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The role and value of metastatic breast care nurses in Australia

**SUPPORTING WOMEN AND THEIR FAMILIES TO LIVE WELL
WITH METASTATIC BREAST CANCER**

February 2022

Report prepared by Macquarie University in
partnership with the McGrath Foundation


**McGrath
Foundation**

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EXECUTIVE SUMMARY

Introduction

Metastatic breast cancer (mBC) (also known as secondary, advanced or stage IV breast cancer) occurs when the primary breast cancer spreads beyond the breast and lymph nodes to distant sites such as the bones, liver, lungs or brain. Although Australian cancer registries do not routinely collect breast cancer recurrence data, modelling indicates that 9,000-12,000 people are currently living with mBC in Australia.^{1,2}

People diagnosed with mBC require treatment for the rest of their lives. Living with a treatable but incurable cancer such as mBC means that these people, and their families, often experience negative physical, social and emotional health issues, presenting unique challenges for health and supportive care often over many years.³⁻⁶

A 2016 international survey found that emotional support and quality of life improvements were the top two needs reported by patients with mBC beyond basic medical care.⁷ An international consensus workshop in 2019 reported that significant patient knowledge gaps exist relating to the diagnosis and management of mBC, and the availability of patient-focused information to support these gaps in knowledge remains limited.⁸ Furthermore, the authors reported that the development of meaningful relationships between patients and healthcare professionals, and the role of patients in decision making, is often overlooked for people with mBC.

Breast care nursing is an established discipline in breast oncology, providing care predominantly during the diagnostic and early-stage treatment phases.^{9,10} In Australia, relatively few people with mBC have access to a breast care nurse.¹¹ It has been argued that current models of breast cancer care are not designed to manage patients with a potentially prolonged and unpredictable illness trajectory.⁹

In the past 5 years, patient advocates, clinicians and breast cancer organisations (such as the McGrath Foundation and Breast Cancer Network Australia) have recognised the need to extend the role of the breast care nurse to provide care for women diagnosed with mBC. In 2019, the Federal Government allocated funding for 22 mBC nurses, to be administered by the McGrath Foundation. Consequently, a number of hospitals and cancer centres in Australia have been able to employ specialist mBC nurses. However, given the diversity of settings and the inevitable variations in roles and responsibilities, little has been reported about the type and quality of care provided by these mBC nurses, how this care differs from the care provided by traditional breast care nurses, and what women with mBC think about this care.

Project funding

This project was made possible through an Enterprise Partnership Agreement between the Australian Institute of Health Innovation at Macquarie University and The McGrath Foundation.

Project aims

The primary aim of this project was to understand the role and value of the specialised mBC nurse from the perspective of: (1) women diagnosed with mBC; (2) the families of women diagnosed with mBC; and (3) the specialised mBC nurses.

The secondary aim was to understand from the mBC nurses' perspective how the role was established and challenges to the sustainment of the role.

It was anticipated that this study would build the evidence base around the current role and value of the specialised mBC nurse in providing supportive care to women living with mBC and to contribute to the future development of the mBC nursing role in Australia.

Research questions

1. What is the role and value of the mBC nurse?
2. What factors influence the establishment and sustainment of the mBC nurse role?

Methods

Ethics approval for this qualitative study was granted by the Human Research Ethics Committee at Macquarie University (Project ID 7965).

Participants

Eligible participants included people diagnosed with mBC, their family members (>18 years of age), and mBC nurses or breast care nurses who had a significant responsibility for women with mBC.

Recruitment

Women with mBC

Purposive sampling was used to recruit women with mBC who had received support from a breast care nurse. A range of community-based recruitment strategies were used to ensure a diversity of participants. Recruitment aimed to include women with mBC:

- from a range of geographic locations (urban, regional and rural)
- with differences in socio-demographic characteristics (e.g., age, ethnicity, socio-economic status)
- with differing times since mBC diagnosis
- who were receiving different types of treatment and care (e.g., those receiving life-prolonging treatment, those receiving palliative and supportive care only).

Family member of woman with mBC

Women with mBC who agreed to participate in the study could nominate a family member (e.g. partner, parent, sibling) to take part in the study.

mBC nurses

Nurses were recruited through convenience sampling. Recruitment was primarily through The McGrath Foundation network of breast care nurses as McGrath employs the majority of mBC nurses in Australia. Women with mBC who decided to participate in the study could also invite their breast care nurse to take part in the study.

Data collection

In-depth semi-structured interviews were used to collect data from: (a) women with mBC who had received supportive care from a breast care nurse; (b) family members of women with mBC; and (c) mBC nurses. Data collection took place between August and December 2020.

The interviews with women living with mBC (Appendix A) explored experiences of supportive care received from breast care nurses at different points in their disease trajectory, compared the type and value of supportive nursing care received during their diagnosis of early breast cancer (eBC) (if applicable) with the care received during their diagnosis and treatment for mBC, gaps in supportive nursing care and suggestions of how these could be met, and how supportive care extends beyond symptom relief and control of pain to include support around work, finances, childcare and preparation for end of life.

Interviews with family members (Appendix B) explored their experiences of support from a breast care nurse focused on different stages in the disease trajectory, in particular the support received during crises related to treatment failures and disease progression, and how the nurse helped the patient and family members to make decisions about their care.⁵

Interviews with mBC nurses (Appendix C) explored how they provide care and support across multiple domains – physical, psychosocial, spiritual and financial; including support and information about disease progression, treatment options, living with uncertainty, supporting family members and friends, and preparing for end-of-life care.

Data analysis

Interviews were audio recorded, transcribed verbatim, deidentified and coded in QSR NVivo 11 (a qualitative data software package). The data were analysed thematically. This involved repeatedly reading the interview transcripts, coding, and identifying preliminary themes and categories. Coding was performed by MF and AS using the qualitative data analysis program QSR NVivo 11. Analysis focused on identifying commonalities, differences, and patterns of shared meaning across the three data sets (mBC patient, family member and mBC nurse). Members of the project team met regularly to discuss the development and refinement of the themes.

