a great deal of difficulty accessing information and support.

“Our breast care nurses are highly regarded within the community – so they know the services to refer patients on to,” Paynter says. “They know if there is a lymphoma, a therapist nearby, a counsellor or psychologist whom patients may need to see, or even who the local prosthetics provider is – and they can refer clients on with ease.”

The nurses were found to be critical in the provision of emotional support, particularly in rural and remote settings, as some areas simply did not have access to required services.

“The nurse was able to fill the gap to a certain extent,” Paynter says.

Tracey Ahern is calling for expressions of interest from breast care nurses willing to participate in her survey. Email her at tracey9014@myacu.edu.au for further details.

**Q&A WITH A BCN**

A concern for how patients coped after cancer surgery led **Nancy Scott** to become a breast care nurse.

**MR. WHY DOES A BREAST CARE NURSE PLAY A VITAL ROLE IN THE IMPROVEMENT OF OUTCOMES FOR AUSTRALIANS DIAGNOSED WITH BREAST CANCER?**

Nancy Scott: A cancer diagnosis can be devastating and cause physical, social and psychological morbidity. The role of the BCN evolved to meet the complex needs of women and men diagnosed with breast cancer.

A breast care nurse’s role comprises:

- The provision of supportive care, which includes physical, social, emotional, spiritual and psychological needs for clients and their families. The BCN can help clients and their families and/or carers understand any technical or complex information that enables clients to deal with cancer and its side effects, helping them feel empowered to participate in, and make informed decisions about, their care.

- The BCN is the key member of the breast multidisciplinary team and is often cited as the most valuable contact and most robust empirical support for clients. The BCN acts as the principle liaison between the woman diagnosed with breast cancer, her GP and the whole breast care team.

- The BCN provides coordination and continuity of care from the time of diagnosis through the continuum of breast cancer, which provides clients and their families with one consistent source of information and care, and avoids gaps in the system.

- Offering continuous support, which can greatly minimise the stress and trauma of the breast cancer experience.

- Being an invaluable source of information regarding other support services and a referral to available resources for clients and families.

**WHAT DO YOU ENJOY MOST ABOUT YOUR JOB?**

How do you narrow this question down when there are so many positive aspects? Seeing what a difference you can make to someone’s life and seeing someone who was vulnerable at the time of their diagnosis come out at the end of their breast cancer continuum empowered the friendship that you make with the client and their family as you guide them, along with carers and...
A BURDEKIN super mum’s university research into breast cancer support for women in rural and remote areas will be exhibited at the ninth European Breast Cancer Conference in the United Kingdom.

PhD student, Tracey Ahern will travel to Glasgow, Scotland next month to present the results of the first phase of her doctoral research, “Exploring the Breast Care Nurse role in supporting women with breast cancer”.

The conference, held from March 19-21, is the largest breast cancer conference to be held outside of the United States and provides a unique, multi-disciplinary setting for professionals with a common interest in breast cancer, to navigate, discuss, inform and educate themselves about the disease.

Mrs Ahern’s abstract was one of hundreds of research reports selected by a panel to be displayed at the three-day event. The research focuses on information and support available to women with breast cancer, where important comparisons were made between those living in urban areas and those living in rural and remote Australia.

She said she hopes her study results will lead to benefits for people with cancer in rural and remote areas. Currently, Mrs Ahern is in the final year of a three-year PhD in Nursing Midwifery and Paramedicine through correspondence at the Australian Catholic University (ACU) in Canberra.

After graduating with a Bachelor of Nursing Science in 2007, Mrs Ahern completed her honours program and was influenced to delve further. She said her university supervisor encouraged her to apply for a scholarship to study her PhD, in which she was successful.

A former teacher at Ayr State High School, after losing her former husband to cancer in 2004, Tracey was driven to study nursing and said she never imagined she would come this far. “You learn lots of new things every day and I really do enjoy the research side of it.”

After completing studies, Mrs Ahern aspires to work in healthcare research, possibly at a hospital in Townsville or lecture a university class. Lecturing at a university level is another area of interest that Mrs Ahern will seek out after the completion of her PhD.

Information and support needs of women following primary treatment of breast cancer: a 10 year replication study.

Study Results

3 February 2014

Dear Register4 members,

Our study aimed to investigate the use of and satisfaction with information and support following the primary treatment of breast cancer by replicating a study done in 2002. This letter provides a brief overview of what we found.

A total of 325 participants completed the online survey and this included members Register4, as well as members of the BCNA Review and Survey Group. Of participants, 69% lived in major cities, 19% resided in inner regional Australia and the remaining 12% lived in outer regional, remote or very remote areas of Australia and this is representative of Australian Bureau of Statistics geographical data.

Use of and satisfaction with information received following breast cancer treatment

Compared to the original study, completed in 2002, we found that the top four information issues important to women were the same in 2002 and 2013. These issues included information about recognising a recurrence, chances of cure, risk to family of breast cancer and information about Tamoxifen and anti-oestrogen drugs. For many of the issues important to women, only one-third of women reported receiving information about these issues in the previous 6 months.

We found that women used a variety of sources of information, but the most frequently used source of information was the internet (70%, n=229). Other frequently used sources of information included the surgeon (58%) and the cancer specialist (58%). Not surprisingly, women are using the Internet at a statistically significantly higher rate in 2013 compared to 2002.

The highest levels of satisfaction with information were for information received from face-to-face sources as opposed to online sources. Sources of information that women rated moderately or extremely useful include the Cancer Helpline (91%), the breast care nurse (88%), the surgeon (85%), the cancer specialist (85%), and the complementary or alternative therapist (85%).

Use of and satisfaction with support following breast cancer treatment

The most frequently used sources of support in the previous 6 months were from family (81%) and friends (80%), followed by the GP and surgeon (both 61%). In terms of satisfaction with support, women were generally very satisfied with the support they had received. The highest levels of satisfaction were for the complementary and
alternative therapist (89%), the breast cancer support group (86%), the psychiatrist or psychologist (85%) and the breast care nurse (83%). In the free text responses, women clearly highly regarded breast cancer organisations such as the Breast Cancer Network Australia (BCNA) and the Cancer Council as helpful sources of support.

Geographical comparisons

Geographical comparisons reveal women in outer regional, remote and very remote areas reported receiving information at a lower rate in seven out of the 13 information areas measured. However, this difference was not statistically significant. The breast care nurse was reported as a source of support at a statistically significantly higher percentage in the outer regional, remote and very remote areas (41%) compared to the major cities (22%) and inner regional areas (27%).

Results from this study have been used to develop two further studies investigating the role of the breast care nurse in the provision of information and support to Australian women with breast cancer. Recruitment for the final study will once again involve women with a diagnosis of breast cancer and is likely to begin in March/April 2014. A paper has been written to inform clinicians about the results of this first study and this paper has been submitted to an international health journal and is awaiting approval.

Researchers at Australian Catholic University would like to extend a very warm thank you to all the participants who contributed to our study. We would also like to sincerely thank Register4 for their assistance with recruitment for this research study. If you have any concerns, please do not hesitate to contact me.

Kind regards,

[Signature]

Tracey Ahern (PhD Candidate, Australian Catholic University).
Ttaher001@myacu.edu.au
Many years ago, I was shocked by reports from the Cancer Council Queensland, stating that the further someone lives from a metropolitan city, the more likely they are to die from cancer. I designed my doctoral research with a focus on the information and support available to women with breast cancer in urban compared to rural and remote areas.

A review of the literature revealed there had been few, large scale, quantitative studies of the role of the Australian breast care nurse. Therefore, it was clear that more research in this area was necessary.

Phase One of the research, a geographical comparison of the information and support needs of Australian women following treatment for breast cancer, found the internet to be the most commonly used source of information regardless of geographical location. However, satisfaction with information found using this source was lower compared with face-to-face sources of information such as the breast care nurse, surgeon or cancer specialist. This reliance on online information sources reinforces a need to educate patients about the use of credible internet information and to provide them with details of high-quality websites for health related information.

A comparison of sources of support used by women with breast cancer showed that those in outer regional, remote and very remote areas were statistically significantly more likely to use the breast care nurse for support. This supports the important work of the breast care nurse, particularly for patients in geographically isolated areas.

Phase Two of the research, a study of the role of breast care nurses Australia-wide, was the first such national investigation. This study of 50 breast care nurses, spanning all parts of Australia, has provided useful data about the differences in work depending on geographic location. It was found that breast care nurses from outer regional, remote and very remote areas were less likely to be involved in multi-disciplinary team meetings compared with their peers in major cities and inner regional areas. Given the fact that breast care nurses are recommended as a core member of the multi-disciplinary team in Australia, improving access to multi-disciplinary team meetings for those working in outer regional, remote and very remote areas is an area recommended for improvement.

In the third and final stage of the research, over 800 women with breast cancer participated in a study to examine the unmet needs and self-efficacy of those with access to a breast care nurse, compared to those without access to a breast care nurse. Analysis of the results of this study is currently underway.

Assistance to recruit appropriate participants for this research was received through the use of Register4 and the Breast Cancer Network Australia Review and Survey Group and I thank these two organisations for their support of the project.

Overall, this research has explored the perspectives of both breast care nurses and those living with and beyond breast cancer. The results will serve as a knowledge base to expand theory and inform research and practice. Comparisons between those living in urban and rural/remote areas have shown important differences which I hope will be able to be used to improve services for cancer patients living in rural and remote areas.

Tracey Ahern

Tracey Ahern is a Registered Nurse from rural Queensland and is a PhD candidate at the Australian Catholic University. She is researching the differences encountered by women with breast cancer living in urban areas and those living in rural and remote areas.
Information and Support Needs

Recruitment for this project has now been successfully completed.

About the project

This study investigated the use of and satisfaction with information and support following the primary treatment of breast cancer by replicating a study done in 2002.

What were the results of this project?

Register4 was able to provide 208 participants to this study. Of participants, 64% lived in major cities, 19% resided in inner regional Australia and the remaining 12% lived in outer regional, remote or very remote areas of Australia and this is representative of Australian Bureau of Statistics geographical data.

Compared to the original study, completed in 2002, we found that the top four information issues important to women were the same in 2002 and 2013. These issues included Information about recognising a recurrence, chances of cure, risk to family of breast cancer and information about Tamoxifen and anti-oestrogen drugs. For many of the issues important to women, only one-third of women reported receiving information about these issues in the previous 6 months.

We found that women used a variety of sources of information, but the most frequently used source of information was the internet (70%, n=228). Other frequently used sources of information included the surgeon (58%) and the cancer specialist (56%). Not surprisingly, women are using the Internet at a statistically significantly higher rate in 2013 compared to 2002.

The highest levels of satisfaction with information were for information received from face-to-face sources as opposed to online sources. Sources of information that women rated moderately or extremely useful include the Cancer Helpline (91%), the breast care nurse (89%), the surgeon (85%), the cancer specialist (85%), and the complementary or alternative therapist (85%).

The most frequently used sources of support in the previous 6 months were from family (81%) and friends (80%), followed by the GP and surgeon (both 61%). In terms of satisfaction with support, women were generally very satisfied with the support they had received. The highest levels of satisfaction were for the complementary and alternative therapist (86%), the breast cancer support...
Article 7 (Continued)

group (86%), the psychiatrist or psychologist (85%) and the breast care nurse (83%). In the free text responses, women clearly highly regarded breast cancer organisations such as the Breast Cancer Network Australia (BCNA) and the Cancer Council as helpful sources of support.

Geographical comparisons reveal women in outer regional, remote and very remote areas reported receiving information at a lower rate in seven out of the 13 information areas measured. However, this difference was not statistically significant. The breast care nurse was reported as a source of support at a statistically significantly higher percentage in the outer regional, remote and very remote areas (41%) compared to the major cities (22%) and inner regional areas (27%).

The researcher: Professor Ann Gardner

Professor Anne Gardner joined the School of Nursing, Midwifery and Paramedicine at the Australian Catholic University on the Canberra Campus in late 2011 as Professor of Nursing with a research intensive focus. Anne came from Townsville where she spent 4 years as the inaugural Professor of Tropical Health at James Cook University. This was a joint appointment between the university and Townsville Health Service District. Anne has a background in critical care nursing, nurse education and clinical research. She has a PhD in Epidemiology and Population Health from the ANU. Anne’s clinical research interests focus primarily on infection control and wound care. Anne is especially well known nationally and internationally for her collaborative research into nurse practitioner scope of practice.

Who was the project for?

This project was for women, living in Australia, aged 18 years or older who had been diagnosed with breast cancer and had completed treatment between 6 and 30 months ago.

What did this project involve?

Participants were asked to complete a one-off survey which took 20 - 30 minutes to complete. The questions related to the information and support women received during and after their treatment for breast cancer. One of the questions asked for your address so that the researcher could categorise place of residence in one of 5 geographical categories; Bureau of Statistic indication of remoteness.

Where was the project conducted?

The survey was conducted online and was run through Australian Catholic University.

What outcomes were achieved as a result of this project?

Results from this study have been used to develop two further studies investigating the role of the breast care nurse in the provision of information and support to Australian women with breast cancer. Recruitment for the final study will once again involve women with a diagnosis of breast cancer and is likely to begin in March/April 2014. A paper has been written to inform clinicians about the results of this first study and this paper has been submitted to an international health journal and is awaiting approval.

Researchers at Australian Catholic University would like to extend a very warm thank you to all the participants who contributed to our study. We would also like to sincerely thank Register4 for their assistance with recruitment for this research study.

Our Research (/public/our-research) »
Research results (/public/our-research/63-research-results) » Information and Support Needs
E) Other Invited Speaking Engagements During Candidature


REVIEW

Literature review: An exploration of the role of the Australian breast care nurse in the provision of information and supportive care

Tracey Ahern, RN BNSc (Hons) BEd Dip Teach*, Anne Gardner, RN Crit Care Cert MPH PhD

Australian Catholic University, School of Nursing, Midwifery and Paramedicine, PO Box 256, Dickson, ACT 2602, Australia

Received 10 July 2013; received in revised form 25 November 2013; accepted 1 December 2013

Summary Breast care nurses (BCNs) were introduced to the Australian health care system in the 1990s to facilitate better continuity of care and increase psychosocial support to women with breast cancer. Yet women with breast cancer, particularly those in rural and remote Australia have high levels of unmet supportive needs. The purpose of this literature review was to examine the role of the Australian breast care nurse in the provision of information and support to women with breast cancer.

A literature review was conducted using a number of databases from January 2006 to November 2012. Pre-set criteria were used, and nine research papers were identified; one randomised control trial, five quantitative studies, two qualitative studies and one mixed method study. Of the nine studies identified, only one attempted to explore the national perspective, however participants from Tasmania were not used.

Overall, the review revealed very few published Australian studies evaluating the role of the BCN since 2006. The results demonstrate a need for larger studies conducted on a national scale, using participants from diverse geographical areas to gain more insight into the level of access to BCN care experienced by Australian women from both urban and rural and remote areas. It is recommended that further research be undertaken in order to build up a body of quantitative data about the role of the Australian BCN in providing information and support to women.

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Introduction

Cancer is a major cause of death in Australia (AIHW, 2012a). Approximately one-third of people affected by cancer live in rural, regional or remote areas (Clinical Oncological Society of Australia & Medical Oncology Group of Australia, 2010). A number of studies have revealed that people with cancer in these areas have poorer survival rates than those living in major metropolitan centres (Australian Institute of Health and Welfare (AIHW), 2010, 2012a; Cancer Council Queensland (CCQ), 2009; National Rural Health Alliance Inc., 2009; Phillips, 2009; Underhill, Goldstein, & Grogan, 2006). The further from a metropolitan centre patients with cancer live, the more likely they are to die within five years of diagnosis (CCQ, 2009). Therefore, there is still more work to be done to assist the many people who are diagnosed with cancer, especially those living in rural or remote areas.

Breast cancer is the most common cancer among Australian women with 12,567 cases diagnosed in 2007 (AIHW, 2012b). By 2015, the number of new breast cancer cases among women is projected to be 22% higher than in 2006, with the numbers of women diagnosed with breast cancer estimated to be around 15,409 (AIHW, 2012a). Despite the growing numbers of women being diagnosed with cancer, there has been an increase in relative survival after diagnosis of breast cancer from 72.6% in the five years 1982–1987 to 88.3% in the five years 2000–2006 (Cancer Australia, 2012). In 2006, it was estimated that there were 143,967 breast cancer survivors who had been diagnosed in the previous 25 years (Cancer Australia, 2012).

With the growing numbers of breast cancer survivors, there is a high need for accessible and quality post-treatment medical and psychosocial care (Lawler, Spathonis, Masters, Adams, & Eakin, 2011). There is evidence that many women do not have adequate information about their disease and treatment, nor receive enough practical and emotional support from health professionals (Aranda et al., 2006; Davis et al., 2004; Girgis, Boynes, Sanson-Fisher, & Burrows, 2000; Lawler et al., 2011; McGrath et al., 1999; Raupach & Hiller, 2002). Addressing these needs for rural women can prove even more difficult with rural health service provision challenged by issues of equity, coverage and supply (National Breast Cancer Centre (NBCC), 2001).

In Australia in the 1990s, breast care nurses (BCNs) were formally introduced to the Australian health care system to facilitate better continuity of care and psychosocial support (Jones, Leach, Chambers, & Occhipinti, 2010). The consensus is that BCNs are valued highly by their patients (Eicher, Marquard, & Aebi, 2006; Halkett, Arbon, Scutter, & Borg, 2006; Jones et al., 2010; Reed, Scanlon, & Fenlon, 2010), however, there has been little contemporary research conducted to investigate and report the role of the Australian BCN (Halkett et al., 2006; Jones et al., 2010). The following review identified Australian research papers where breast care nurses and the provision of information and support were a component of research and discussion.

Aim

To conduct a review of the literature examining the Australian breast care nurse role in supporting women with breast cancer. The research questions the literature review aims to answer include:

1. What is the role of the Australian breast care nurse as reported in the current literature?
2. What evidence is there to report on the role of the Australian breast care nurse and what are the gaps in the literature?

Methodology

A number of databases including CINAHL, Medline, The Cochrane Library, and Academic Search Complete were searched. Two major searches were conducted to extract specific information for this literature review. First, a search was completed where the main search term used was ‘breast cancer’, combined with the term ‘breast care nurse’. Papers were limited to those published from 2006 to 2012 since papers published earlier than 2006 had been reviewed in a Cochrane Review (Cruickshank, Kennedy, Lockhart, Dossier, & Dallas, 2008) and a systematic review (Eicher et al., 2006). Other limiters were added to extract only research papers written in the English language, with a geographical subset of Australia and New Zealand, simply to examine only research relating to the Australian context. This search revealed 71 articles. To check for any other relevant papers, the main search term ‘breast care nurse’ was combined with terms such as ‘supportive care’, ‘psychosocial care’ and ‘follow up care’. This search did not reveal any further relevant papers. The abstracts of 71 papers were read and papers not meeting the selection criteria were excluded, leaving a total of 9 papers to review. Reference lists of key articles...
were manually scanned and important papers identified were accessed for additional information. This literature review was limited to original research only. Table 1 details the inclusion and exclusion criteria.

### Results

The nine Australian published studies found since 2006 included one randomised control trial, five quantitative studies, two qualitative studies and one mixed method study. Four of the studies investigated the role of the breast care nurse and provided a list of roles undertaken by the BCN in their findings (Halkett et al., 2006; Jiwa et al., 2010; Jones et al., 2010; Watts et al., 2011). Two of the studies reported on the patient satisfaction of information and support received from BCNs (Eley & Rogers-Clark, 2012; Redman, 2006), one explored patient preferences for follow-up care by a BCN (Jiwa, Halkett, Deas, & Meng, 2011) and the remainder examined the effectiveness of a brief nurse-led intervention to address the needs of women with advanced breast cancer (Aranda et al., 2006). Many of the studies were conducted using exploratory research based at a single site. Only one study attempted to explore the national perspective. Eight of the nine studies were conducted using participants from a single state, therefore not exploring the national perspective. The papers are summarised in Table 2.

Only one randomised control trial was identified (Aranda et al., 2006), where 105 participants at four large urban hospitals were given a baseline survey and then randomised into two groups. The control group received the standard care given at the treatment site. The intervention group received carefully structured and timed care with a BCN. All participants were surveyed again at one month and three months post intervention. The results indicate that there were no significant differences between the two groups in terms of changes in quality of life or unmet needs from baseline. The researchers identified three possible explanations. First, the sample size was not large enough to detect differences between the two groups. Second, the uptake of recommended strategies were not implemented sufficiently, therefore negatively affecting the success of the intervention. Third, the intervention was not intense enough to achieve change, indicating the need for more intervention sessions. As well as these problem areas, the BCNs involved in conducting the intervention noted that the one week time frame between the two components of the intervention was too short.

Three quantitative studies using cross sectional survey methodology were identified (Campbell et al., 2006; Eley & Rogers-Clark, 2012; Eley et al., 2008). Campbell et al. (2006) surveyed 344 women with early breast cancer and produced a comparison between women who received systematic BCN care and those who had no contact with a BCN. The results demonstrated that the provision of service of BCNs in Australia has been slow to occur as less than half (48%) of the women surveyed recalled having contact with a breast care nurse. Furthermore, only 1 in 9 participants received systematic BCN care, where systematic care involved care at three points in time, preoperatively, postoperatively and at follow-up. Those who received systematic BCN care were better informed and reported feeling better supported than those who did not. The researchers claimed that they have provided evidence of benefit in the Australian context and their findings lend weight to the consumer demand for enhanced BCN access. Eley et al. (2008) surveyed women with breast cancer in a rural and remote area of Queensland (n = 51) and staff from multidisciplinary teams and senior managers to explore the role of the BCN in the Queensland’s Supporting Rural Women with Breast Cancer Project. The findings demonstrate that BCNs were of great value to patients from regional, rural and remote areas. However, this study has two major limitations; first, the rural and remote area under study was serviced by only one BCN. Second, the study did not interview women who had not received support from a BCN.

In the third study of this type, Eley and Rogers-Clark (2012), aimed to provide quantitative and qualitative data useful for understanding the experience of those who have support from a BCN. This study used a before and after retrospective design in which some of the sample were surveyed between 1 and 3 years after having contact with the BCN. It is possible that surveying people three years later may lead to inaccurate information being provided. In addition, the differences reported over the three year period may be explained by other, unrecognised changes in health services over time. The authors also expressed concern about participants’ ability to distinguish and therefore report accurately on the role as opposed to personality of the BCN. Yet again, this study did not explore the national perspective recruiting participants from a single site/state. However, in their favour, the researchers used participants representing both those who do and don’t have access to a BCN. Additionally, participants were from a regional health service, therefore exploring the perspectives of women from regional, rural and remote areas.

One quantitative study used longitudinal surveys (Jiwa et al., 2011). This study aimed to explore women with breast cancers’ preferences for surveillance follow-up, surveying participants at two time points, follow-up and three months post follow-up. They found that not all women with breast cancer prefer to consult a GP following breast cancer.

<table>
<thead>
<tr>
<th>Table 1 Initial inclusion/exclusion criteria.</th>
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<tr>
<td>Inclusion criteria</td>
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<tr>
<td>• Published 2006 or later</td>
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<tr>
<td>• Original research papers, focus on</td>
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<tr>
<td>breast care nurse role in the provision of</td>
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<td>information and support to women with</td>
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<td>breast cancer</td>
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<td>• English language only</td>
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<tr>
<td>Authors and year of publication</td>
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</table>
| Aranda et al. (2006) | Randomised controlled trial | 105 | Four large urban hospitals in Melbourne, Australia | • No significant differences between the two groups in terms of changes in quality of life or unmet needs  
• Women with high psychological needs benefit  
• BCNs should undertake a routine assessment of patient’s needs and psychological status  
• BCNs need skills to respond to emotional concerns | • Timeframe between intervention and follow-up too short  
• More intervention sessions may have produced greater changes in outcomes  
• A larger sample may have detected more significant differences  
• Sample — urban, English speaking women only  
• Low consent and retention rate  
• Participants from a single state |
| Campbell et al. (2006) | Quantitative study (cross-sectional survey design) | 544 (76% response rate) | Population based sample, randomly selected through state and territory cancer registries | • Slow uptake of BCN use in Australia; 48% recalled having contact with a BCN  
• Only 1 in 9 received systematic BCN care  
• Systematic BCN contact positively influenced women’s perceptions of care, particularly re provision of support | • All states/territories represented, except Tasmania |
| Halkett et al. (2006) | Qualitative, study (in-depth interviews) | 18 | One major hospital in South Australia | • Provided women’s perspectives on BCN role and recognised that BCNs are important to women with breast cancer | • Single site study  
• Sample — urban, English speaking women only |
| Eley et al. (2008) | Quantitative study (2 cross sectional surveys) | 51 patients, 18 stakeholders | Patients from rural and remote locations in Queensland. Stakeholders; Qld Health Staff | • First study reflecting current national information of breast cancer patients’ views of BCN  
• BCN considered of great value to regional, rural and remote patients  
• Continuation of BCN program recommended by consumers and stakeholders | • The area under study was serviced by only one BCN  
• No comparison group; interviews were not done with women receiving no BCN support |
<table>
<thead>
<tr>
<th>Authors and year of publication</th>
<th>Study design</th>
<th>Sample size</th>
<th>Population/site used</th>
<th>Summary of findings and recommendations</th>
<th>Limitations</th>
</tr>
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<tbody>
<tr>
<td>Jones et al. (2010)</td>
<td>Mixed Method Study (in-depth interviews and survey)</td>
<td>18 (Study 1 In-depth interviews) 48 (Study 2 Survey)</td>
<td>Queensland Health employees (nurses and medical staff, including BCNs)</td>
<td>Results describe scope of practice of the BCN from the perspectives of the BCN and other key health professionals</td>
<td>Small sample size in one Australian state&lt;br&gt;The health professional sample was limited to administrators, nurses and doctors</td>
</tr>
<tr>
<td>Jiwa et al. (2010)</td>
<td>Qualitative study (taping nurse-led consultations)</td>
<td>21 patients under the care of 4 breast care nurses</td>
<td>Participants attended hospital-based breast cancer follow-up clinic in Western Australia</td>
<td>The specialist breast nurse led follow-up model has potential to improve patient follow-up and reduce clinical workloads in both tertiary and primary health care settings</td>
<td>Participants limited to one Australian state</td>
</tr>
<tr>
<td>Watts et al. (2011)</td>
<td>Quantitative, intervention study (post-test only)</td>
<td>31 patients 17 health professionals</td>
<td>Metropolitan, major teaching hospital</td>
<td>Metastatic BCN provides the opportunity to tailor treatment and supportive care to the needs of the individual and addresses a significant gap in service provision</td>
<td>Single site study&lt;br&gt; Limited to women with metastatic breast cancer</td>
</tr>
<tr>
<td>Jiwa et al. (2011)</td>
<td>Quantitative, study (longitudinal survey)</td>
<td>101 (Survey 1, response rate 38%) 60 (Survey 2, response rate 59.4%)</td>
<td>One hospital based clinic</td>
<td>Not all patients prefer to consult with a GP after treatment. Many in this study were observed to consult a BCN instead</td>
<td>Single site study&lt;br&gt;The two services being compared were not equivalent service providers — one offered free of charge (hospital-led BCN clinic), the other was offered at a cost (GP)</td>
</tr>
<tr>
<td>Eley and Rogers-Clark (2012)</td>
<td>Qualitative and Quantitative data collected (cross sectional survey)</td>
<td>28 (BCN care) 22 (no BCN care)</td>
<td>Large Australian regional health service</td>
<td>The BCN model has been slow to be adopted in QLD and this study supports continuation of the programme and the creation of additional positions</td>
<td>Author expressed concern about participants’ ability to evaluate the BCN role, and not the person&lt;br&gt;Recall bias due to a reliance on memories from past events</td>
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</table>
treatment, and many women preferred to consult with a BCN. The study participants were limited to a group based at a single site.

Watts et al. (2011) conducted an intervention study whereby the development and evaluation of a specialist metastatic BCN role was implemented. This study aimed to address the gaps in service provision of BCNs for women with metastatic disease and the results of the study suggest strong support from both patients and health professionals for the continuation and expansion of the service. Like many of the studies critiqued in this review, this study was limited to participants at a single site in a large metropolitan area.

The mixed methods study by Jones et al. (2010) aimed to describe the scope of practice of the BCN by conducting in-depth interviews (Study 1) and a survey (Study 2) gaining the perspectives of BCNs and other key health professionals about BCN scope of practice. The researchers found that provision of information and support to people with breast cancer and their families were central to the role of the BCN. They also concluded that the BCN scope of practice differed across practice contexts. A small sample size of BCNs (Study 1 n = 11, Study 2 n = 27) located in only one Australian state and the limited sample of health professionals (Study 1 n = 7, Study 2 n = 21) were recognised as limitations and the authors recommended that the survey be replicated with a larger sample of BCNs and a more diverse sample of health professionals.

One qualitative study used in-depth, semi structured interviews of women after treatment for breast cancer (Halkett et al., 2006). This study aimed to explore patient’s perspectives on the role of the breast care nurse. The authors state that their study builds on the knowledge that most women appreciated the support that BCNs provide and provided insight into women’s perceptions of the different roles that the BCN takes on. This study was conducted at a single site, comprising urban, English speaking women only. It can be argued that the information gained from this study supports the role of the BCNs, but does not add any new information.

Jiwa et al. (2010) undertook a qualitative study, taping BCN-led consultations with 21 women attending a hospital-based breast cancer follow up clinic in order to report a thematic analysis of the consultations between BCNs and patients. The researchers concluded that the BCN model of care evaluated in this study has the potential to improve the follow-up experience of patients, while also reducing the clinical workloads for health practitioners in both tertiary and primary health care settings. Like many of the exploratory studies critiqued here, this study was limited to participants from a single site.

Discussion

After reviewing the literature pertaining to breast care nurse practice in Australia, several themes have emerged which are worthy of discussion. First, despite the BCN being a part of the Australian health system for 20 years, women with breast cancer still have high unmet support needs. Second, BCNs are not regulated by a professional body, nor do they have a consistent structure to their practice. They practice in a variety of different settings, all of which have different roles and expectations of BCNs. Third, the research literature surrounding Australian BCNs has consisted of predominantly exploratory, single site studies many of which were conducted in metropolitan areas. There was only one RCT identified in this review, therefore a clear lack of level one or two evidence (National Health & Medical Research Council, 2009). Each of the three identified areas is discussed below in the context of the wider literature about the needs of women diagnosed with breast cancer.

Meeting the needs of women diagnosed with breast cancer

Breast care nurses were introduced in Australia to help provide continuity of care to women with breast cancer, and most studies in this review report that the breast care nurse is highly valued by patients (Campbell et al., 2006; Eley & Rogers-Clark, 2012; Eley et al., 2008; Halkett et al., 2006; Jiwa et al., 2010; Watts et al., 2011). However, current literature reporting on the role of the breast care nurse and their ability to meet the information and support needs of women with breast cancer is sparse. Psychosocial and psychological information and support remain largely unmet for women with breast cancer even though health services such as that offered by the BCN are available in Australia. Research spanning the past decade provides evidence that women diagnosed with breast cancer need a high amount of information and support especially in the psychosocial and psychological domains and many of these needs remain unmet (Beatty, Oxlad, & Wade, 2008; Davis et al., 2004; Girgis et al., 2000; McGrath et al., 1999). Although women report high needs in the psychosocial and psychological support domains, follow-up care tends to focus on clinical aspects of the disease and treatment process (Brennan, Butow, Spillane, & Boyle, 2008) and clinicians need to be more receptive to symptoms related to treatment morbidity and to the information needs of their patients (Roche, 2006). Further to this, Beatty et al. (2008) found that many patient education guides given to women with breast cancer address physical and medical concerns, but detailed information related to psychological concerns were lacking.