Findings

Twenty-five in-depth, semi-structured interviews were conducted with women with mBC (n=10), family members (i.e., partners and mothers) (n=5) and mBC nurses (n=10) from various states (i.e., ACT, NSW, Vic, Tas, and WA) and settings (i.e., nurses based in public, private and community settings) across Australia.

Research question 1. What is the role and value of the mBC nurse?

This section reports on participants' perspectives of the role and value of the mBC nurse in providing care and support to women with mBC and their family members.

Key facets of the mBC role

Despite the diversity of the mBC nurses' roles and the different settings in which they worked (e.g. public versus private, metropolitan versus regional), the following key elements were identified as integral to the role:

- complex care coordination and navigation within and beyond the healthcare system to ensure patient receives holistic, integrated and patient-centred care
- active identification of patients with mBC (rather than direct referral of patients to the nurse or routine contact with patients during hospital admission for surgery)
- management of a wide-range of disease symptoms and treatment-related side effects
- management and support through critical transitions, such as initial mBC diagnosis and treatment, disease progression and changes in treatment
- psychosocial and practical support for patient and family members
- end-of-life planning and palliative care, including determining goals of care
- education and information about treatments, side-effects and support within and beyond the healthcare system
- patient advocacy, including educating others about the supportive needs of people with mBC.

A distinctive and multidimensional role in breast cancer care

Data on the role of the mBC nurse are reported primarily from the perspective of the mBC nurse. An overarching theme across the mBC nurse dataset was that the mBC nurse has a distinctive and multidimensional role in breast cancer care. Three sub-themes were identified that helped to explain this distinctness: (a) the role is complex and varied rather than ordered and formulaic; (b) the role demands a high-level mix of skills and experience spanning clinical, psychosocial, social care domains; and (c) the role requires extended and often in-depth engagement with patients and family members.

From the nurses' perspective, the need to provide complex, high-level clinical *and* supportive care was what distinguished the role from other roles in cancer care (e.g. patient navigators, care coordinators or social workers). This was in part because mBC is a systemic rather than localised disease requiring a 'whole of body' approach to nursing care. The mBC nurses also reported that the prognostic uncertainty and variability in the mBC disease trajectory meant that patient care was neither standardised nor routine but had to be constantly tailored to meet the specific needs of the individual patient and their families across the different stages of the disease trajectory. Consequently, nurse participants reported that caring for those with mBC required a particular mix of skills. Many nurse

participants reported that they had qualifications in oncology, breast cancer care, palliative care and counselling as well as many years of nursing experience. And finally, the complexity of care and challenging psychosocial issues meant that in-depth, respectful, and highly effective health care relationships often developed between nurses, patients and families. Given the long-term nature of mBC, many of these relationships spanned years rather than months.

Improving the patient and family's experience of cancer care and reducing the impact of an mBC diagnosis

Women with mBC and their family members reported that they placed considerable value on the role of the mBC nurse. An overarching theme across the mBC nurse, patient and family members datasets was that the mBC nurse improves the patient and family's experience of cancer care thereby reducing the impact of an mBC diagnosis. Three sub-themes were identified from participants' experiences of giving and receiving care that helped to explain how the mBC nurse improves the experience of care and creates meaningful, effective relationships: (a) validating the experience of living with mBC; (b) creating a safe place to share fears and concerns thereby easing the emotional burden of living with uncertainty and incurability; (c) simplifying access to and passage through the health, social and community care systems.

From the patients' and family members' perspectives, it was the skillful melding of clinical and supportive care elements, especially psychosocial support, that added significant value to the role of the mBC nurse. This was accomplished through multiple means, including:

- making those with mBC feel seen and heard within a healthcare system in which they often felt invisible, thereby reducing some of the isolation often reported by people with mBC
- providing acknowledgement and validation of the often unrecognised and therefore unmet supportive care needs of those with mBC
- creating an effective healthcare relationship built on trust, respect and confidence in the mBC nurses' skills, knowledge and experience as well as their accessibility and responsiveness
- providing a safe place for the patient to share fears and concerns that they were reluctant or unable to discuss with anyone else, including family, friends and other healthcare professionals such as their oncologist
- bringing clarity to periods of high stress and confusion by improving the patients' and their families' understanding and knowledge of what an mBC diagnosis means, and what treatment and care would look like
- acting as an advocate and care coordinator to ensure that the person with mBC receives the right care at the right time, thereby minimising the care burden for women and their family members
- providing reassurance that they are not alone, and that the mBC nurse would be there for them now and in the future, thereby reducing some of the existential fear and loneliness associated with an mBC diagnosis
- easing the intense emotional burden associated with living with an incurable condition with an uncertain disease trajectory, particularly during the acute or active phase of the disease
- reducing cancer-related financial toxicity by providing practical and logistical advice to help reduce out-of-pocket costs.

Overall, it appeared that the mBC nurse played a critical role in ensuring the patient received holistic, integrated and patient-centred care. From the patient and family members' perspective, the mBC nurse played an invaluable role in improving continuity of care. Consequently, participants reported that the mBC nurse supported them not just to live longer with mBC, but to live as well as possible with mBC.

Potential benefits of the mBC nurse to the healthcare system

The role of the mBC nurse was also identified by participant groups as having potential benefits for the healthcare system through:

- reducing unplanned hospital and emergency department admissions
- reducing the number and length of consultations with clinicians
- facilitating shared care and self-management in the home.

Additionally, the role of the mBC nurse reportedly contributed to improvements in quality of care through:

- facilitating early detection and improved management of symptoms and side-effects
- facilitating earlier access to palliative and supportive care
- improving information flow between health professionals, and across different healthcare settings and community care sectors.

Research question 2. What factors influence the establishment and sustainment of the mBC nurse role?