When reading the wider literature about the unmet needs of women with breast cancer, it becomes clear that those living in rural and remote areas often have additional barriers to face. A number of studies reported that patients in rural and remote areas may experience lengthy travel distances for specialised treatment, the financial burdens of travel and accommodation, disruption to family lives, lack of treatment choice and lack of access to information (Bettencourt, Schlegel, Talley, & Molix, 2007; Clavarino, Lowe, Carmount, & Balanda, 2002; Girgis et al., 2000; McGrath et al., 1999). Furthermore, these studies concluded that those in rural and remote areas also have higher unmet psychosocial needs. In particular, Bettencourt et al. (2007) argue that rural women have a unique set of needs such as feelings of isolation due to lack of psychosocial support, greater stress resulting from the higher demands of traditional gender roles in rural and remote areas, and feel a greater loss of privacy as a result of living in smaller communities. There is strong evidence reporting the additional barriers faced by those living in rural and remote areas even though models of care such
as that of the BCN were introduced in Australia to help to address the urban and rural or remote divide.

The role of the breast care nurse

Since introduction to the Australian health system the number of BCNs has grown, however it is difficult to ascertain exact numbers of BCNs currently employed in Australia. In recent years, organisations such as the McGrath Foundation have helped to raise the profile of breast care nurses in Australia. The McGrath Foundation was established in 2002 to create more breast care nurse roles to support Australian families experiencing breast cancer, particularly those in rural and remote areas. The McGrath Foundation sourced additional funding from the Australian Government in 2008 to support breast care nurses in 44 communities nationwide over four years. The latest figures reveal that as at April 2013, the McGrath Foundation has placed 83 breast care nurses in Australian communities (McGrath Foundation, 2013). Further to this, the McGrath Foundation has received additional Government funding of $19.5 million to increase the number of breast care nurses working for the McGrath Foundation (Australian Bureau of Statistics, 2013).

Although the BCN position has been operating in Australia for almost 20 years, there is some doubt about whether all women with breast cancer have adequate access to a BCN (Campbell et al., 2006; Eley & Rogers-Clark, 2012). Eley and Rogers-Clark (2012) explain that at the time of their study in 2008, there were only 16 BCN positions for a population of four million in Queensland. In the past there has been some debate about the smaller caseload of BCNs in rural and remote areas, making the role of the BCN in these settings unsustainable (National Breast Cancer Centre & National Cancer Control Initiative, 2003). The overall number is estimated to be between 300 and 500 Australia wide, but exact numbers are unknown (Cancer Council Victoria, 2013). With the growing numbers of women being diagnosed with breast cancer, it is important that all of these women have adequate access to a BCN and little has been done to quantify the BCN access available to women with breast cancer.

Breast care nurses in Australia do not appear to be overseen by a professional body and although available since the mid 1990s, the delivery of this health care service varies widely and is somewhat inconsistent, often dependent upon the practice context or geographical area in which they work. Past research of BCN practice in Australia suggests limited use by breast nurses of a structured clinical pathway, wide variation in clinical aspects of the role, and an inconsistent approach to providing continuity of care from diagnosis through to the end of treatment (Victorian Centre for Nursing Practice Research, 2001; White, Wilkes, & Campbell, 1997). The Specialist Breast Nurse Competency Standards were introduced in 2005 (National Breast Cancer Centre (NBCC), 2005), however, there is little current evidence to report on the validity and use of these standards. Currently, the McGrath Foundation is developing a National Breast Care Nurse Directory. Improved networking and collaboration between breast care nurses, and improved referral pathways between BCNs and from other healthcare professionals are two of the intended benefits of the Directory (McGrath Foundation, 2012). Four of the studies in this literature review focussed on describing the role of the breast care nurse (Halkett et al., 2006; Jiwa et al., 2010; Jones et al., 2010; Watts et al., 2011). The roles of the BCN common across each of these articles are shown in Table 3. The information provided in these studies is somewhat generic, and research about the how the role of the BCN differs according to different work contexts or geographical locations does not exist in the current literature.

Even though, the BCN has been a part of the Australian health care service for the past two decades, there is a lack of rigorous research evaluating BCN service delivery in Australia and the information in the discussion below further illustrates this.

Gaps in the research

Reviewing specific literature and reading the wider literature surrounding research based on breast care nurses, has revealed a number of gaps in the research. There are many studies where researchers conclude they have provided strong evidence of the positive impact that BCNs have on the quality of care of women with breast cancer (Amir, Scully, & Borrill, 2004; Eicher et al., 2006; Eley et al., 2008; Halkett et al., 2006; Jiwa et al., 2010; Liebert & Furber, 2004; Szwarz, Hannan, Donoghue, & Mitten-Lewis, 2004). However, a Cochrane Review of five randomised controlled trials assessing the effects of interventions carried out by BCNs on quality of life outcomes for women with breast cancer between the years 1966 and 2006 found the evidence to be inconclusive. The Cochrane Review concluded that further research is required before the impact of BCNs on aspects of quality of life for women with breast cancer can be known (Crucickshank et al., 2008). Possibly, the reason for paucity of evidence in this area may be the lack of internationally established definition of roles and functions of BCNs and the lack of methodically high quality studies.

Since the development of the role of the BCN both in Australia and internationally, clear definition of the BCN role has not been achieved (Amir et al., 2004; Yates et al., 2007). Breast care nurses may have a variety of training, education and experience and their roles have developed in a variety of settings (Eicher et al., 2012). A systematic review of the effectiveness of specialised nursing in breast cancer postulated that there is a need for a more specific definition of the role and required skills of specialised nurses in breast care (Eicher et al., 2006). Ten studies were included in this review; however the studies differed with respect to the roles of specialised nurses as well as the measured outcome variables, making the comparability and generalizability of results limited. The findings of this review called for a more uniform definition of models of specialised nursing in breast care, as well as rigorous studies to evaluate their practice. Yates et al. (2007) also highlighted the inconsistencies in BCN role definition and suggested that these are likely to cause varied outcomes for women with breast cancer.

Investigating the differences in the BCN service based on geographical location has been identified as an area in need of more research. Two Australian qualitative studies, established that more research is needed to evaluate the provision of BCNs and the role of BCNs in varying geographical areas and practice contexts (Halkett et al., 2006; Jones et al.,...
Table 3  Breast care nurse roles identified in the peer-reviewed Australian Literature 2006—2012.

<table>
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<tr>
<th>Study</th>
<th>Provision of information and support to cater for individual needs of patients</th>
<th>Co-ordination of patient care</th>
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<tr>
<td></td>
<td>Developing therapeutic relationships with patients</td>
<td>Referral to other services as needed</td>
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<tr>
<td></td>
<td>Providing of support: emotional, informative and practical</td>
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<tr>
<td></td>
<td>Provision of treatment information</td>
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<tr>
<td></td>
<td>Provision of ongoing support, advice and information at different stages of the cancer journey</td>
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<tr>
<td></td>
<td>Educate, encourage, and support patients to self-manage different aspects of their disease</td>
<td></td>
</tr>
<tr>
<td>Jiwa et al. (2010). How do specialist breast nurses help breast cancer patients at follow-up? Collegian, 17, 143—149</td>
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Although these roles are highlighted in one paper only (Jiwa et al., 2010), the authors identified several themes relating to the self-management of disease.
The role of the Australian breast care nurse

2010). This need is supported by (Garcia & McQueen, 2005; Minstrell, Winzenburg, Rankin, Hughes, & Walker, 2008) who suggested that investigating the ability of the BCN to address the unmet needs of women with breast cancer in rural areas is an area that is worthy of more research. Another area recognised as worthy of more research involves investigating the financial benefits gained by the health service using BCNs (Eley & Rogers-Clark, 2012; Eley et al., 2008).

Conclusion

The provision of information and support to all Australian women with breast cancer through the BCN service is an area that needs more research as evidenced by the information provided in this review. It is clear that studies conducted on a larger scale, using participants from diverse geographical areas are needed to gain more insight into the level of access to BCN care experienced by Australian women from both urban and rural and remote areas. Additionally, there is a need for further research to investigate the differing roles that BCNs are expected to take on in varying geographical and practice contexts. It is recommended that further research be undertaken in order to build up a body of quantitative data about the role of the Australian BCN in providing information and support to women. These quantitative data will provide evidence on which to base recommendations to assist the efficiency of this health service which will in turn provide better outcomes for women using this service. Further to this, research into the differences based on work context or geographic location may assist to inform policy surrounding the role and scope of the Australian breast care nurse. For example, there are Competency Standards for Specialist Breast Care Nurses (National Breast Cancer Centre (NBCC), 2005) but an exploration of the validity and use of these standards is not evident in the research literature. An evaluation of the usefulness of these competency standards is therefore needed.

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References


Geographical comparisons of information and support needs of Australian women following the primary treatment of breast cancer: a 10-year replication study

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Keywords: breast cancer, breast care nurse, information, patient satisfaction, supportive care, unmet needs

Abstract

Background In 2002, Raupach and Hiller examined the use of and satisfaction with information and support following treatment of breast cancer from a sample of participants in South Australia. In 2013 this study was replicated to include participants Australia wide and analyse comparisons based on geographical location. Statistical comparisons with the original study were also conducted.

Design A 10 year replication study using a cross-sectional needs analysis survey.

Setting and participants Women aged 18+ years diagnosed with breast cancer between 6 and 30 months ago were sourced from two national databases of women diagnosed with breast cancer.

Results A total of 325 participants completed the survey. The Internet was the most commonly used source of information with 70% (n = 229 of 325) of women using the internet for information, a statistically significantly higher percentage compared with the 2002 study. The study found the top four information issues rated as moderately/extremely important by women in 2013 were identical in 2002. A comparison of sources of support used showed that women in outer regional, remote and very remote areas were statistically more likely to use the breast care nurse (BCN) for support (P = 0.044).

Conclusions The study provides useful, up-to-date data about information and support services used by Australian women with breast cancer. Comparisons with the earlier study show some of the needs of women have changed over time, but others have remained the same. Geographic comparisons overall, demonstrate many consistent findings regardless of location, however, the important work of the breast care nurse is an area in need of further research.
Introduction

In Australia in 2002, Raupach & Hiller\(^1\) concluded women experience a heightened need for information concerning breast-cancer-related issues following primary treatment for breast cancer with many such needs largely unmet. Since then, several studies continued to find women with breast cancer have high unmet needs.\(^2\)-\(^9\)

In 2012, the Australian Institute of Health and Welfare (AIHW) reported breast cancer is the most common cancer among Australian women with 12,567 cases diagnosed in 2007 (AIHW\(^{10}\)). By 2015, the number of new breast cancer cases among women is projected to be 22% higher than in 2006, with numbers of women diagnosed estimated to be around 15,409 (AIHW\(^{11}\)). For women with a diagnosis of breast cancer, receiving adequate information is essential to make informed treatment decisions.\(^3\) Additionally, adequate support is required to help women cope with their diagnosis.\(^3\) There is evidence many Australian women do not have adequate information concerning their disease and treatment, nor do they receive sufficient practical and emotional support from health professionals.\(^1,2,5,12-14\)

Needs of women with breast cancer vary depending on their particular circumstances. For example, those with more advanced disease report higher levels of unmet needs in the psychological and physical and daily living domains.\(^8\) On the other hand, young women with breast cancer report needing more age-specific information and support.\(^15\)

Similarly, those living in rural and remote areas of Australia have needs specific to their situation, and in fact, there is great regional and remote disadvantage for Australians diagnosed with cancer. Addressing the needs of Australian women in rural and remote areas has proven difficult due to rural health service provision being challenged by issues of equity, coverage and supply.\(^16\) New figures reveal people in regional and remote Australia are much more likely to die from cancer than those in metropolitan areas.\(^17\) A study by Underhill and Bartel et al.\(^{18}\) highlighted marked cancer service deficiencies in rural and regional Australia, leading to poorer outcomes for patients with cancer living in these areas. Many patients with cancer are geographically isolated from care facilities and therefore do not experience the same access to specialists, GPs and allied health services as those in metropolitan areas.\(^19\)

Over the past decade, due to therapeutic advances and early detection initiatives such as the BreastScreen Australia Program, there have been reductions in morbidity and mortality from breast cancer in Australian women.\(^20\) However, despite therapeutic advances, those living with and beyond a breast cancer diagnosis can still experience physical, functional and psychosocial morbidities impacting on their quality of life.\(^4,21-24\) The primary aim of this study was to replicate a previously validated need analysis survey completed by Raupach & Hiller\(^1\) and to compare the findings with those of a decade ago, with the addition of making comparisons based on geographical location of participants.

Research questions

1. What information is currently available to Australian women with breast cancer?
2. What is the level of satisfaction with information sources used by Australian women with breast cancer?
3. What sources of support are currently available to Australian women with breast cancer?
4. What is the level of satisfaction with sources of support used by Australian women with breast cancer?
5. What are the findings compared to a decade ago?
6. Are there geographic differences with information and support sources used by Australian women with breast cancer?

Methods

Design

A cross-sectional replication study was undertaken using a previously validated survey
with both structured and semi-structured questions.

**Survey instrument**

Permission to replicate was obtained from researchers conducting the original survey. The original survey was developed using interviews with women and service providers, a focus group with women with breast cancer, findings from a literature review and a report from a National Breast Cancer Conference for women. The original survey was evaluated by women and providers, before being formally pilot tested on a random sample of 25 women diagnosed with breast cancer. For the current study, six questions were added to determine the principal place of residence of each participant so geographical differences could be analysed.

The original survey was paper based; however, the replication survey was undertaken using an online format using Qualtrics survey software. The online format was tested by five people and minor modifications to layout completed. The self-report survey consisted of 150 items (142 closed questions and 8 open questions) and was distributed to women diagnosed with breast cancer belonging to two national databases. In the years since the original survey, general Internet access across Australia has risen to 83% of households having access to the Internet in the home. This and the availability of women with breast cancer belonging to two national databases willing to participate in online research studies influenced the decision to use an online survey in this study.

**Participants**

Participant criteria for inclusion were replicated to match the original study, with women living in Australia aged 18 years and over who had been diagnosed with breast cancer between 6 and 30 months ago targeted. No other eligibility criteria were stipulated. The original study sourced participants from a single, urban hospital over a period of 25 months. However, due to a lack of national perspective of evidence on current unmet needs, participants from across Australia were targeted.

Participants were sourced from two national databases of women diagnosed with breast cancer that assist with recruitment of participants through online measures: Register4 has 34 000 members Australia-wide and is open to people over 18 years old with and without cancer and the BCNA Review and Survey Group containing membership of 2500 women with breast cancer across Australia.

A total of 402 participants commenced the survey. Nineteen participants did not provide geographical information essential for allocating a geographical code enabling analysis of geographic differences, and 58 participants submitted an incomplete survey, and examination of incomplete surveys revealed random patterns of exit points in the survey. Therefore, 325 responses or 81% were analysed.

**Procedures**

Following ethical approval from Australian Catholic University Human Research Ethics Committee, members of Register4 and the Breast Cancer Network Australia Review and Survey Group were forwarded information about the study and directed to the online survey which included a participant information letter. Participants were given the option to receive a hard copy of the survey and a stamped, self-addressed envelope if they were unable to complete the online version of the survey. One participant chose to take this option. Voluntary participation was achieved by participants completing and submitting a survey.

An Australian Bureau of Statistics (ABS) Remoteness Area (RA) code was manually allocated to the physical residential address of each participant to identify their geographical location. These RA codes were consistent with the latest available information from the ABS and were allocated using an address...
coding tool on the ABS website. Once the RA code was allocated, all other information relating to place of residence was deleted from the database to protect the identity of participants.

A de-identified summary of results was published on the Register4 website and sent via email to BCNA Review and Survey Group members.

Data analysis

The data were analysed using IBM SPSS software, version 20.0: IBM Corporation, Ireland, United Kingdom. Descriptive statistics were calculated for all variables to determine missing and inappropriate (out of range) values. Frequency tables for each section of the survey were generated enabling a summary of results at a glance. After checking responses were consistent, some RA codes were combined, resulting in the reduction of the number of categories from 5 to 3. Major cities and inner regional categories remain unchanged, whereas the remaining three categories were combined: outer regional, remote and very remote. Variables measured on a four-point Likert scale were collapsed into two categories. Responses in the ‘not’ or ‘slightly’ (important/useful/helpful) categories were combined, and responses in the ‘moderately’ and ‘extremely’ (important/useful/helpful) categories were combined. This latter reduction of codes was a recoding undertaken prior to reporting the original survey.

Open-ended questions were analysed using content analysis to identify common themes about women’s need or lack of need for information and support.

Results

Three hundred and twenty-five women completed the survey. Table 1 describes the demographic and treatment characteristics of respondents. Respondents from major Australian cities comprised 69% of the total sample. Nineteen per cent resided in inner regional Australia, with the remaining 12% residing in outer regional, remote or very remote Australia. Age ranged from 27 to 81 years with a mean of 54 years. The number of women in outer regional, remote and very remote areas were significantly more likely to be aged under 50 years (n = 18 of 39, 45%) than women in major cities (n = 74 of 224, 33%) compared to inner regional areas (n = 14 of 62, 23%) (χ² = 6.111, P = 0.0047). Two hundred and sixty-nine participants (83%) were born in the continent of Australia and Oceania, with the remaining 17% (n = 56) being born in Europe, Asia, Africa or North America. Seventy-eight per cent (n = 254) of women were married or committed. Just over half of respondents (53%, n = 173) had completed a university education, however, the percentages of university graduates from major cities (n = 124 of 224, 55%) and inner regional areas (n = 33 of 62, 53%) were higher than those living in outer regional, remote or very remote areas (n = 16 of 39, 41%).

When analysing treatment characteristics, at least 98% of respondents had undergone surgery to treat their breast cancer. The percentage of respondents treated with chemotherapy (62–66%) or radiotherapy (68–72%) was comparable regardless of geographical residence. Respondents in outer regional, remote or very remote areas had much higher percentages of hormone therapy treatment (n = 31 of 39, 80%) compared to those living in major cities (n = 161 of 224, 72%) and inner regional areas (n = 38 of 62, 61%). Breast reconstruction percentages were similar in all three geographical areas, with around one fifth of women choosing to have breast reconstruction.

Just under a quarter of respondents (24%, n = 78) had an immediate family member diagnosed with breast cancer. However, percentages of an immediate family member being diagnosed with breast cancer were significantly higher in the outer regional, remote or very remote category 41% (n = 16 of 39) compared to 22% (n = 49 of 224) in the major cities and 21% (n = 13 of 62) in inner regional areas (χ² = 14.329, P = 0.006). Almost all (97%,
n = 315) of respondents had a regular general practitioner (GP).

Information about specific issues
Table 2 shows the issues for which women rated a need for information was moderately or extremely important. The number of women receiving information about these issues in the last 6 months is also reported in the table.

In the current study for six of the 13 issues presented to women 74% or more women rated the issue as moderately or extremely important to them. The three top issues were recognizing a recurrence (n = 304, 94%), chances of cure (n = 274, 84%) and risk to family of breast cancer (n = 269, 83%). At
least 50% of women rated 11 of the 13 issues as moderately or extremely important to them. The lowest need was expressed for information about breast reconstruction \( (n = 125, 38\%) \) and prostheses \( (n = 98, 30\%) \).

To enable comparisons, the results of the 2002 study are also provided in the table. The top four issues for women in 2002 are the same top four issues rated for women in the current study (recognizing a recurrence, chances of cure, risk to family of breast cancer, Tamoxifen and other anti-oestrogen drugs). Ninety-five per cent confidence intervals comparing the two studies reveal that women in the current study were statistically more likely to rate information about sexuality and relationships \( (n = 171, 54\%, 95\% CI = 48–58) \) as moderately or extremely important compared with the 2002 study \( (n = 81, 39\%, 95\% CI = 32–46) \).

Despite rating these issues as important, for many of the issues, information received in the past 6 months was reported on average by only 30% of women. In this study, the three top issues that women received information about in the past 6 months included tamoxifen and other anti-oestrogen drugs \( (n = 166, 51\%) \), where to go for more support \( (n = 150, 46\%) \) and chance of cure \( (n = 121, 37\%) \). It is important to note, however, that the percentages of women actually receiving information in the previous 6 months are statistically significantly higher in this study in ten of the 13 information areas listed.

### Sources of information

Women used a variety of sources of information, and Table 3 shows the use of and extent of satisfaction with these sources of information. In this study, the most frequently used source of information was the Internet \( (70\%, n = 229) \). Other frequently used sources of information include the surgeon \( (58\%, n = 190) \), the cancer specialist \( (56\%, n = 181) \) and the television \( (53\%, n = 172) \).

A comparison with 2002 data revealed statistically significant differences for the receipt of

In the free text, many women indicated there were difficulties experienced in obtaining information such as having to self-source information, receiving too little information after completion of treatment or receiving confusing or conflicting information (Box 1).

**Box 1** Difficulties encountered in seeking out and obtaining information and support

Difficult to obtain reliable, credible information.
After treatment is completed, not much information is available.
I am 20 months post breast cancer. I don’t receive any information.
I feel there is very little ongoing support.
I have had to source all information myself on anything I need.
Little support available outside the city.
Little information is offered unless specifically asked for.
Not given written information. Have found extra on www.
There is no central place to find good information.
Have not received any information and I have been discharged.
I have sourced all information myself.
Information has been confusing and contradictory.
Little information has been received.
Information is not always useful – vague at times.
Information is not easily available in my area.

**Satisfaction with information sources**

The highest levels of satisfaction with information sources were for information received from the Cancer Help Line (n = 10 of 11, 91%), the breast care nurse (n = 75 of 84, 89%), the surgeon (n = 161 of 190, 85%), the complementary or alternative therapist (n = 46 of 54, 85%) and cancer specialist (n = 154 of 181, 85%). There were six other sources of information where at least 74% of women rated the information received as moderately or extremely useful. The lowest levels of satisfaction were for information received from television (n = 65 of 172, 38%), newspapers (n = 48 of 129, 37%) and magazines (n = 30 of 90, 33%).


In the free text, many women indicated that the medical team (surgeon, oncologist, radiologist, BCN and GP) and cancer organizations and support groups were very useful sources of information. However, a strong theme emerged where women felt that if they needed additional information, they had to search for it themselves, usually turning to the Internet. In terms of using the Internet, women’s experiences were both negative and positive (Box 2).

**Box 2** Positive and negative comments about the use of the Internet as an information source

Positive:
I received a lot of my information from the internet - pretty useful.
I would be lost without the internet.
If I need information, I generally search online.
Much of my information was helpful and came via the internet.
Internet is most helpful as you can look up what you want.
Some internet sites are extremely good.

Negative:
The internet has been helpful, but may not be accurate.
Internet information can be overwhelming.
I received information mainly from the internet.
Usefulness varied.
The internet often has conflicting information.
Internet has too much information and it is difficult to know what is accurate.

**Sources of support**

The frequency of use and extent of satisfaction with sources of support are reported in
Table 4. The most frequently used sources of support in the past 6 months were friends (n = 263, 81%) and family (n = 261, 80%), followed by the GP and surgeon (both 61%). The least frequently used sources of support were the psychiatrist or psychologist (n = 54, 17%), the breast cancer support service volunteer (n = 31, 10%) and the Cancer Help Line (n = 10, 3%).

Comparisons with 2002 data revealed significant differences were found in the support received with the previous 6 months from the cancer specialist (CI: 2013 = 54–64%, 2002 = 23–36%), the Internet (CI: 2013 = 45–55%, 2002 = 1–6%), the breast cancer support group (CI: 2013 = 27–37%, 2002 = 2–9%), the psychiatrist or psychologist (CI: 2013 = 13–21%, 2002 = 3–10%) and the breast cancer support service volunteer (CI: 2013 = 7–13%, 2002 = 1–6%).

Satisfaction with support sources

In terms of satisfaction with support, women were generally very satisfied with the support they had received. All 12 sources of support were rated as moderately or extremely helpful by at least 76% of women (See Table 4). The highest levels of satisfaction were for the complementary or alternative therapist (n = 63 of 71, 89%), the breast cancer support group (n = 90 of 105, 86%), the psychiatrist or psychologist (n = 46 of 54, 85%), and the breast care nurse (n = 69 of 83, 83%). The lowest levels of satisfaction were for the Internet (n = 125 of 164, 76%).

Support from family (CI: 2013 = 78–86%, 2002 = 87–96%), the surgeon (CI: 2013 = 77–85%, 2002 = 87–96%) and the cancer specialist

Table 4 Sources of information used and satisfaction with those sources (ranked by frequency of use based on current results)

<table>
<thead>
<tr>
<th>Source of information</th>
<th>Current study</th>
<th>2002 study</th>
<th>Current study</th>
<th>2002 study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 325</td>
<td>%</td>
<td>95% CI</td>
<td>n = 217</td>
</tr>
<tr>
<td>Received information within the previous 6 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internet</td>
<td>229</td>
<td>70</td>
<td>65–75</td>
<td>9</td>
</tr>
<tr>
<td>Surgeon</td>
<td>190</td>
<td>58</td>
<td>53–63</td>
<td>125</td>
</tr>
<tr>
<td>Cancer specialist</td>
<td>181</td>
<td>56</td>
<td>51–61</td>
<td>49</td>
</tr>
<tr>
<td>Television</td>
<td>172</td>
<td>53</td>
<td>48–58</td>
<td>114</td>
</tr>
<tr>
<td>Newspapers</td>
<td>129</td>
<td>40</td>
<td>35–45</td>
<td>66</td>
</tr>
<tr>
<td>General practitioner</td>
<td>122</td>
<td>38</td>
<td>33–43</td>
<td>65</td>
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<tr>
<td>Breast cancer support group</td>
<td>120</td>
<td>37</td>
<td>32–42</td>
<td>10</td>
</tr>
<tr>
<td>Brochures</td>
<td>107</td>
<td>33</td>
<td>28–38</td>
<td>44</td>
</tr>
<tr>
<td>Magazines</td>
<td>90</td>
<td>28</td>
<td>23–33</td>
<td>91</td>
</tr>
<tr>
<td>Friends</td>
<td>90</td>
<td>28</td>
<td>23–33</td>
<td>46</td>
</tr>
<tr>
<td>Breast care nurse</td>
<td>84</td>
<td>26</td>
<td>21–31</td>
<td>37</td>
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<tr>
<td>Breast cancer support service volunteer</td>
<td>57</td>
<td>18</td>
<td>14–21</td>
<td>9</td>
</tr>
<tr>
<td>Complementary or alternative practitioner</td>
<td>54</td>
<td>17</td>
<td>13–21</td>
<td>19</td>
</tr>
<tr>
<td>Radio</td>
<td>54</td>
<td>17</td>
<td>13–21</td>
<td>44</td>
</tr>
<tr>
<td>Family</td>
<td>28</td>
<td>9</td>
<td>6–12</td>
<td>24</td>
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<td>Cancer Help Line</td>
<td>11</td>
<td>3</td>
<td>1–5</td>
<td>10</td>
</tr>
</tbody>
</table>

* Satisfaction = (number of women who rated information received from that source as moderately or extremely useful/total number of women who received information from that source) expressed as a percentage.

† One-sided 95% CI.

‡ Statistically significant findings.
(CI: 2013 = 78–86%, 2002 = 90–100%) revealed significant differences in 2013 compared with 2002.

In the free text, women also regarded friends, family (including husband/partner), the oncologist, surgeon, GP and breast cancer organizations such as the Breast Cancer Network Australia (BCNA) and The Cancer Council highly in terms of being most helpful sources of support.

**Comparisons by geographical location**

Table 5 shows percentages of women in each of the geographical areas reporting having received information or support about specific issues or from specific sources within the previous 6 months. The table also reports the satisfaction with information and support sources in each of the geographical areas. There were a number of items measured in each of the categories; however, only the top four issues in each of the three categories measured are displayed in this table. Statistically significant findings for each of the categories are also displayed.

**Information issues received**

Of the 13 issues where information had been received by women in the previous 6 months (see Table 2), only one issue recorded a percentage above 50% (tamoxifen and other anti-oestrogen drugs, n = 166, 51%). In the remaining 12 information areas, a range of between 21 and 46% of women reported receiving information about these issues in the previous 6 months. There are no statistically significant differences found based on geographic location (see Table 4 for a summary of these). However, there were lower percentages of women receiving information in outer regional, remote and very remote areas in seven of the 13 information areas measured (see Table 2).

**Sources of information used**

Percentages across all geographic areas were consistent for the top four sources of information. However, percentages of women using the newspaper as an information source are statistically significantly lower ($\chi^2 = 8.033$, $P = 0.018$) in outer regional, remote and very...
remote areas (n = 8, 21%) compared with major cities (n = 91, 41%) and inner regional areas (n = 30, 48%).

**Satisfaction with information received**

The percentage of women in outer regional, remote and very remote areas satisfied with the information they received from the complementary or alternative practitioner (n = 3, 50%) was much lower compared with women in major cities (n = 34, 87%) and inner regional areas (n = 9, 100%). Furthermore, the percentages of women in major cities who were satisfied with information received from breast cancer support groups (n = 69, 85%) outweighed women in inner

<table>
<thead>
<tr>
<th>Information or support received/used within the previous 6 months</th>
<th>Total n = 325</th>
<th>Major cities n = 224</th>
<th>Inner regional n = 62</th>
<th>Outer regional, remote and very remote n = 39</th>
<th>Chi-square</th>
<th>P value</th>
</tr>
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<tr>
<td><strong>Information issues received</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Tamoxifen and other anti-oestrogen drugs</td>
<td>166</td>
<td>51</td>
<td>122</td>
<td>54</td>
<td>28</td>
<td>45</td>
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<tr>
<td>Where to go for more support</td>
<td>150</td>
<td>46</td>
<td>106</td>
<td>47</td>
<td>26</td>
<td>42</td>
</tr>
<tr>
<td>Chances of cure</td>
<td>121</td>
<td>37</td>
<td>86</td>
<td>38</td>
<td>24</td>
<td>39</td>
</tr>
<tr>
<td>Arm problems and lymphoedema</td>
<td>114</td>
<td>35</td>
<td>77</td>
<td>34</td>
<td>24</td>
<td>39</td>
</tr>
<tr>
<td><strong>Sources of information used</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internet</td>
<td>229</td>
<td>70</td>
<td>158</td>
<td>71</td>
<td>44</td>
<td>71</td>
</tr>
<tr>
<td>Surgeon</td>
<td>190</td>
<td>58</td>
<td>132</td>
<td>59</td>
<td>39</td>
<td>63</td>
</tr>
<tr>
<td>Cancer specialist</td>
<td>181</td>
<td>56</td>
<td>128</td>
<td>57</td>
<td>32</td>
<td>52</td>
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<tr>
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<td>53</td>
<td>118</td>
<td>53</td>
<td>30</td>
<td>48</td>
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<tr>
<td>Newspapers</td>
<td>129</td>
<td>40</td>
<td>91</td>
<td>41</td>
<td>30</td>
<td>48</td>
</tr>
<tr>
<td><strong>Satisfaction with information received</strong></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Cancer Help Line (n = 11)</td>
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<td>91</td>
<td>9</td>
<td>90</td>
<td>1</td>
<td>100</td>
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<td>Breast care nurse (n = 84)</td>
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<td>89</td>
<td>46</td>
<td>90</td>
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<td>90</td>
</tr>
<tr>
<td>Surgeon (n = 190)</td>
<td>161</td>
<td>85</td>
<td>112</td>
<td>85</td>
<td>32</td>
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<tr>
<td>Cancer specialist (n = 181)</td>
<td>154</td>
<td>85</td>
<td>112</td>
<td>88</td>
<td>25</td>
<td>78</td>
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<td>Complementary or alternative practitioner (n = 54)</td>
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<td>85</td>
<td>34</td>
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<td>100</td>
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<td>Breast cancer support group (n = 120)</td>
<td>94</td>
<td>76</td>
<td>69</td>
<td>85</td>
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<td>67</td>
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<td><strong>Sources of support used</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Friends</td>
<td>263</td>
<td>81</td>
<td>175</td>
<td>78</td>
<td>54</td>
<td>87</td>
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<tr>
<td>Family</td>
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<td>80</td>
<td>174</td>
<td>78</td>
<td>56</td>
<td>90</td>
</tr>
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<td>General practitioner</td>
<td>198</td>
<td>61</td>
<td>140</td>
<td>63</td>
<td>36</td>
<td>58</td>
</tr>
<tr>
<td>Surgeon</td>
<td>197</td>
<td>61</td>
<td>135</td>
<td>60</td>
<td>36</td>
<td>58</td>
</tr>
<tr>
<td>Breast care nurse</td>
<td>83</td>
<td>26</td>
<td>50</td>
<td>22</td>
<td>17</td>
<td>27</td>
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<td><strong>Satisfaction with sources of support received</strong></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complementary or alternative practitioner (n = 71)</td>
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<td>89</td>
<td>44</td>
<td>86</td>
<td>12</td>
<td>100</td>
</tr>
<tr>
<td>Breast cancer support group (n = 105)</td>
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<td>86</td>
<td>63</td>
<td>88</td>
<td>16</td>
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<td>69</td>
<td>83</td>
<td>44</td>
<td>88</td>
<td>13</td>
<td>77</td>
</tr>
<tr>
<td>Cancer specialist (n = 191)</td>
<td>157</td>
<td>82</td>
<td>108</td>
<td>83</td>
<td>33</td>
<td>92</td>
</tr>
</tbody>
</table>

Although many items were measured, only the top four results in each category are listed, as well as statistically significant results found for each category.