This section reports the factors that mBC nurses (n=10) believed contributed to the successful establishment and implementation of the mBC nursing role in their setting, as well as factors that might support the long-term sustainability of their role. The mBC nurses' experiences provide insights into factors that may need to be paid attention to if the role is to develop further, within a particular setting and more generally in Australia. Participants' responses were broadly categorised into three thematic areas: (a) establishing the role of the mBC nurse; (b) ensuring the role remains sustainable; (c) supporting the wellbeing of the mBC nurses.

Establishing the role of the mBC nurse

Participants discussed how the role of specialist mBC nurse emerged out of growing awareness of inequities in care experienced by women living with mBC. All nurse participants said that they had played a key role in establishing their role. Yet, the degree to which their role had been integrated into different settings was variable and linked to:

- the support of hospital administrators and other health professionals
- the extent to which the mBC nurse was known to others and familiar with the setting in which they worked
- the availability of data on the number of women living with mBC within their particular hospital setting or catchment area.

Key activities identified as helpful to supporting the establishment of the role included service reviews and service mapping, establishing the patient cohort, and developing strong relationships with clinicians for referral pathways before initiating contact with patients.

Ensuring the role remains sustainable

Nurse participants mentioned concerns relating to the long-term sustainability of the role. These included coping with increasing patient caseloads, redefining the scope of the role, managing

increasing complexities in care coordination, obtaining cover for when the mBC nurse was on leave and developing the future workforce of mBC nurses.

Supporting the wellbeing of the mBC nurses

Nurse participants drew attention to the emotional and stressful nature of mBC nursing, with several expressing concerns about burnout. While acknowledging that the role was on the whole rewarding and satisfying, the length and intensity of involvement with women with mBC and their families resulted in unique personal pressures and stresses, sometimes placing demands on the mBC nurses' own emotional well-being.

Nurse participants reported a variety of strategies that were helpful for managing wellbeing such as job sharing, dual roles, being part of a community of practice, debriefing with colleagues, maintaining boundaries, clinical supervision, and self-care. While many nurse participants used a combination of these personal self-care strategies, they all said that additional forms of support were required, including formally institutionalised support such as clinical supervision.

Summary

In line with the project aims, this study advances our understanding of mBC experiences in the Australian health context, where gaps in supportive care for those with metastatic cancer are known to exist. In particular this study increases our understanding of the contribution the specialised mBC nurse (or an appropriately trained and experienced general breast care nurse) can make to the care received by women with mBC. Those with mBC are a diverse population with significant unmet needs in areas such as symptom and side-effect management, psychosocial support and access to appropriate health services. This knowledge is directly relevant to key end-users such as patients, advocacy organisations, policy makers, hospital administrators and nurse and clinical oncology practitioners in the metastatic and advanced cancer space.

The mBC nurse provided a vital first point of contact for women and their family members at all stages of the illness trajectory, providing an integral and continuous link across clinical, supportive, and palliative care. In addition to complex care coordination and system navigation, the mBC nurse managed a wide range of disease symptoms and treatment side-effects, provided high-level emotional and practical support to patients and family members, and acted as a patient advocate to ensure the patient received the care they needed. Nurses not only played a critical role in reducing the care burden on patients and family members, but they also improved the way in which the patient moved through the system.

Importantly, the mBC nurses were integral to improving the experience of care for women with mBC and their families. Of particular importance to patients and family members was the mBC nurse's support through critical and often highly stressful transitions, such as initial mBC diagnosis, disease progression, changes in treatment, end-of-life planning and palliative care, including determining goals of care. In part this was because the nurse was reportedly one of the few healthcare professionals who fully understood the impact of the diagnosis and the complex, often highly psychosocial, supportive care needs of these patients. A defining characteristic of the role was the quality of the healthcare relationship that developed between the mBC nurse and the person with mBC, a consequence of the length and depth of the nurse's engagement with the patient. Crucially, mBC nurses reportedly helped

patients with mBC to feel cared for and their needs validated in a system that has historically been designed primarily to meet the supportive care needs of those with eBC.⁹

Success in the role reflected the nurses' commitment to those with mBC, their high-level clinical and healthcare system knowledge, their connections to other healthcare professionals within and beyond the hospital setting, and the high levels of respect and recognition with which they were held by other staff within the healthcare system. Critical to this success were the years of accumulated experience as an oncology or breast care nurse combined with in-depth knowledge of other disciplines such as palliative care, psychosocial care and counselling. Given the relative scarcity of appropriate supportive care or survivorship services for those with metastatic or advanced cancer, the role of the mBC nurse was viewed as filling an important supportive care gap in oncology care in Australia today.

Recommendations

1. Given the potential benefits to patients, families and the healthcare system, the specialised metastatic nurse role should be considered as a standardised option in healthcare settings for people with mBC.
2. Many aspects of the metastatic nurse role are likely to be generalisable beyond mBC. The potential applicability of this role to people living long-term with a metastatic or advanced cancer diagnosis should be considered.
3. To optimise scalability and long-term sustainability of the mBC nurse role, the core aspects of the role most valued by people diagnosed and living with mBC need to be clarified. This would allow identification of tasks and responsibilities that could potentially be provided by others such as administrative or healthcare staff (e.g. social workers, counsellors, patient navigators or care coordinators).
4. Part of the mBC nurse role (including the funding model for the mBC nurse positions) should include succession planning and staff development to ensure appropriately trained staff are available to meet current and future demand for these positions.
5. Set-up and establishment of the mBC nurse role requires time to establish effective integration into the healthcare setting. Adequate time should be allowed for the mBC nurse to:
 - a. identify people recently diagnosed and those living with mBC
 - b. establish relationships with the healthcare professionals who will potentially be referring patients to the mBC nurse.
6. For newly established mBC nurse roles and services, education and awareness at the hospital management and executive level are key to establishing and ensuring ongoing support for mBC nurse roles.
7. mBC nurse roles would benefit from formally institutionalised support structures to manage wellbeing and prevent burnout, such as additional clinical supervision.