*Statistically significant finding.

†No statistic possible due to values <5.
regional \((n = 16, 67\%)\) and outer regional, remote and very remote areas \((n = 9, 60\%)\). The remainder of information areas assessed for satisfaction revealed no major differences based on geographical location.

**Sources of support used**

Percentages across all geographical areas were consistent for the top four sources of support. However, notable is the statistically significant difference found with the breast care nurse as a source of support \((\chi^2 = 6.253, P = 0.044)\) at a much higher percentage in the outer regional, remote and very remote areas \((n = 16 of 39, 41\%)\) compared with the major cities \((n = 50 of 224, 22\%)\) and inner regional areas \((n = 17 of 62, 27\%)\).

**Satisfaction with sources of support received**

The percentage of women in outer regional, remote and very remote areas satisfied with the support received from the psychiatrist or psychologist \((n = 2, 40\%)\), as well as the cancer specialist \((n = 16, 64\%)\), were much lower than that reported by women in major cities \((n = 37, 90\% and n = 108, 83\%, respectively)\) and inner regional areas \((n = 7, 88\% and n = 33, 92\%, respectively)\). The percentage of women from inner regional areas satisfied with support received from a complementary or alternative practitioner \((n = 12 100\%)\) outweighed the satisfaction reported by women in major cities \((n = 44, 86\%)\) and outer regional, remote and very remote areas \((n = 7, 88\%)\). No other major differences were found; however, in eight of the 12 sources of support measured, women from outer regional, remote and very remote areas were less satisfied than women in the major cities and inner regional areas.

**Discussion**

Women facing a diagnosis of breast cancer need information and support to help them make informed treatment decisions and cope with their diagnosis. Over a decade ago, Raupach and Hiller\(^1\) identified the lack of information and support available to women following treatment for breast cancer. Replicating this study enabled comparisons over time. The study findings overall reveal that some of the needs of women with breast cancer have changed, but many have remained the same.

**Information issues important to women**

Raupach and Hiller\(^1\) found issues such as recognizing a recurrence, chances of cure, risk to family of breast cancer, and tamoxifen and other anti-oestrogen drugs were the most important information issues for women. This study found these four issues were also the most important issues proving women diagnosed with breast cancer have some of the same information needs as 10 years ago. Furthermore, the study shows in most cases, only one-third of women are receiving information they report is important to them, and therefore, the majority have unmet information needs. Therefore, the findings add to the volume of Australian and international literature reporting that despite advances in cancer care, women continue to have high unmet information and support needs.\(^1,3,4,8,9,32–34\)

**Internet information sources vs. face-to-face information sources**

Perhaps, not surprisingly, this study confirms the Internet as an information source has become more popular. Having access to information and support when the need arises, despite location, is important for patients.\(^35\) Significantly, however, both qualitative and quantitative findings demonstrated satisfaction with information retrieved from the Internet is not as high as information received through face-to-face delivery. As was found in previous studies,\(^1,34\) women were most satisfied with the information they received from members of the health-care team, including the surgeon, the cancer specialist, the breast care nurse and the complementary or alternative ther-
apist, confirming that delivery of information through face-to-face sources continues to be highly valued.

Although satisfaction was rated highest from face-to-face medical sources, patients in the present day rely heavily on non-medical information sources such as the Internet. The information presented via the Internet is under no guidance or regulation and therefore can be of questionable reliability and quality. O’Grady explains despite calls for research into the credibility of health-care websites for a number of years, little has been undertaken. Consistent with other research, our study found the Internet to be widely used as a health information source, highlighting a need for providing patients with the details of high-quality websites to access for information.

Sources of support for women

The findings also reveal the highest sources of support came from friends and family, with the general practitioner and the surgeon also offering high levels of support. Interestingly, these top four sources of support were also the top four sources of support in the original study. These findings once again highlight the importance that women place on receiving information in a supportive and caring context where information and support can be tailored to meet individual needs.

A new finding was that women in outer regional, remote and very remote areas were more likely to use a breast care nurse as a source of support. It is not clear why this is so, but it may be that BCNs are more accessible to those in rural and remote areas; however, no national comparative data exist about the geographical distribution of BCNs. It is well publicized that patients in rural and remote Australia experience limited access to health professionals including cancer specialists, GPs or allied health services, and perhaps, BCNs are more accessible. The value of BCNs has been reported in several Australian and international studies. However, a review of contemporary Australian literature has revealed little is known about the role of the Australian BCN, indicating a need for more research in this area.

Importantly, our study revealed overall women in outer regional, remote and very remote areas have lower levels of satisfaction with sources of support they receive, compared with women in major cities and inner regional areas. This adds to the volume of evidence reporting on the geographical disadvantage that exists in health-care services and support available in Australia.

Policy and research implications

As the Internet is so widely used, the opportunity exists for health professionals when interacting face-to-face to educate women on the appropriate use of only reputable and credible Internet sites. Research in the United States has revealed when using the Internet, patients have trouble knowing what information is relevant and what is reliable, and it is the health-care provider that patients turn to for consistent, reliable information and answers. Australian BCNs could take on the role of educating women about the appropriate use of the Internet for attaining health information and provide a list of appropriate Internet sites. BCNs in Australia may already do this; however, as limited research exists about the BCN role, this is not known.

Previous research suggests increasing health literacy, and access to good targeted information can improve patient compliance and satisfaction with treatment options. Prolific use of the Internet to access health information is irreversible, and therefore, there is a high need for further research to investigate the characteristics of reputable and informative breast cancer Internet sites and inform policymakers about the potential regulation of such Internet sites.

The study found that patients value the information and support they receive from their BCN. Perhaps, BCNs could be further utilized to improve patient education and care through the use of e-health solutions. The use of such initiatives has the potential to not only...
improve health outcomes for patients, but save time and resources for health professionals and patients alike. Therefore, further research is recommended to investigate interventions whereby additional BCNs could be employed to specialize in offering e-health solutions enabling the delivery of health services to all women with breast cancer, but particularly those in rural and medically underserved populations on a more regular basis, for example video-linked appointments. Such services enable health-care providers to educate their patients within the confines and time constraints of today’s medical system, and these targeted services may also address the levels of low satisfaction experienced by women in outer regional, remote and very remote Australia.

Strengths and limitations

A particular strength of this study was that comparisons of the demographic data with Australian Bureau of Statistics demographic data indicated that in terms of numbers, the sample was representative of women living in metropolitan, regional and rural and remote areas. Furthermore, the sample size was adequate to provide ample data about the information and support needs of women in each of the geographical areas and perform comparisons between the different geographical areas.

There are a number of limitations of this study. First, we did not know exactly where women were in the participant treatment trajectory and therefore could not report on differences experienced due to time since diagnosis. Second, participants in this study belonged to one of two national databases of women diagnosed with cancer, and participants self-selected their involvement in the study. Using a convenience sample such as this meant, it was not possible to clearly identify the population from which the sample was derived. Third, it is also recognized that using online recruiting methods may potentially exclude those who do not have Internet access. Finally, non-completion of surveys may have been due to respondent burden.

Conclusion

This study has provided quantitative findings about the information and support services that are currently available to and used by women with breast cancer. Importantly, the respondents were a geographically representative sample enabling comparison of those living in metropolitan areas, with those living in inner regional, outer regional, remote and very remote areas. The methods provide a platform which further studies can emulate to attain data based on a national perspective. It is suggested that the findings from this study be used to drive further targeted research to improve information and support services available to women with breast cancer, thereby improving outcomes for the many Australian women diagnosed with cancer each year.

Acknowledgements

Tracey Ahern is supported by an Australian Postgraduate Award Scholarship. University supervisors are Prof Anne Gardner and Prof Mary Courtney.

Conflict of interest

There is no conflict of interest declared.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1: Sample Survey Questions.

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A survey of the breast care nurse role in the provision of information and supportive care to Australian women diagnosed with breast cancer

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Abstract

Aim
To explore the role of the Australian breast care nurse in the provision of information and support to women with breast cancer, with a focus on the differences experienced depending on geographic work context.

Design
A cross-sectional study.

Methods
This study conducted in 2013, involved surveying BCNs currently working in Australia, using a newly developed self-report online survey.

Results
Fifty breast care nurses completed the survey, 40% from major cities, 42% from inner regional Australia and 18% from outer regional, remote and very remote Australia. Patterns of service indicated higher caseloads in urban areas, with fewer kilometres served. Breast care nurses in outer regional, remote and very remote areas were less likely to work in multi-disciplinary teams and more likely to spend longer consulting with patients. Breast care nurses reported they undertook roles matching the competency standards related to the provision of education, information and support; however, there were barriers to fulfilling competencies including knowledge based limitations, time constraints and servicing large geographical areas.

Conclusions
This was the first Australian study to describe the role of the breast care nurse nationally and the first study to investigate breast care nurses perceived ability to meet a selection of the Australian Specialist Breast Nurse Competency Standards. Important differences were found according to the geographical location of breast care nurses.

Introduction
Breast cancer is the second most common cancer in the world and the most frequent cancer among women worldwide (Ferlay et al. 2013). Consistent with worldwide prevalence, breast cancer is the most common cancer amongst Australian women with incidence continuing to increase (Australian Institute of Health and Welfare (AIHW) 2012). Best practice for care of Australians with breast cancer involves health professionals working collaboratively in multidisciplinary teams aiming to meet the multiple health needs of patients (National Breast Cancer...
Centre and National Cancer Control Initiative 2003, National Breast Cancer Centre 2005a,b). As a member of the multidisciplinary team, the specialist breast care nurse (BCN) was introduced in Australia in the mid-1990s to facilitate better continuity of care and psychosocial support (Jones et al. 2010) for people undergoing treatment for breast cancer. Specialist breast care nursing has evolved over the past twenty years not only in Australia, but in Canada, Europe, the UK and the US (Eicher et al. 2012).

In the Australian context, the BCN role involves assisting people with breast cancer across all stages of the continuum of care, including diagnosis, treatment, rehabilitation and palliative care by providing clinical care, information, education, psychological and emotional support, and taking an active role in the co-ordination of care (National Breast Cancer Centre 2005b). Further, the BCN model of practice is defined as a specialist practice, therefore requiring a higher level of knowledge and skill in the care of women with breast cancer (National Breast Cancer Centre 2005b). Usual requirements include experience in oncology nursing and the recommended minimum education such as a Bachelor of Nursing and a Post Graduate Diploma of Breast Care Nursing (Yates et al. 2007). The scope of specialist breast nursing practice is defined as occurring in the context of a model of care that enables the nurse to work collaboratively with patients contributing to patient-centred care, while also working collaboratively within the multi-disciplinary team (National Breast Cancer Centre 2005b).

The consensus view is that BCNs are valued highly by their patients (Eicher et al. 2006, Halkett et al. 2006, Jones et al. 2010, Reed et al. 2010). However, despite advances in healthcare initiatives including the introduction of BCNs, women with breast cancer still have high unmet support needs. Several studies have found that many women do not have adequate information about their disease and treatment, nor receive enough practical and emotional support from health professionals (McGrath et al. 1999, Girgis et al. 2000, Raupach & Hiller 2002, Davis et al. 2004, Vivar & McQueen 2005, Aranda et al. 2006, Lawler et al. 2011). Historically, addressing these needs for rural or remote Australian women has proven more difficult because cancer service capabilities in Australia are restricted by many factors including challenges in attracting and retaining a sufficiently skilled workforce and servicing large geographical areas (National Breast Cancer Centre 2001, Health Workforce Australia 2013). For example, in Australia, the large geographical mass means that a women living in the rural town of Richmond, Queensland, would need to travel 500 km to reach the closest regional hospital offering cancer treatment services. Further, to have their treatment in the closest metropolitan city, they would need to travel 1584 km to Brisbane, Queensland.

**Background**

In Australia, BCNs are either employed by the McGrath Foundation or by public or private healthcare providers. In 2013, at the time of this study, there were no existing statistics on BCNs working in Australia; however, it was estimated that there were around 400, with 84 of these being employed by the McGrath Foundation (McGrath Foundation 2013, Paynter 2013).

Like many nurses who work in advanced practice roles or specialized practice areas, Australian BCNs practice in a variety settings (Yates et al. 2007), with a range of expectations for the role, leading to lack of role clarity (Eicher et al. 2006, Lowe et al. 2011). Previous research shows there is some doubt about whether all Australian women with breast cancer have adequate access to a BCN (Campbell et al. 2006, Eley & Rogers-Clark 2012). Furthermore, there has been debate about the smaller caseload of BCNs in rural and remote areas, suggesting the role of the BCN in these settings is unsustainable (National Breast Cancer Centre and National Cancer Control Initiative 2003).

The research literature about Australian BCNs consists of predominantly exploratory, single site studies conducted primarily in metropolitan areas (Ahern & Gardner 2015) indicating a need for further research to investigate differing BCN roles in varying geographical and practice contexts. This study was designed in response to this finding and, therefore, explores the role of the Australian BCN in providing information and support to women diagnosed with breast cancer, with a particular focus on reporting the differences experienced in varying geographic work contexts. The research questions addressed are:

1. What role differences occur between rural/remote and urban BCNs in Australia?
2. How does the self-report role of an Australian BCN compare with Australian Specialist Breast Care Nurse Competency Standards relating to the provision of education, information and support?

**The study**

An online survey, known as the Breast Care Nurse Survey was developed for this study and issued using a cross-sectional design. Ethical approval was granted by the Australian Catholic University Human Research Ethics Committee (approval number 2013 196N). Participants were BCNs currently working in Australia recruited using snowball sampling. Of the 60 participants who began the survey, 50 completed it, giving a completion rate of 83%.
Consent was indicated by submission of a completed survey and this was explained in the participant information. A literature search revealed no suitable pre-existing survey instrument. Therefore, a new survey instrument was developed, consisting of 59 structured items and allowance for 26 open-ended responses, divided into three sections. Section 1 (13 items) collected demographic information about participants. Section 2 (20 items) collected primarily interval and ratio data about caseloads, consults and multi-disciplinary team involvement. Section 3 (26 structured items with Likert scales and allowance for additional free text) was based on the Specialist Breast Nurse Competency Standards. In this section, the performance criteria for Specialist Breast Nurse Competency Standards 1-1, 1-2, 1-3, 4-1 and 4-2 (see Figure 1) were used as a framework for generating items to explore the breadth of the BCN role in the provision of education, information and support, and the perceived barriers to undertaking each of the performance criteria. Details of development, face validity and reliability of the survey are being prepared for publication separately.

All data were stored electronically in password protected files. Detailed address data were collected to identify the geographic location of each participant; however, names of participants were not collected. Collection of Internet Protocol (IP) address of each participant was a default process of the online survey software. However, steps were taken to ensure that confidentiality and privacy were maintained by first deleting all IP addresses from the database and identifying each record by a unique number. Second, an Australian Bureau of Statistics (ABS) Remoteness Area (RA) code was manually allocated to the physical residential/workplace address of each participant to identify their geographical location (Australian Bureau of Statistics, 2013a). These RA codes were consistent with the latest available information from the ABS and were allocated using an address coding tool on the ABS website (Australian Bureau of Statistics, 2013b). Once the RA code was allocated, all other information relating to place of residence was deleted from the database to protect the identity of participants.

Structured items collected both nominal and ordinal data and were analysed using descriptive statistics with SPSS Statistics software, version 20.0 (IBM Corp 2011). Categories where cell numbers were small were combined. For example, number of years working as a BCN was collapsed from five categories down to three. Thematic analysis was applied to open-ended questions, where responses were used to add richness to the quantitative data.

**Results**

Fifty BCNs completed the survey. Respondents working in major Australian cities comprised 40% \((n = 20)\) of the total sample. Forty-two per cent \((n = 21)\) worked in inner regional Australia, with the remaining 18% \((n = 9)\) working in outer regional, remote or very remote Australia. Respondents worked in a variety of healthcare settings.
Breast care nurse education, experience and qualifications

The majority of respondents had worked fewer than 6 years as a BCN (64%, \( n = 32 \)) and this pattern was consistent regardless of geographic location (Table 1). Forty per cent of respondents were employed full time. Most BCNs employed in major cities worked between 3 and 5 days per week (80%, \( n = 16 \)) in contrast to less than half of those employed in outer regional, remote or very remote areas. Overall, BCNs in outer regional, remote and very remote areas also reported being less highly qualified.

Current patient and consult characteristics

Higher caseloads and higher percentages of patients newly diagnosed with breast cancer were seen in major cities and inner regional areas (Table 2). Results indicate that BCNs in outer regional, remote and very remote areas were more likely to continue to follow patients from diagnosis through to and after completion of adjuvant treatment, than BCNs in major cities. Ninety percent of all BCNs reported seeing patients within one week of diagnosis, with 64% reporting consulting patients at least weekly within the first month of diagnosis. No BCNs reported spending less than 20 minutes each consult with breast cancer patients and BCNs in outer regional, remote and very remote areas were more likely to spend an hour or more consulting with patients.

Consult methods and multi-disciplinary team involvement

Regardless of geographic location, BCNs mostly used face-to-face and telephone consultations, only spending 10% of their working week using electronic consultations. Those working in geographically distant areas report less likelihood of involvement in multidisciplinary teams (MDTs). Overall, the majority of BCNs reported spending up to 30% of their working week in MDT meetings and most of these reported feeling encouraged to share their views in MDT meetings (Table 3).

Perceived ability to undertaking competencies related to provision of information and support

Respondents reported regularly undertaking the performance criteria embedded in competency standards 1-1, 1-2, 1-3, 4-1 and 4-2 (National Breast Cancer Centre 2005b). Analysis of relationships using cross tabulation between responses and years’ experience revealed those with more than 5 years’ experience were more likely to reporting to ‘always’ undertake performance criteria in 22 out of the 26 criteria listed. Relationships between responses and level of education revealed those with post-graduate education were more likely to report ‘always’ undertaking performance criteria in 19 out of the 26 criteria listed. Notably, much lower percentages of BCNs perceived an ability to ‘always’ undertake performance criteria 1-1c, than was reported in any of the other performance criteria listed and these percentages were equivalent regardless of levels of experience and education.

**Figure 2.** Kilometres served by Australian BCNs working in different geographical areas.
Barriers to undertaking competencies related to provision of information and support

Free text information revealed the most common barriers to undertaking performance criteria were large patient loads, limited time constraints and knowledge base limitations. In the supportive care domain, BCNs working in rural or remote centres reported limited resources and limited access to other healthcare workers and identified geographical distances to main treatment centres as barriers to fulfilling competencies. The existence of ethnic and cultural barriers was also acknowledged, especially by those working in remote and very remote settings.

In the domain of information provision and education, a number of BCNs reported lack of private spaces to address matters needing discretion. Some reported they lacked experience, knowledge, skills and confidence dealing with sensitive matters, but many explained they were increasing their skill and knowledge base through education. Those in geographically isolated areas reported that although ongoing education was available, access was difficult due to factors such as distance, cost and time away from work. Free text responses also revealed the difficulties experienced accessing the MDT due to geographical distance. Additionally, some BCNs reported MDT meetings were held infrequently, leading to barriers in provision of timely advice.

Discussion

Current evidence about the role of the Australian BCN providing information in support to women with breast cancer is lacking (Ahern & Gardner 2015). This study provides insights into the role of the Australian breast care nurse particularly in the context of different geographical locations.

A comparison of BCNs based on geographical location

As the majority of respondents had less than 6 years’ experience in their position, assessing the educational needs of this group and providing additional educational support may be required. Access to additional education through continued professional development (CPD) is an important factor regardless of geographical location and ensures that nursing practice is evidence-based, maintains best-practice standards and meets the current needs of communities (Black & Farmer 2013).

Although the ratios of full-time to part-time BCNs were consistent across the three geographical areas, there were major differences in total working hours. Perhaps,
like many other rural nursing roles, BCNs working in outer regional, remote and very remote areas may be predominantly part-time in this role and combine the BCN role with other nursing roles, increasing role diversity (Francis & Mills 2011).

The higher caseloads experienced by those working in major cities and inner regional areas may contribute to reduced regularity and duration of consult time. These results support findings of Jones et al. (2010) who noted BCNs in metropolitan areas had a wider range of responsibilities, higher caseloads with the potential for more limited care being provided to patients.

Findings related to length of consultations and regularity with which BCNs see their patients throughout the cancer trajectory suggest that women in outer regional, remote and very remote areas may have higher levels of access to their BCNs and therefore more time and opportunity to receive information and support from their BCN. This reinforces the findings from a previous study that found a statistically significantly higher percentage of women in outer regional, remote and very remote areas reported using the BCN for support than women in major cities and inner regional areas (Ahern et al. 2014). An increase in the number of BCNs available to meet the needs of women in major cities and inner regional areas would decrease caseloads, enabling BCNs in these areas to increase regularity and duration of consultations, potentially improving the levels of BCN support experienced by these women.

Limited use of electronic consultations were surprising considering that Internet-based telemedicine is readily available and regularly used by many health professionals (Fatehi et al. 2014). Increased uptake of the telemedicine model would provide advantages for BCNs and patients.
alike saving BCN travel time, while allowing patients the convenience of consulting from the privacy of their own home (Sabesan & Piliouras 2009).

**BCN perceived ability to undertake competencies consistent with their role**

Perceptions of BCNs with more experience and/or higher qualifications associated with higher levels of ability to undertake competencies related to the provision of information and support reinforce once again the benefit of continued professional development, training or education relevant to BCN roles. Importantly, BCN perceptions highlighted a specific area of need to enable them to more confidently meet performance criteria 1-1c. This performance criterion indicates that BCNs are required to routinely assess all clients for psychosocial risk factors and distress at the time of diagnosis and on a regular basis using a systematic evidence-based approach (National Breast Cancer Centre 2005b). Therefore, BCNs may need further education and access to appropriate evidence-based screening tools to assist them to become more confident and competent in addressing psychosocial and psychological needs of patients.

Online courses are one way of delivering CPD to rural and remote nurses through organizations such as CRANAplus and EdCaN (Australian Government 2010, CRANAplus Incorporated 2014). Each offer web-based learning resources useful to rural nurses and within cancer control, but more specific resources for BCNs could be developed. However, through an open forum discussion at a national cancer nurses conference, the point was made that often BCNs fail to take up online education that is offered (Ahern 2014), although the reason behind the lack of uptake are unknown.

Reported barriers to undertaking the selected competencies included a lack of culturally appropriate resources available to meet the multiple care needs of women with breast cancer. While there are now resources available through the Breast Cancer Network Australia and Cancer Australia, at the time this study was conducted these resources may not have been readily available (Cancer Australia 2012, Breast Cancer Network Australia 2013).

**Policy and research implications**

Continued professional development (CPD), training and support are recommended for all BCNs (Yates 2015).
et al. 2007). It is well documented that continued professional development and education of nurses in the rural setting is difficult due to limited resources (Fahey & Monoghan 2005, McCoy 2009, Health Workforce Australia 2013); however, these are critical elements supporting the role and professional practice of BCNs (Francis & Mills 2011, Black & Farmer 2013). Therefore, individual BCNs should commit to CPD offered and employers need to support and fund nurses to undertake CPD through post-graduate study and clinical learning opportunities (Black & Farmer 2013). Ongoing assessment of gaps in the education and training provided to BCNs is recommended for educating bodies, and additionally, the reasons for failure to take up online CPD is an area worthy of further investigation.

The lack of access to and participation for BCNs in outer regional, remote and very remote areas compared with their peers in major cities and inner regional areas is consistent with a recent study evaluating the McGrath BCN service which found 47% of rural BCNs participated in MDT meetings (Paynter et al. 2013). Multidisciplinary care benefits both clinicians and patients and it is well recognized that cancer care is most effectively delivered by MDTs (Catt et al. 2005, National Breast Cancer Centre 2005a, Health Workforce Australia 2013). The BCN is positioned between cancer specialists and patients enabling the nurse to advocate for patients and assist in their medical management (Amir et al. 2004), thus the importance of BCN involvement in MDT meetings conducted by the cancer treatment team. Diverse geographical locations make it difficult for face-to-face MDT meetings. However, Internet and videoconferencing software can be used not only for outpatient consultations, but also case discussions between health professionals (Doolittle & Spaulding 2006, Sabesan et al. 2012). Therefore, it is recommended that clinicians seek opportunities to use videoconferencing technologies enabling inclusion of BCNs from all geographical areas in regular MDT meetings. Current availability of and use of videoconferencing technologies by MDTs is an area in need of more research.

**Strengths and limitations**

Importantly, this is the first study to describe the Australian BCN role nationally and to investigate BCNs’ perceived ability to meet the Specialist Breast Nurse Competency Standards relating to the provision of education, information and support (National Breast Cancer Centre 2005b). Limitations include using a newly developed self-report survey tool and a small convenience sample. Further validation of the instrument would be beneficial before it is used in other contexts.

**Conclusion**

This study reports the differences in characteristics and practice of BCNs working in urban areas and those working in regional, rural and remote areas. Findings suggest BCNs in outer regional, remote and very remote areas require improved support through better access to continued professional development and training, and better inclusion in MDT meetings. Innovative use of web-based resources such as online training and videoconferencing should be investigated and used to achieve improved access to CPD and MDTs for BCNs working in outer regional, remote and very remote areas. For BCNs working in major cities and inner regional areas, an increase in numbers of employed BCNs may decrease caseloads and increase patient contact time. All recommendations have the capacity to improve the professional practice of Australian BCNs and outcomes for women with breast cancer.

**Acknowledgements**

University supervisors are Prof Anne Gardner and Prof Mary Courtney.

**Conflict of interest**

There are no conflicts of interest declared.

**Author contributions**

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (http://www.icmje.org/recommendations/)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

**References**


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National Breast Cancer Centre (2005a) Multidisciplinary Meetings for Cancer Care: A Guide for Health Service Providers. NBCC, Camperdown, NSW.
Appendix C  Study One: Ethics Approval and Participant Information

A) Evidence of human research ethics approval:

From: Jo Mushin <Jo.Mushin@acu.edu.au>
Sent: Wednesday, 10 April 2013 1:33 PM
To: Anne Gardner; Tracey Ann Ahern
Subject: Ethics Approval 2012 321N

Dear Anne and Tracey,

Principal Investigator: Prof Pamela Anne Gardner
Student Researcher: Tracey Ahern
Ethics Register Number: 2012 321N
Project Title: Information and support needs of women following primary treatment of breast cancer: a 10 year replication study.
Risk Level: Low Risk 2
Date Approved: 10/04/2013
Ethics Clearance End Date: 31/12/2013

This email is to advise that your application has been reviewed by the Australian Catholic University's Human Research Ethics Committee and confirmed as meeting the requirements of the National Statement on Ethical Conduct in Human Research.

This project has been awarded ethical clearance until 31/12/2013. In order to comply with the National Statement on Ethical Conduct in Human Research, progress reports are to be submitted on an annual basis. If an extension of time is required researchers must submit a progress report.

Whilst the data collection of your project has received ethical clearance, the decision and authority to commence may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance or permissions from other organisations to access staff. Therefore the proposed data collection should not commence until you have satisfied these requirements.

If you require a formal approval certificate, please respond via reply email and one will be issued.

Decisions related to low risk ethical review are subject to ratification at the next available Committee meeting. You will only be contacted again in relation to this matter if the Committee raises any additional questions or concerns.

Researchers who fail to submit an appropriate progress report may have their ethical clearance revoked and/or the ethical clearances of other projects suspended. When your project has been completed please complete and submit a progress/final report form and advise us by email at your earliest convenience. The information researchers provide on the security of records, compliance with approval consent procedures and documentation and responses to special conditions is reported to the
NHMRC on an annual basis. In accordance with NHMRC the ACU HREC may undertake annual audits of any projects considered to be of more than low risk.

It is the Principal Investigators / Supervisors responsibility to ensure that:

1. All serious and unexpected adverse events should be reported to the HREC with 72 hours.
2. Any changes to the protocol must be approved by the HREC by submitting a Modification Form prior to the research commencing or continuing.
3. All research participants are to be provided with a Participant Information Letter and consent form, unless otherwise agreed by the Committee.

For progress and/or final reports, please complete and submit a Progress / Final Report form:
www.acu.edu.au/465013

For modifications to your project, please complete and submit a Modification form:
www.acu.edu.au/465013

Researchers must immediately report to HREC any matter that might affect the ethical acceptability of the protocol eg: changes to protocols or unforeseen circumstances or adverse effects on participants.

Please do not hesitate to contact the office if you have any queries.

Kind regards,
Jo Mushin

Ethics Officer | Research Services
Office of the Deputy Vice Chancellor (Research) Australian Catholic University

THIS IS AN AUTOMATICALLY GENERATED RESEARCHMASTER EMAIL
Dear Participant,

You are invited to participate in the research project described below.

**What is the project about?**
This study aims to examine the use of and satisfaction with information and support for women after receiving treatment for breast cancer. An important part of this study is to compare the responses of women living in metropolitan areas with women living in rural and remote areas. This will provide important information about the differences that exist based on geographic location.

**Who is undertaking the project?**
This project is being conducted by Tracey Ahern and is one of three studies in a research program for the degree of Doctor of Philosophy at Australian Catholic University under the supervision of Professor Anne Gardner.

**Who can be involved?**
Are you a woman, living in Australia, aged 18 years and over who has been diagnosed with breast cancer and completed treatment between 6 and 30 months ago? If so, we would like you to participate in our study.

**Are there any risks associated with participating in this project?**
By participating in this project, you are asked about your experiences with information and support following a diagnosis of breast cancer. It is possible that answering these questions may upset you. Should you need additional support, you can call one of the free cancer helplines available in Australia such as:

- For general cancer support, you can call the Cancer Council Helpline 13 11 20. This is a free, confidential telephone information and support service run by Cancer Councils in each state and territory.
- For support on breast cancer specific issues, you can call the Cancer Council Helpline (13 11 20) and ask to be put through to the Cancer Council Breast Cancer Support Service.
What will I be asked to do?

- You will be asked to complete an online survey about your experiences with the information and support available to you following the treatment you received when you were first diagnosed with breast cancer.
- The majority of the questions on the survey have been designed so that you can answer quickly, by ticking/clicking a box. There are 140 questions like this. There are also 8 questions which ask you to write your response in the space provided.
- You will be asked for your address so that we can categorize your place of residence in one of 6 geographical categories; a Bureau of Statistics indication of remoteness. Once the classification has been assigned your address will be deleted from the study database.
- The survey is an online survey, but if you would prefer to receive a paper copy of the survey, this can be arranged, by emailing the student researcher and providing your name and address. A stamped addressed envelope for return of the survey will be provided.
- Completion of the survey is taken as indication of your consent to participate in the study.

How much time will the project take?
This study involves completing one survey. This survey takes approximately 20 minutes to complete.

What are the benefits of the research project?
This study will help to collect up-to-date information about the support that is currently available to women following primary treatment of breast cancer. This study may provide important information about the different experiences of women living in cities compared to women living in rural and remote areas. The results of this study may be used to make recommendations about addressing these differences in further research.

Can I withdraw from the study?
Participation in this study is completely voluntary. You are not under any obligation to participate. If you agree to participate, you can withdraw from the study at any time during completion of the survey without adverse consequences. However, you cannot withdraw after you submit your survey, as surveys are non-identifiable.

Will anyone else know the results of the project?
Data will be stored electronically and is protected by password security. Results of the study will be discussed by the student researcher and her supervisors. The results of the study will be published in Australian or international nursing journals.