For full list of recommendations, see page 41

1. INTRODUCTION

1.1 Metastatic breast cancer: incidence and mortality

Metastatic breast cancer (mBC) occurs when the primary breast cancer spreads beyond the breast and lymph nodes to distant sites such as the bones, liver, lungs or brain. In all but a few cases it is incurable.^{12,13} Median survival is now 4–5 years for ER-positive and HER2-positive patients receiving targeted treatments.^{14,15} In Australia, 1 in 15 of those who are diagnosed with breast cancer are diagnosed with stage IV (de novo) mBC as their first diagnosis.¹⁶ Between 25% and 30% of those diagnosed with early (stage I–III) breast cancer (eBC) will eventually experience disease recurrence and develop mBC.^{17,18} In 2018, there were 3,034 deaths from breast cancer in Australia (35 males and 2,999 females), the vast majority from mBC.¹ Although data are not collected in relation to prevalence of mBC in Australia, modelling indicates that approximately 9,000–12,000 people are currently living with a diagnosis of mBC in Australia.²

1.2 Supportive care in cancer

Supportive care in cancer covers care across five inter-related domains: physical, psychological, social, information and spiritual (Box 1).^{19,20} Supportive care includes provision of 'the services, information and resources that may be required to live as well as possible after a diagnosis of cancer. It complements cancer treatment and forms an important part of comprehensive cancer care'.

Box 1 Five inter-related domains of supportive care

1. **Physical domain**, which includes a wide range of physical symptoms that may be acute, relatively short-lived or ongoing, requiring continuing interventions or rehabilitation.
2. **Social domain**, which includes a range of social and practical issues that will impact on the individual and family such as the need for emotional support, maintaining social networks, and financial concerns.
3. **Psychological domain**, which includes a range of issues related to the person's mental health, wellbeing and personal relationships.
4. **Spiritual domain**, which focuses on the person's changing sense of self and challenges to their underlying beliefs and existential concerns.
5. **Information domain**, which transects the above domains with people needing to access information about their disease and treatment, support services and the health system overall.

Fitch, M. Supportive care framework. *Can Oncol Nurs J* 18, 6–14 (2008).

1.3 Supportive care needs in mBC

People diagnosed with mBC require ongoing treatment and care. Care is often complex owing to the wide range of tumour types, treatment options, disease symptoms and treatment side-effects. In addition, living with an incurable condition with an inherently unpredictable disease course can result in high levels of psychological distress. Consequently, those diagnosed with mBC have complex supportive care needs that differ from those diagnosed with eBC.^{5,7,8,21,22} Furthermore, it has been reported that the frequency and severity of many of the symptoms impacting on the quality of life of women living with mBC tend to be under-reported and under-recognised, resulting in symptoms

being undertreated.²³ In 2018, the ABC Global Alliance identified the need for those with mBC to have greater access to multidisciplinary care including palliative, supportive and psychosocial assistance.²⁴

1.4 Breast care nurses

The breast care nurse specialist role was first introduced in the UK in the 1990s and has subsequently been adopted and adapted internationally. Breast care nurse specialists have training and expertise in the management, treatment and follow-up of patients diagnosed mostly with eBC.²⁵⁻²⁷ Breast care nurse specialists ensure the continuity of care and psychosocial support of people diagnosed with breast cancer.^{25,28}

1.5 Discrepancies in levels of supportive care for eBC versus mBC

Up until recently the focus of breast care nurse specialists has typically been on supporting patients diagnosed with eBC. Significant discrepancies have been reported in the UK in the level of supportive care available to women diagnosed with eBC versus mBC.^{29,30} Breast care nurses in both the UK and Australia have reported that they feel ill equipped or have insufficient time to address the multidimensional needs of those with mBC.³¹⁻³³ Consequently, women with mBC report inadequacies in the information and support they received compared to the services available to them upon their diagnosis of eBC.²¹ In 2008, the UK's Secondary Breast Cancer Taskforce recommended that every breast care team should have a dedicated clinical nurse specialist who has the skills and knowledge to manage patients with mBC.³⁴

1.6 Specialised mBC nurses in Australia

A 2011 evaluation of the specialised mBC nurse role in Australia reported strong support from both patients and health professionals for the continuation and expansion of the service to meet the unique supportive care needs of patients with mBC. The evaluation noted that the new mBC nurse role provided the opportunity to tailor treatment and supportive care to the needs of the individual patient and that the role addressed a significant gap in service provision for this specific patient group.³⁰ In response to this gap in service provision, the Australian Federal Government allocated \$27 million to The McGrath Foundation in 2019 for the recruitment and training of 41 additional breast care nurses, of whom 22 will be specialised mBC nurses.

1.7 Project funding

This project was made possible through an Enterprise Partnership Agreement between the Australian Institute of Health Innovation at Macquarie University and The McGrath Foundation.

1.8 Project aims

The primary aim of this project was to understand the role and value of the specialised mBC nurse from the perspective of: (1) women diagnosed with mBC; (2) the families of women diagnosed with mBC; and (3) the specialised mBC nurses.

The secondary aim was to understand from the mBC nurses' perspective how the role was established and challenges to the sustainment of the role.

It was anticipated that this study would build the evidence base around the current role and value of the specialised mBC nurse in providing supportive care to women living with mBC and to contribute to the future development of the mBC nursing role in Australia.

1.9 Significance to The McGrath Foundation and breast cancer sector

The McGrath Foundation currently employs the largest group of specialised mBC nurses in Australia and proportionally one of the largest groups in the world. The McGrath Foundation is in a unique position to directly and indirectly influence change in the mBC setting. The Foundation is committed to ongoing improvements and investing in further support to improve breast care nursing generally and is strategically investing in improvements to mBC nursing and patient care, an under-researched area in Australia and internationally. The partnership between Macquarie University and McGrath Foundation will inform further research and guide practical improvements in the McGrath Foundation Breast Care Nursing Program as well as other breast care nursing staff throughout the country. It is hoped that the research will deliver insights to help enhance service delivery and inform future research to better support patients with metastatic and advanced cancer.