Will I be able to find out the results of the project?
A short report of the findings will be published on the Register 4 website. Please note that it will take some time to analyse and report the findings so the report may take a year or more to be published.

Who do I contact if I have questions about the project?
You can contact the student researcher, Tracey Ahern by email at ttaher001@myacu.edu.au. You can also contact the student’s supervisor, Anne Gardner by email at anne.gardner@acu.edu.au.
What if I have a complaint or any concerns?
The study has been approved by the Human Research Ethics Committee at Australian Catholic University (register number 2012 321N). If you have any complaints or concerns about the conduct of the project, you may write to the Chair of the Human Research Ethics Committee, care of the Office of the Deputy Vice Chancellor (Research).

Chair, HREC
c/o Office of the Deputy Vice Chancellor (Research)
Australian Catholic University
Melbourne Campus
Locked Bag 4115
FITZROY, VIC, 3065
Ph: 03 9953 3150
Fax: 03 9953 3315
Email: res.ethics@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

I want to participate! How do I sign up?
Go ahead and complete the online survey that follows. If you would prefer to receive a hard copy of the survey, email your name and address to ttaher001@myacu.edu.au and a survey will be posted to you shortly.

Yours sincerely,

Tracey Ahern  Professor Anne Gardner  Professor Mary Courtney
Student Researcher  Principal Supervisor  Co-supervisor
Appendix D  Study Two: Ethics Approval and Participant Information

A) Evidence of human research ethics approval:

From: Jo Mushin <Jo.Mushin@acu.edu.au>
Sent: Monday, 12 August 2013 10:53 AM
To: Anne Gardner; Tracey Ann Ahern
Subject: Ethics Approval 2013 196N

Dear Anne and Tracey,

Principal Investigator: Prof Pamela Gardner
Student Researcher: Tracey Ahern
Ethics Register Number: 2013 196N
Project Title: The role of the breast care nurse in supporting Australian women with breast cancer: The breast care nurse perspective
Risk Level: Negligible Risk
Date Approved: 12/08/2013
Ethics Clearance End Date: 31/12/2013

This email is to advise that your application has been reviewed by the Australian Catholic University's Human Research Ethics Committee and confirmed as meeting the requirements of the National Statement on Ethical Conduct in Human Research.

This project has been awarded ethical clearance until 31/12/2013. In order to comply with the National Statement on Ethical Conduct in Human Research, progress reports are to be submitted on an annual basis. If an extension of time is required researchers must submit a progress report.

Whilst the data collection of your project has received ethical clearance, the decision and authority to commence may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance or permissions from other organisations to access staff. Therefore the proposed data collection should not commence until you have satisfied these requirements.

If you require a formal approval certificate, please respond via reply email and one will be issued.

Decisions related to low risk ethical review are subject to ratification at the next available Committee meeting. You will only be contacted again in relation to this matter if the Committee raises any additional questions or concerns.

Researchers who fail to submit an appropriate progress report may have their ethical clearance revoked and/or the ethical clearances of other projects suspended. When your project has been completed please complete and submit a progress/final report form and advise us by email at your earliest convenience. The information researchers provide on the security of records, compliance with approval consent procedures and documentation and responses to special conditions is reported to the
NHMRC on an annual basis. In accordance with NHMRC the ACU HREC may undertake annual audits of any projects considered to be of more than low risk.

It is the Principal Investigators / Supervisors responsibility to ensure that:

1. All serious and unexpected adverse events should be reported to the HREC with 72 hours.
2. Any changes to the protocol must be approved by the HREC by submitting a Modification Form prior to the research commencing or continuing.
3. All research participants are to be provided with a Participant Information Letter and consent form, unless otherwise agreed by the Committee.

For progress and/or final reports, please complete and submit a Progress / Final Report form: www.acu.edu.au/465013. For modifications to your project, please complete and submit a Modification form: www.acu.edu.au/465013.

Researchers must immediately report to HREC any matter that might affect the ethical acceptability of the protocol eg: changes to protocols or unforeseen circumstances or adverse effects on participants.

Please do not hesitate to contact the office if you have any queries.

Kind regards,
Jo Mushin

Ethics Officer | Research Services
Office of the Deputy Vice Chancellor (Research) Australian Catholic University

THIS IS AN AUTOMATICALLY GENERATED RESEARCHMASTER EMAIL
B) Participant Information Letter

PARTICIPANT INFORMATION LETTER

PROJECT TITLE: The role of the breast care nurse in the provision of information and support to Australian women with breast cancer: The breast care nurse perspective.
PRINCIPAL INVESTIGATOR: Prof Anne Gardner
STUDENT RESEARCHER: Tracey Ahern
STUDENT’S DEGREE: PhD

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?
This study aims to explore the perspective of the Breast Care Nurse (BCN) to gain an insight into the role that the BCN plays in providing information and support to Australian women with breast cancer. An important aspect of this study is to explore the differing demands of the BCN role according to geographic locations and practice contexts.

Who is undertaking the project?
This project is being conducted by Tracey Ahern and is one of three studies in a research program for the degree of Doctor of Philosophy at Australian Catholic University under the supervision of Professor Anne Gardner.

Who can be involved?
Are you a breast care nurse currently working in Australia? If so, we would like you to participate in our study.

Are there any risks associated with participating in this project?
It is not anticipated that there are any risks associated in being involved in this study.

What will I be asked to do?
- The first step will involve you sending an email to the student researcher, Tracey Ahern (taher001@myacu.edu.au) to express an interest in being involved in this study.
- You will then be sent a reply email which includes a link to an online survey.
- Once you click the link, you will be directed to take the online survey.
- Completion of the survey is taken as indication of your consent to participate in the study.
- Please note that on the survey, you will be asked for the address of your place of work so that we can categorise your place of work in one of 6 geographical categories; a Bureau of
Statistics indication of remoteness. Once the classification has been assigned your work address will be deleted from the study database in order maintain confidentiality and privacy.

**How much time will the project take?**
This study involves you completing one survey. This survey takes approximately 30-45 minutes to complete. The majority of the questions on the survey have been designed so that you can answer quickly, by ticking a box. There are also some short answer questions to answer. We would ask that you complete the survey within two weeks of receiving the survey link. The data will take some time to analyse and results will not be available until 2014 at the earliest.

**What are the benefits of the research project?**
The results of this survey will help to collect up-to-date information about the role of the breast care nurse. Clearer definitions of the role of the breast care nurse will help to inform policy and further research. Important comparisons between BCNs working in urban areas and rural or remote areas will be conducted. The results of this study may be used to make recommendations about addressing these differences in further research.

**Can I withdraw from the study?**
Participation in this study is completely voluntary. You are not under any obligation to participate. If you agree to participate, you can withdraw from the study at any time during completion of the survey without adverse consequences. However, you cannot withdraw after you submit your survey, as surveys cannot be traced back to individuals.

**Will anyone else know the results of the project?**
Data will be stored electronically and is protected by password security. Results of the study will be discussed by the student researcher and her supervisors. The results of the study will be published in Australian or international nursing journals in a non-identifiably format.

**Will I be able to find out the results of the project?**
The researcher will aim to report the results of the project at a National Breast Care Nurses Conference. Please note that it will take some time to analyse and report the findings so results may not be ready to report for a year or more.

**Who do I contact if I have questions about the project?**
You can contact the student researcher, Tracey Ahern by email at ttaher001@myacu.edu.au. You can also contact the student’s principal supervisor, Anne Gardner by email at anne.gardner@acu.edu.au.

**What if I have a complaint or any concerns?**
The study has been approved by the Human Research Ethics Committee at Australian Catholic University (register number 2013 196N). If you have any complaints or concerns about the conduct of the project, you may write to the Chair of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Chair, HREC
c/o Office of the Deputy Vice Chancellor (Research)
Australian Catholic University
Melbourne Campus
Locked Bag 4115
FITZROY, VIC, 3065
Ph: 03 9953 3150
Fax: 03 9953 3315
Email: res.ethics@acu.edu.au

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Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

**I want to participate! How do I sign up?**
Continue to take the survey that follows this letter. Thank you very much for your support of this very worthwhile study.

Yours sincerely,

Tracey Ahern  
Student Researcher  

Professor Anne Gardner  
Principal Supervisor  

Professor Mary Courtney  
Co-supervisor
Appendix E  Study Three: Ethics Approval and Participant Information

A) Evidence of human research ethics approval:
From: Kylie Pashley <Kylie.Pashley@acu.edu.au> on behalf of Res Ethics <Res.Ethics@acu.edu.au>
Sent: Tuesday, 1 April 2014 10:18 AM
To: Anne Gardner; Tracey Ann Ahern
Cc: Res Ethics
Subject: 2014 61N Ethics application approved!

Dear Applicant,

Principal Investigator: Prof Pamela Gardner
Student Researcher: Ms Tracey Ahern
Ethics Register Number: 2014 61N Project
Title: Unmet needs and self-efficacy in women diagnosed with breast cancer with and without the care of a breast care nurse
Risk Level: Low Risk 3
Date Approved: 01/04/2014
Ethics Clearance End Date: 31/12/2014

This email is to advise that your application has been reviewed by the Australian Catholic University's Human Research Ethics Committee and confirmed as meeting the requirements of the National Statement on Ethical Conduct in Human Research.

This project has been awarded ethical clearance until 31/12/2014. In order to comply with the National Statement on Ethical Conduct in Human Research, progress reports are to be submitted on an annual basis. If an extension of time is required researchers must submit a progress report.

Whilst the data collection of your project has received ethical clearance, the decision and authority to commence may be dependent on factors beyond the remit of the ethics review process. The Chief Investigator is responsible for ensuring that appropriate permission letters are obtained, if relevant, and a copy forwarded to ACU HREC before any data collection can occur at the specified organisation. Failure to provide permission letters to ACU HREC before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.

If you require a formal approval certificate, please respond via reply email and one will be issued.

Decisions related to low risk ethical review are subject to ratification at the next available Committee meeting. You will only be contacted again in relation to this matter if the Committee raises any additional questions or concerns.

Researchers who fail to submit an appropriate progress report may have their ethical clearance revoked and/or the ethical clearances of other projects suspended. When your project has been completed please complete and submit a progress/final report.
form and advise us by email at your earliest convenience. The information researchers provide on the security of records, compliance with approval consent procedures and documentation and responses to special conditions is reported to the NHMRC on an annual basis. In accordance with NHMRC the ACU HREC may undertake annual audits of any projects considered to be of more than low risk.

It is the Principal Investigators / Supervisors responsibility to ensure that:

1. All serious and unexpected adverse events should be reported to the HREC with 72 hours.
2. Any changes to the protocol must be approved by the HREC by submitting a Modification Form prior to the research commencing or continuing.
3. All research participants are to be provided with a Participant Information Letter and consent form, unless otherwise agreed by the Committee.

For progress and/or final reports, please complete and submit a Progress / Final Report form:  

For modifications to your project, please complete and submit a Modification form:  

Researchers must immediately report to HREC any matter that might affect the ethical acceptability of the protocol eg: changes to protocols or unforeseen circumstances or adverse effects on participants.

Please do not hesitate to contact the office if you have any queries.

Kind regards,
Kylie Pashley
on behalf of ACU HREC Chair, Dr Nadia Crittenden

Ethics Officer | Research Services
Office of the Deputy Vice Chancellor (Research) Australian Catholic University

THIS IS AN AUTOMATICALLY GENERATED RESEARCHMASTER EMAIL
B) Participant Information Letter

PARTICIPANT INFORMATION LETTER (Register4)

PROJECT TITLE: An examination of unmet needs and self-efficacy in women diagnosed with breast cancer under the care of a breast care nurse.
PRINCIPAL INVESTIGATOR: Prof Anne Gardner
STUDENT RESEARCHER: Tracey Ahern
STUDENT’S DEGREE: PhD

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?
This study will compare the unmet needs and perceived self-efficacy of women who have access to a breast care nurse (BCN) to women who do not have access to a BCN. An important part of this study is to compare the responses of women living in urban areas with women living in rural and remote areas. This will provide important information about the differences that exist based on geographic location.

Who is undertaking the project?
This project is being conducted by Tracey Ahern and is the final study of three studies in a research program for the degree of Doctor of Philosophy at Australian Catholic University under the supervision of Professor Anne Gardner.

Who can be involved?
Are you a woman, living in Australia, aged 18 years and over who has been diagnosed with breast cancer and completed treatment between 6 months and 5 years ago? If so, we would like you to participate in our study.

Are there any risks associated with participating in this project?
By participating in this project, you are asked about your experiences with information and support following a diagnosis of breast cancer. It is possible that answering these questions may upset you. Should you need additional support, you can call one of the free cancer helplines available in Australia such as:

- For general cancer support, you can call the Cancer Council Helpline 13 11 20. This is a free, confidential telephone information and support service run by Cancer Councils in each state and territory.
- For support on breast cancer specific issues, you can call the Cancer Council Breast Cancer Support Service 13 11 20 and ask to be put through to the Cancer Council Breast Cancer Support Service.
What will I be asked to do?

- You will be asked to complete an online survey about your experiences with the information and support available to you following the treatment you received when you were first diagnosed with breast cancer.
- The majority of the questions on the survey have been designed so that you can answer quickly, by ticking/clicking a box.
- You will be asked for your address so that we can categorize your place of residence in one of 5 geographical categories; a Bureau of Statistics indication of remoteness. Once the classification has been assigned your address will be deleted from the study database.
- The survey is an online survey, but if you would prefer to receive a paper copy of the survey, this can be arranged, by emailing the student researcher and providing your name and address. A stamped addressed envelope for return of the survey will be provided.
- Completion of the survey is taken as indication of your consent to participate in the study.

How much time will the project take?
This study involves completing one survey. This survey takes approximately 20-30 minutes to complete.

What are the benefits of the research project?
This study has the potential to improve health outcomes for patients diagnosed with breast cancer through a better understanding of the unmet needs and self-efficacy of women diagnosed with breast cancer. Overall, the information collected in this study will lead to recommendations for the improvement of services to people diagnosed with breast cancer.

Can I withdraw from the study?
Participation in this study is completely voluntary. You are not under any obligation to participate. If you agree to participate, you can withdraw from the study at any time during completion of the survey without adverse consequences. However, you cannot withdraw after you submit your survey, as completed surveys are non-identifiable.

Will anyone else know the results of the project?
Data will be stored electronically and is protected by password security. Results of the study will be discussed by the student researcher and her supervisors. The results of the study will be published in Australian or international health care journals.

Will I be able to find out the results of the project?
A short report of the findings will be published on the Register 4 website. Please note that it will take some time to analyse and report the findings so the report may take a year or more to be published.

Who do I contact if I have questions about the project?
You can contact the student researcher, Tracey Ahern by email at ttaher001@myacu.edu.au. You can also contact the student’s supervisor, Anne Gardner by email at anne.gardner@acu.edu.au.

What if I have a complaint or any concerns?
The study has been reviewed by the Human Research Ethics Committee at Australian Catholic University (register number 2014 61N). If you have any complaints or concerns about the conduct of the project, you may write to the Chair of the Human Research Ethics Committee, care of the Office of the Deputy Vice Chancellor (Research).
Manager
c/o Office of the Deputy Vice Chancellor (Research)
Australian Catholic University
North Sydney Campus
PO Box 968
NORTH SYDNEY  NSW  2059
Ph: 02 97392519
Fax: 02 97392870
Email: res.ethics@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of
the outcome.

_I want to participate! How do I sign up?_
Go ahead and complete the online survey that follows. If you would prefer to receive a hard copy of
the survey, email your name and address to ttaher001@myacu.edu.au and a survey will be posted to
you shortly.