2. METHODOLOGY

The scope of the study, including the research questions and methodology, was decided in consultation with members of the project team. Ethics approval was granted by the Human Research Ethics Committee at Macquarie University (Project ID 7965).

2.1 Sampling and recruitment

2.1.1 Inclusion criteria

Eligible participants included people diagnosed with mBC, their family members (>18 years of age), and mBC nurses or breast care nurses who had a significant responsibility for women with mBC. All participants were provided with a Participant Information Sheet and Consent Form informing them of the voluntary nature of the study.

2.1.2 Recruitment: women with mBC

Purposive sampling was used to recruit women with mBC who had received support from a breast care nurse. A range of community-based recruitment strategies were used to ensure a diversity of participants. Recruitment aimed to include women with mBC:

- from a range of geographic locations (urban, regional and rural)
- with differences in socio-demographic characteristics (e.g., age, ethnicity, socio-economic status)
- with differing times since mBC diagnosis
- who were receiving different types of treatment and care (e.g., those receiving life-prolonging treatment, those receiving palliative and supportive care only).

Community-based recruitment strategies included promotion through: Breast Cancer Network Australia; Counterpart; Think Pink; Support for Women with Advanced Breast Cancer (hosted on Facebook); professionally run mBC support groups; and mBC nurses.

2.1.3 Recruitment: family members of women with mBC

Women with mBC who decided to participate in the study could nominate a family member (e.g. partner, parent, sibling) to invite to take part in the study. This was optional. Participants did not have to nominate a family member, and nominated family members were under no obligation to take part.

2.1.4 Recruitment: mBC nurses

Nurses were recruited through convenience sampling. Recruitment was primarily through The McGrath Foundation network of breast care nurses as McGrath employing the majority of mBC nurses in Australia. Women with mBC who decided to participate in the study could also invite their breast care nurse to participate. This was optional. The participant's nurse was under no obligation to take part.

2.2 Data collection

Data collection took place between August and December 2020. In-depth, semi-structured interviews were used to capture a diverse range of experiences and perceptions. Interviews were conducted by phone or video conferencing and lasted between 40 and 90 minutes. Interviews were conducted by MF and AS. Interview questions, including demographic information, were informed by the literature and developed in consultation with the project team.

The interviews with women living with mBC (Appendix A) explored experiences of supportive care received from breast care nurses at different points in their disease trajectory, compared the type and value of supportive nursing care received during their diagnosis of eBC (if applicable) with the care received during their diagnosis and treatment for mBC, gaps in supportive nursing care and suggestions of how these could be met, and how supportive care extends beyond symptom relief and control of pain to include support around work, finances, childcare and preparation for end of life.

Interviews with family members (Appendix B) explored their experiences of support from a breast care nurse focused on different stages in the disease trajectory, in particular the support received during crises related to treatment failures and disease progression, and how the nurse helped the patient and family members to make decisions about their care.⁵

Interviews with mBC nurses (Appendix C) explored how they provide care and support across multiple domains – physical, psychosocial, spiritual and financial; including support and information about disease progression, treatment options, living with uncertainty, supporting family members and friends, and preparing for end of life care.

2.3 Data analysis

The interviews were audio recorded and transcribed verbatim by an external transcription agency experienced in medical transcription. Transcripts were de-identified by removing the names of individuals and locations.

The data were analysed thematically. This involved repeatedly reading the interview transcripts, coding, and identifying preliminary themes and categories. Coding was performed by MF and AS using the qualitative data analysis program QSR NVivo 11. Analysis focused on identifying commonalities, differences and patterns of shared meaning across the three data sets (mBC patient, family member and mBC nurse). Members of the project team met regularly to discuss the development and refinement of the themes.

3. FINDINGS

3.1 Participants

Twenty-five participants were interviewed (Table 1). Participants included 10 women diagnosed with mBC (aged 43–64 years); 5 family members (aged 51–71 years);^a and 10 mBC nurses (aged 39–64 years). Participants were from various states and territories including the Australian Capital Territory, New South Wales, Tasmania, Victoria and Western Australia and from a range of settings including public and private hospitals and community settings. All nurse participants had experience working with women with eBC and mBC, and some had also been in other roles such as patient navigators, palliative care nursing, or other types of oncological nursing.

Table 1. Characteristics of participants

Women with mBC (n=10)	
Age	43–64 years
Type of mBC diagnosis	
De novo	n=5
Recurrence (secondary diagnosis)	n=5
Years since mBC diagnosis	<1 to 9 years
Partnership status	
Partner	n=7
No partner	n=3
Children aged <18 years	n=3
Working status	
Working full-time	n=2
Working part-time or casual	n=2
Studying, retired, or not working	n=6
Family members of women with mBC (n=5)	
Age*	51–71 years
Gender	
Female	n=3
Male	n=2
Relationship to woman with mBC	
Partner	n=3
Mother	n=2
Working status*	
Working full-time	n=2
Retired or not working (full-time carer)	n=2
mBC nurses (n=10)	
Age	39–64 years
Years in nursing	20–40+ years
Years in current role	<1–11 years
Employment status	
Full-time	n=4
Part-time	n=6
Setting	
Public	n=2
Private	n=2
Public and private	n=4
Community	n=2

* Data missing for 1 participant. mBC = metastatic breast cancer.

^a The number of family members differed from the number of patients as not all patients had a family member involved in their care or chose not to invite a family member to participate in the study.

3.2 Role and value of mBC nurses

Key points

- The responsibilities and capabilities of the mBC nurse are markedly different from those of cancer care professionals in similar roles.
- Instead of focusing on care during curative treatment, mBC nurses support people to live as well as they can, with incurable and life-limiting cancer.
- Care provided by mBC nurses often extends to supporting the person's family.
- mBC nurses play a vital role in helping people with mBC navigate services, treatments and care.
- The role of mBC nurses contributes to optimising delivery of high-quality cancer care for people with mBC with potential cost-effectiveness benefits to the healthcare system.

This section reports on participants' perspectives of the role and value of the mBC nurse in providing care and support to women with mBC and their family members.

First, we report key facets of the role as identified by mBC nurse participants. Second, we explain that the mBC nurse role is distinctive and multidimensional and provide an overview from the mBC nurses' perspective of what makes the role of the mBC nurse distinct from similar roles in cancer care. Third, we highlight the value of the mBC nurse role by reporting the mBC nurses' experiences of delivering nursing care to women with mBC, and the patients' and family members' experiences of receiving nursing care. We explain what it is about the role that improves patients' and family members' experiences of cancer care and how support from the mBC nurse helps to reduce the impact of an mBC diagnosis. Finally, based on the participants' accounts of the role and value of the mBC nurse, we highlight some of the potential benefits of the mBC nursing role to the healthcare system.

3.2.1 Key facets of the mBC nursing role

Despite the diversity of the mBC nurses' roles and the different settings in which they worked (e.g. public versus private, metropolitan versus regional), the multi-faceted role of an mBC nurse was described by nurse participants as encompassing the following key elements:

- complex care coordination and navigation, including acting as key contact person, ensuring continuity of care, facilitating integrated clinical and supportive care and shared-care, and attending multidisciplinary team meetings
- active identification of patients with mBC (rather than direct referral of patients to the nurse or routine contact with patients during hospital admission for surgery)
- management of symptoms and treatment side-effects
- management and support through critical transitions (e.g., diagnosis, disease progression, treatment changes)

- psychosocial support (e.g., monitoring for distress and reducing the burden on family members)
- end-of-life planning and palliative care, including negotiating goals of care
- information about mBC, tests, treatments and side-effects
- information on how to identify and access support within and beyond healthcare system (e.g. online and printed resources from hospitals, breast cancer support organisations and pharmaceutical companies)
- patient advocacy, including educating others on the supportive needs of women with mBC
- leadership and mentoring of other breast care nurses to improve knowledge of mBC care
- research and evaluation (e.g. pilot projects for new service delivery, service evaluation, research to inform resource development, assist with recruitment for research projects, needs based research).

The different ways in which the mBC role was conceptualised by participants is also evident in the terms that participants used to describe the mBC nurse (Box 2).

Box 2 How women with mBC, their family members and the mBC nurses talk about the mBC nursing role

mBC nurses were referred to as organisers, negotiators, advocates, coordinators, guides, facilitators, cost-savers, time-savers. They were the “go to person” and “the doer”, “the jack of all trades”. They were also referred to as “the relationship builder” and as the person who opens doors and removes obstacles.

The mBC nurses often saw themselves as being the “meat in the sandwich”, caught between the patient and the clinician and tasked with resolving differences of opinion, such as differing goals of care, or breakdowns in communication.

The mBC nurse was viewed as integral to a holistic team approach to cancer care across a range of diverse and at times highly scattered teams, spanning different healthcare systems and sectors. In this regard, the mBC nurse was referred to as “the conduit”, “the linker”, “the networker”, “the super, super connector”, and the “information sharer”.

3.2.2 A distinctive and multidimensional role in breast cancer care

An overarching theme across the mBC nurse dataset was that the mBC nurse has a distinctive and multidimensional role in breast cancer care. Three sub-themes were identified that helped to explain this distinctness: (a) the role is complex and varied rather than ordered and formulaic; (b) the role demands a high-level mix of skills and experience spanning clinical, psychosocial, social care domains; and (c) the role requires extended and often in-depth engagement with patients and family members.

From the nurses' perspective, the need to provide complex, high-level clinical *and* supportive care was what distinguished the role from other roles in cancer care (e.g. patient navigators, care coordinators or social workers). This was in part because mBC is a systemic rather than localised disease requiring a ‘whole of body’ approach to nursing care. The mBC nurses also reported that the prognostic uncertainty and variability in the mBC disease trajectory meant that patient care was neither standardised nor routine but had to be constantly tailored to meet the specific needs of the individual patient and their families across the different stages of the disease trajectory. Consequently, nurse participants reported that caring for those with mBC required a particular mix of skills with many nurse participants reporting that they had qualifications in oncology, breast cancer care, palliative care and counselling as well many years, often decades, of nursing experience. And finally, the complexity of care and challenging psychosocial issues meant that in-depth, respectful, and highly effective health care relationships often developed between nurses, patients and families. Given the long-term nature of mBC, many of these relationships spanned years rather than months.

3.2.2.1 *The role is complex and varied rather than ordered and formulaic*

The mBC nurse participants drew on their varied experiences working with patients with eBC and mBC, and in palliative care nursing, or other types of oncological nursing to highlight similarities and differences between their current and previous roles.

Participants, especially nurses, referred to complexities inherent to the mBC nurse role. For instance, one nurse described the role as "a complex jigsaw puzzle ... it's not routine. You're not getting the same things over and over again". Similarly, another nurse participant stated: "There is no one recipe in this. The orders are changed, so you don't necessarily do things in a succinct order, you do what that patient needs at that time". Participants attributed this complexity to the:

- systemic (whole of body) rather than localised (breast) nature of the disease
- unpredictable and at times rapidly changing disease trajectory, with alternating acute (consisting of rapid symptomatic changes) and stable phases (relatively few symptoms)
- increasing number, variety and complexity of treatment options
- involvement of numerous clinical and supportive care clinicians and services
- impact of ever-present existential concerns
- diversity of care needs (e.g. primary and secondary healthcare, community, employment, finances, relationships).