Yours sincerely,

Tracey Ahern  Professor Anne Gardner  Professor Mary Courtney
Student Researcher  Principal Supervisor  Co-supervisor
Appendix F  Professional Navigation Framework

Table 3. Professional Navigation Framework

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Process and Function</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dimension: Facilitating continuity of care (experience of care as coherent and connected) Organizational functions of the role (Dimension health system-oriented)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information continuity</td>
<td>Use of information, disease- or person-focused, to make current care appropriate for each individual. Information is relevant to link care from one provider to another and from one healthcare event to another (Haggerty et al., 2003).</td>
<td>Having access to, and understanding, a high level of information on the patients with cancer and their care. Providing timely and tailored information and advice to the interdisciplinary team(s) and patients with cancer (patient-centered information). Working closely with the interdisciplinary team(s) to improve continuity of the information and knowledge of family and patients’ needs and changes. Using communication tools and strategies to increase continuity of information.</td>
</tr>
<tr>
<td>Management continuity</td>
<td>A consistent and coherent approach to the management of cancer that is responsive to a patient’s changing needs. Providing a sense of predictability and security in future care for both patients and providers (Haggerty et al., 2003).</td>
<td>Conducting comprehensive screening and needs and resources assessment (initial and ongoing). Matching unmet needs with services, resources available, and support systems within the cancer-care organization and the community. Identifying lack of resources, finding temporary solutions, and reporting the system gaps. Mapping continuum of care, explaining treatment and care plans, minimizing uncertainty (patient orientation), and decreasing barriers to cancer care adherence. Referring to and communicating with hospital and community teams. Doing prompt liaison. Facilitating coordination and organization of medical and psychosocial care (using care coordination tools).</td>
</tr>
<tr>
<td>Relational continuity</td>
<td>A therapeutic relationship between a patient and at least one provider, who develops accumulated knowledge of the patient as a person and bridges the past to current and future care (Haggerty et al., 2003).</td>
<td>Initiating and maintaining an ongoing relationship with the patient with cancer. Being easily accessible through the cancer continuum. Mapping on the cancer trajectory how the professional navigator is involved and until when. Being part of an oncology team. Being trusted by health providers and team members.</td>
</tr>
</tbody>
</table>

CASE—cancer—Communication and Attitudinal Self-Efficacy Scale for Cancer; CaSUN—Cancer Survivors Unmet Needs Measure; CHI—Coping With Health Injuries and Problems Scale; CIPS—Cancer Inventory of Problem Situations; COPE—Multidimensional Coping Inventory; CSE—Coping Self-Efficacy Scale; ECC— Experienced Continuity of Care; EORTC-QLQ-SAT32—European Organization for Research and Treatment of Cancer Quality-of-Life Group Cancer Inpatient Satisfaction Questionnaire; FACT—Functional Assessment of Chronic Illness Therapy; HADS—Hospital Anxiety and Depression Scale; heiQ—Health Education Impact Questionnaire; IRLS—Inventory of Recent Life Experiences for Cancer Patients; MOS—Social Support Survey; PCAT—Primary Care Assessment Tool; PCCQ—Patient Continuity of Care Questionnaire; PES—Patient Empowerment Scale; POMS—Profile of Mood States; PSSCAN—Psychosocial Screen for Cancer; SCONS—Supportive Care Needs Survey; SDS—Symptom Distress Scale; SECON—Sequential Continuity Index; SUNS—Survivors
### Table 3. Professional Navigation Framework (Continued)

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Process and Function</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dimension: Promoting patient and family empowerment</strong> (care providers as supportive partners in care) Clinical functions of the role (Dimension patient-centered) <strong>Active coping</strong> Process of taking active steps to try to remove or circumvent the stressor or to ameliorate its effects (Carver et al., 1989).</td>
<td><strong>Active coping</strong> Process of taking active steps to try to remove or circumvent the stressor or to ameliorate its effects (Carver et al., 1989).</td>
<td><strong>Active coping</strong> Process of taking active steps to try to remove or circumvent the stressor or to ameliorate its effects (Carver et al., 1989).</td>
</tr>
<tr>
<td><strong>Cancer self-management</strong> Supporting the person and family and reinforcing his or her ability to accept the illness and regain control, regardless of prognosis (Bulsara et al., 2006).</td>
<td><strong>Cancer self-management</strong> Supporting the person and family and reinforcing his or her ability to accept the illness and regain control, regardless of prognosis (Bulsara et al., 2006).</td>
<td><strong>Cancer self-management</strong> Supporting the person and family and reinforcing his or her ability to accept the illness and regain control, regardless of prognosis (Bulsara et al., 2006).</td>
</tr>
<tr>
<td><strong>Supportive care</strong> Providing the necessary services as defined by those living with or affected by cancer to meet their physical, informational, practical, emotional, psychological, social, and spiritual needs (Fitch, 2008).</td>
<td><strong>Supportive care</strong> Providing the necessary services as defined by those living with or affected by cancer to meet their physical, informational, practical, emotional, psychological, social, and spiritual needs (Fitch, 2008).</td>
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</tr>
</tbody>
</table>

CASE-cancer—Communication and Attitudinal Self-Efficacy Scale for Cancer; CaSUN—Cancer Survivors Unmet Needs Measure; CHIP—Coping With Health Injuries and Problems Scale; CPS—Cancer Inventory of Problem Situations; COPE—Multidimensional Coping Inventory; CSE—Coping Self-Efficacy Scale; ECC—Experienced Continuity of Care; EORTC QLQ-C30—European Organisa—tion for Research and Treatment of Cancer Quality-of-Life Group Cancer Inpatient Satisfaction Questionnaire; FACIT—Functional Ass- sessment of Chronic Illness Therapy; HADS—Hospital Anxiety and Depression Scale; heIQ—Health Education Impact Questionnaire; IRL-C—Inventory of Recent Life Experiences for Cancer Patients; MOS—Social Support Survey; PCAT—Primary Care Assessment Tool; PCQ—Patient Continuity of Care Questionnaire; PES—Patient Empowerment Scale; POMS—Profile of Mood States; PSSCAN—Psy—chosocial Screen for Cancer; SCNS—Supportive Care Needs Survey; SDS—Symptom Distress Scale; SECON—Sequential Continuity Index

Appendix G  Breast Cancer Organisations in Australia

Source: Breast Cancer Network Australia (Breast Cancer Network Australia, 2010).
Appendix H  Breast Care Nurse Survey

Please Note: This survey was presented to participants in an online format and not in the format that follows. The information presented below demonstrates the items on the survey only and does not include participant information or participant guidelines.

Section 1: Your education, experience and qualifications

Are you currently employed as a Breast Care Nurse?

- ☐ Yes
- ☐ No

How many years have you been working in this position as a Breast Care Nurse?

- ☐ Less than 1 year
- ☐ 1-2 years
- ☐ 3-5 years
- ☐ 6-10 years
- ☐ 11 or more years

On what basis are you employed?

- ☐ Full time
- ☐ Part time

What percentage of your work week is spent as a Breast Care Nurse?

- ☐ 0.5 day
- ☐ 1 day
- ☐ 1.5 days
- ☐ 2 days
- ☐ 2.5 days
- ☐ 3 days
- ☐ 3.5 days
- ☐ 4 days
- ☐ 4.5 days
- ☐ 5 days
What is your highest qualification?

☐ Hospital Trained Registered Nurse
☐ Bachelor of Nursing
☐ Graduate Certificate
☐ Graduate Diploma
☐ Master of Nursing
☐ PhD

Do you have a qualification in Breast Care Nursing?

☐ Yes
☐ No

What was the title of the qualification in Breast Care Nursing that you completed?

___________________________________________

**Geographical Classification:** We need to know the physical address of your workplace so we can categorise the location of your workplace into one of 6 geographic categories (a Bureau of Statistics indication of remoteness).

Please note: the postcode alone does not give us enough information to classify the geographic category properly. Once the classification (0-5) has been assigned your, workplace address will be deleted from the study database.

Therefore, the six questions that follow, help to determine the full address of your workplace.

What is your street number at the physical address of your workplace? ________________

What is your street name of the physical address of your workplace? ________________

What is the type of street?

☐ Street
☐ Road
☐ Avenue
☐ Crescent
☐ Drive
☐ Other (Please specify) ________________
What Suburb/Town or City is your workplace located? ____________________

What state/territory is your workplace located?

- [ ] New South Wales
- [ ] Victoria
- [ ] Queensland
- [ ] South Australia
- [ ] Western Australia
- [ ] Tasmania
- [ ] Northern Territory
- [ ] Australian Capital Territory

What is the postcode of the suburb of your workplace? __________

Section 2: Your work context

How would you describe the context in which you work as a Breast Care Nurse? (select all that apply)

- [ ] Public hospital
- [ ] Private hospital
- [ ] Private practice (Specialist)
- [ ] Private practice (General)
- [ ] Community health centre

Are you a McGrath Breast Care Nurse?

- [ ] Yes
- [ ] No

Approximately, what area in square kilometres do you serve?

- [ ] Up to 10 km
- [ ] 11 to 50 km
- [ ] 51 to 100 km
- [ ] 101 to 500 km
- [ ] 501 to 1000 km
- [ ] More than 1000 km
Does your position involve travel to patients in surrounding areas?

- Yes
- No

Approximately how much of your time PER WEEK is spent travelling to see your patients?

- 0-10%
- 11-20%
- 21-30%
- 31-40%
- 41-50%
- 51-60%
- 61-70%
- 71-80%
- 81-90%
- 91-100%

What is your CURRENT patient case-load?

- 0-10 patients
- 11-20 patients
- 21-30 patients
- 31-40 patients
- 41-50 patients
- 50-100 patients
- More than 100 patients

How many MALE patients with breast cancer do you currently see?

- None
- 1-5
- 6-10
- 11-20
- More than 20

Approximately how many NEW breast cancer patients do you see each MONTH?

- None
- 1-5
- 6-10
- 11-20
- 21-30
- 31-40
- More than 40
Do you see patients? (select all that apply)

- At diagnosis
- Pre-operatively
- Post-operatively
- During adjuvant chemotherapy/radiotherapy
- After completion of adjuvant treatment

How soon after a patient is diagnosed with breast cancer do you consult with the patient?

- At diagnosis
- Within one or two days
- Within one week
- More than a week

How regularly do you consult with patients within the FIRST MONTH of diagnosis of breast cancer?

- Never
- Daily
- 2-3 times per week
- Once a week
- Once a fortnight
- Once in the month
- As needed basis

Approximately, what percentage of your breast cancer patients are receiving/have received the following treatments? (NOTE: your answers must total 100%).

- Surgery only
- Surgery and radiotherapy only
- Surgery and chemotherapy only
- Surgery, chemotherapy and radiotherapy only
- Surgery, chemotherapy, radiotherapy and hormone therapy
- Surgery and hormone therapy only
- Palliative care only

Approximately, what percentage of your patient consult time PER WEEK is spent with patients in the following ways? (NOTE: your answers must total 100%)

- In face-to-face contact with your patients
- In telephone consults with your patients
- In electronic communication (Skype, email, videoconferencing) with your patients
In a typical consult with a patient, approximately how much time is allocated to the meeting?

- 10 minutes
- 11-20 minutes
- 21-30 minutes
- up to 1 hour
- more than 1 hour

Are your services available to patients after they have completed active treatment and are in the survivor phase of recovery?

- Yes
- No

Do you discharge patients from your service?

- Yes
- No

At what point in their recovery, do you discharge patients?

______________________________

Do you work in a multi-disciplinary team?

- Yes
- No

Approximately, how much of your time PER WEEK is spent in consultation with a multi-disciplinary team?

- 0-10%
- 11-20%
- 21-30%
- 31-40%
- 41-50%
- 51-60%
- 61-70%
- 71-80%
- 81-90%
- 91-100%
Are you encouraged to share your view in multi-disciplinary teams about patient care?

☐ Yes, always
☐ Yes, but only if I have been working with the patient
☐ No, but I feel free to share my view
☐ No, I would not offer my opinion in a multi-disciplinary team

Keep going! You are over half way through the survey now.
Section 3: Provision of support, information and education

The following questions are based on the Specialist Breast Nurse Competency Standards (National Breast Cancer Centre (NBCC), 2005). Please note, we are interested specifically in the INFORMATION AND SUPPORT you provide to women with breast cancer, therefore, only competency standards relating to the provision of support, information and education have been included in the section of the survey.

Are you aware that competency standards have been developed for Breast Care Nurses?

☐ Yes
☐ No

How useful do you find the competency standards to your practice as a Breast Care Nurse?

☐ Not useful at all
☐ Slightly useful
☐ Moderately useful
☐ Very useful
☐ Extremely useful

When thinking about the information and support that you provide in your role as a BCN:

1. How regularly do you undertake any of the following activities? Please select one response from column 2.

2. Do you perceive there to be any barriers to you being able to fulfil each of these activities? Please explain your answer in column 3 and simply write an 'X' if you perceive there to be no barriers.

<table>
<thead>
<tr>
<th>Performance Criteria</th>
<th>Regularity undertaken? Select one of the following options:</th>
<th>Barriers Perceived</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1a Demonstrate comprehensive and advanced knowledge and appreciation of the experience and impact of breast cancer and its treatment on the physical, psychological, social, sexual and spiritual well-being of clients and their family/significant others</td>
<td>Always</td>
<td>Sometimes</td>
</tr>
<tr>
<td>1.1b Use contemporary standards and guidelines to inform comprehensive and timely assessment of current and potential support needs across the continuum of breast cancer care.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.1c Routinely assess all clients for psychosocial risk factors and distress at the time of diagnosis and on a regular basis using a systematic evidence-based approach.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.1d Communicate effectively with other members of the health team to facilitate efficient, timely and comprehensive assessment and identification of current and potential needs of clients and their family/significant others.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.1e Anticipate and respond to potential risks for clients associated with specific health care interventions and treatments related to management of breast cancer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.2a Use advanced and goal-directed communication skills to establish and maintain therapeutic relationships with clients and the family/significant others throughout the cancer journey.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.2b Actively explore client’s preferences and decisions regarding care and treatment throughout the cancer journey, while ensuring the client has access to appropriate information on which to base decisions</td>
<td></td>
<td></td>
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<td>1.2c Promote client’s ability to participate in care decisions and self-management of health needs, according to assessment of client’s preferences and resources.</td>
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<td>1.2d Collaborate with the client in care planning and implementation to achieve therapeutic goals consistent with client’s needs and decisions.</td>
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<tr>
<td>1.3a Collaborate with clients, their family/significant others, and other nurses and members of the health team, in planning and</td>
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implementing care to meet the multiple health and support needs of clients with breast cancer.

1.3b  Exhibits comprehensive and advanced knowledge of clinical and supportive care guidelines and interventions in the context of breast cancer.

1.3c  Demonstrate advanced skills in the use of therapeutic nursing interventions for meeting physical, psychological, social, sexual and spiritual needs of clients with breast cancer care.

1.3d  Consult and collaborate with other members of the health care team to address needs that are more complex, not within the scope of SBCN practice, or which are not able to be met with available resources.

1.3e  Adapt and prioritise guidelines and interventions according to cultural, spiritual and social contexts and clinical circumstances of individual clients with breast cancer.

1.3f  Continuously evaluate the client’s condition and response to interventions in a timely manner and modify the management plan when necessary to achieve optimal health outcomes for clients with breast cancer.

4.1a  Assess the client’s understanding of their clinical circumstances, treatment and care plan, and preference for information.

4.1b  Use advanced supportive communication skills to provide information about potentially distressing or embarrassing issues sensitively and responsively, according to the client’s individual preferences and responses.

4.1c  Demonstrate comprehensive and advanced knowledge of the pathophysiology and progression of breast cancer, and current evidence regarding breast cancer treatments, and the short and longer term effects of breast cancer and its treatments.

4.1d  Demonstrate comprehensive knowledge of informational resources for breast cancer clients and facilitate access to resources relevant to client needs and preferences.

4.1e  Develop, implement and evaluate a plan for providing comprehensive, individualised and timely information to clients about breast cancer and its treatments and effects, throughout
4.1f Use a range of evidence-based strategies for delivering, tailoring and reinforcing information relevant to client’s informational needs and preferences.

4.1g Collaborate with other members of the health team to ensure a coordinated approach to providing consistent and timely information to clients with breast cancer.

4.1h Support and clarify information provided to the client by other members of the health care team regarding breast cancer and its management.

4.2a Implement evidence-based educational interventions to assist clients and their family/significant others to develop knowledge, skills and confidence to manage health needs and problems associated with breast cancer and its treatments.

4.2b Consult and collaborate with other members of the health team to facilitate a multidisciplinary and coordinated approach to promoting the client’s ability to self-manage health needs and problems associated with breast cancer and its treatments.

4.2c Continuously evaluate the client’s response to educational interventions and modifies educational strategies when necessary, to achieve optimal health outcomes for clients with breast cancer
This is the end of the thesis.