Nurse participants indicated these factors could contribute layers of complexity, responsibility, and time commitments to care coordination and navigation. Highlighting this difference, a nurse with experience in both eBC and mBC stated that while a call from a patient with eBC typically meant provision of what was usually standard information and advice, "one call in the metastatic setting sets off a cascade of 20 calls". The time-intensive coordination of a multiple health professionals and services that one call might trigger was further complicated by the need to carefully balance the goals and wishes of women and their families in relation to their care, especially towards end-of-life. Another nurse participant similarly contrasted her experiences providing care to eBC patients to the more complex care integral in caring for mBC patients:

The early breast cancers - I'm not saying all of them, but a lot of them are quite straightforward. If it's a very early breast cancer they'd have surgery, radiotherapy, they might have endocrine therapy, oral treatment. Very straightforward. Whereas my metastatic patients, complex, complicated treatment protocols, lots of social needs, lots of psychosocial needs. (Nurse)

Nurse participants indicated supporting women with mBC required them to have higher levels of clinical knowledge and symptom management than eBC nursing – due to the sites of metastasis, differences in prognosis, and incurability of mBC. Some nurse participants reported that mBC nursing could be more challenging than, for example, eBC nursing as the complexities of mBC necessitated more vigilant monitoring.

The job is a lot scarier for me anyway than when I was an early breast cancer nurse, I felt it was much more simple. Whereas now if someone rings me, I'm like doing 55 checks to see what is going on with them. Do they have a blood clot, what are their symptoms? (Nurse)

A final challenge identified by nurse participants was the lack of standardised referral mechanism for people with mBC at their hospital or cancer centre. Consequently, many nurse participants reported difficulties in identifying patients with mBC who were being treated at their workplace. Nurses reported

that while well-defined referral pathways exist for patients with eBC, patients with mBC enter the healthcare system at different points, depending on the type of diagnosis (de novo versus recurrence) and the specialty of the treating clinician. The diversity of breast cancer subtypes and treatment options also meant that many patients are treated as outpatients and are only admitted as an inpatient for acute, palliative or end-of-life care. Consequently, some patients may be referred to the mBC nurse at point of metastatic diagnosis while others may only become known to the mBC nurse after having been living for many years with mBC; as illustrated in the following excerpt.

I find if it doesn't happen right at the beginning, like if there's a late referral it's really difficult to just jump in at the last minute and suddenly be able to develop that relationship with somebody. Like, for example, I had a situation recently where one of the oncologists had somebody at the private and the lady had been metastatically treated for 18 months or something and I didn't know about them at all, nobody had told me about them. (Nurse)

3.2.2.2 The role demands a high-level mix of skills and experience spanning clinical, psychosocial, social care domains

Due to the many different facets of their role, nurse participants shared the view that to be effective in the role an mBC nurse should ideally have experience and training that cut across clinical oncology, breast cancer, palliative care and psychosocial care. A few nurse participants specifically mentioned that their broad life experience and maturity helped them in their role, particularly in how to have difficult conversations and provide care and support for women about end-of-life care, death and dying.

I think it's important to have a lot of - not that I'm saying young nurses can't do it, but a lot of maturity and life experience up your sleeve to start with ... I've been lucky enough to have had a lot of experience in palliative care in the community, which I think was one of the best things I've ever done. (Nurse)

You need so many skills in this job, different communication skills. It's very challenging having to talk to people about death and dying and progression of disease, and how to tell their children and everything. (Nurse)

3.2.2.3 The role requires extended and often in-depth engagement with patients and family members

A defining characteristic of the role described by participants is the depth and length of the healthcare relationship that can develop between the mBC nurse and the person with mBC owing to the chronic, long-term and incurable nature of mBC. It was noted by several of the nurse participants that in the eBC setting patients typically follow a more predictable treatment pathway with most patients transitioning from active treatment into post-treatment survivorship care within 6-12 months of diagnosis. In contrast, as one mBC nurse reported, mBC nurses need to be "in it for the long haul" as the care and support provided to patients and their families may extend from the point of diagnosis to end-of-life and beyond. It was not unusual for care to be provided by the same mBC nurse to a patient over many years.

Over time an accumulation of clinical practice encounters and conversations between mBC nurse and patient often resulted in a deep, respectful and trusting relationship. In particular, the mBC nurse's ability to fulfill a multitude of roles including support for symptom and treatment side-effects, care

navigation, and psychosocial and practical support was critical in helping to build and sustain these strong relationships.

The proactive development and nurturing of this relationship appeared to be closely related to the delivery of person-centred care and support to the woman with mBC. One nurse participant commented that her role was different from that of care coordinators because of its focus on building strong, supportive interpersonal relationships:

I think it's really special to be dedicated to that particular cohort of patients ... So here at [this hospital] there's actually a generic [care co-ordinator service] team. So they do care co-ordination, but they don't work the way I do. They don't build relationships with patients. They're basically like 'give them general information about their treatment'. It's just a different way of working. (Nurse)

The importance of these relationships to patients was evident in the way participants talked about the nurse, describing her as 'a professional friend', "almost like a muse, a soulmate' or like having 'my mate on my side'.

So I trust her. So trust. I have confidence in her abilities to navigate the system. I really love her [laughs]. She's warm and friendly and knows when things are scary. But she can also be tough and say you can do this. She can give you a kick up the bum when you need one. I love her, she's such a good woman. (Woman with mBC)

She cares; she's a person who cares very deeply about people and that's a lovely, lovely situation to be in.... So, I always get off the phone and I always feel immensely better after I've spoken to [her.] (Woman with mBC)

Furthermore, as the following quotes from two women with mBC exemplify, the relationship that they had with their mBC nurse appeared to be distinct from their relationships with other healthcare professionals involved in their care:

I would be more inclined to maybe speak to them [mBC nurse] than my GP even. I've got a GP who is practical. But he's not one that I could really sit down and have a deep and meaningful with. Whereas I know I could do that with the breast care nurses if I needed to. (Woman with mBC)

To me, [my] breast care nurse is as important as [my oncologist], but it's a different kind of relationship, isn't it? ... I know that if I said to [my breast care nurse] I'm not coping, I need some extra help, I know that she would have all these resources and people, and all sorts of things. (Woman with mBC)

3.2.3 Improving the patient and family's experience of cancer care and reducing the impact of an mBC diagnosis

This section provides insights into women's experiences of being supported by an mBC nurse, including what women and their family members perceive to be the benefits of care from an mBC nurse, both in their own lives and for others living with mBC. This section also provides insights from the mBC nurses' perspective about their experiences of providing care to women with mBC, and their perspective on the value their role brings to people impacted by mBC and to the healthcare system more broadly.

An overarching theme across the mBC nurse, patient and family members datasets was that the mBC nurse improves the patient and family's experience of cancer care thereby reducing the impact of an mBC diagnosis. Three sub-themes were identified from participants' experiences of giving and receiving care that helped to explain how the mBC nurse improves the experience of care: (a) validating the experience of living with mBC; (b) creating a safe place to share fears and concerns thereby easing the emotional burden of living with uncertainty and incurability; (c) simplifying access to and passage through the health, social and community care systems.

3.2.3.1 Validating the experience of living with mBC

Patient participants expressed gratitude that they had an mBC nurse on their team. Several said that before being connected with their mBC nurse they had not previously been seen by nor received support from a breast care nurse. Many women commented that they had felt invisible in the healthcare system, and that their complex needs often went unrecognised. As the below excerpt illustrates, the mBC nurse helped them to feel visible, validated and therefore supported. The mBC nurse was often one of the few people who could acknowledge and understand what they were experiencing.

I think it's just that somebody understands what they are going through because a lot of them say, even my own family doesn't understand this. The general public can understand someone having – you're having a [cancer] diagnosis, having treatment and getting better, but they can't understand someone having a [cancer] diagnosis, having treatment, but they've still got cancer and it is going to kill them at some point. The families can't even understand that. Husbands particularly can't understand that, and women just get so frustrated with people saying, oh well, you've finished your chemo, are you better now? (Nurse)

3.2.3.2 Creating a safe place to share fears and concerns thereby easing the emotional burden of living with uncertainty and incurability

The mBC nurse was viewed as a familiar, trusted, and safe person, someone with whom the patient could share their fears and concerns without worrying about being judged or being a 'burden'. Talking to the mBC nurse provided a space in which they could be honest and open about how they felt, and how they were coping. As one woman with mBC indicated:

We can be very frank and there are no barriers to asking anything at all. We can have a laugh. We can have a cry. We can do whatever. Joke around. Get serious. (Woman with mBC)

Many patient participants indicated that mBC nurses understood their lived experience in ways no one else could, including family and friends. Consequently, patient participants reported that there were few boundaries to what could be discussed with the mBC nurse. Women commented that their mBC nurse was uniquely positioned to support them emotionally, physically, practically and socially because the mBC nurses had in-depth knowledge not only of their mBC but also of their personal experiences and preferences. This contrasted with how some of the women felt about what they could share and discuss with clinicians (who were more disease focused) and family members (whom they wished to protect).

... the oncologist ...[is] there to tell you the facts, whereas a nurse brings in the emotional part of it and just – it's hard to explain. (Woman with mBC)

...the nurses are the ones that – who know you and know how you've journeyed from a personal perspective. They've probably met your family while you've been in hospital. They've come to see you in the ward, that sort of thing. (Woman with mBC)

Furthermore, the long-term and unpredictable nature of mBC could result in compassion fatigue setting in with family and friends. For some participants, the problems generated by dwindling support from family and friends were exacerbated by an underlying reluctance or inability of family and friends to acknowledge, confront or discuss matters that might be deeply concerning to the person with mBC.

They think their family or their friends are sick of [talking about mBC]. [The family and friends] don't want to hear it or [the patients] don't want to bother them with it. [The patients] know [they] can come and talk to [me] and tell [me] that [they're] feeling crappy and [they] don't want to keep going with the treatment, or things like that. So I think they just feel it's a bit more of a comfortable space. (Nurse)

Many participants indicated that support from the emotional support provided by the mBC nurse was valued during all phases of the disease trajectory but particularly during acute or active phases of the disease. During these phases the women and family members often felt depleted physically and mentally, with the woman's energy consumed by the urgency and immediacy of surviving. It was at these points that the mBC nurse could ease the intense emotional burden of living with an incurable condition.

They can do that legwork for me ... A lot of my mental energy has been on surviving. Then trying to get past that surviving mode and just being – just getting on with life as such. Because surviving takes a hell of a lot of energy. Mental energy, emotional energy. As well as physical energy. I work really hard mentally ... I know that [the mBC nurses] are there if I need to ask something. If they can't help me, they'll find out who and where or why on my behalf. That's what I value in them. (Woman with mBC)

The unpredictable and ultimately terminal nature of mBC meant that even women who were currently stable and experiencing relative few symptoms talked about being reassured that the mBC nurse was there for them. Knowing that the mBC nurse was there, and would step in when needed, provided an important sense of reassurance to the women and their families. Simply having access to an mBC nurse whom they trusted helped to allay concerns about what lay ahead, in particular about how they would cope when the disease progressed, or when the woman experienced functional decline, or when treatment options ran out and they neared the end of life phase of care.

It was at these critical junctures in the disease trajectory that many of the women reported needing additional support from the mBC nurses. Women appreciated having someone who could explain complicated information to them in lay terms, who could answer questions outside of structured consultation times, and who could answer questions on a breadth of topics related to living with mBC, including dealing with uncertainty and feelings of being out of control. The mBC nurse was therefore valued for her ability to minimise the feelings of confusion, angst, anxiety and stress related to not knowing what to do next and when difficult decisions need to be made, as is illustrated by a family member:

That's what [our mBC nurse] – that's what she brings, she brings that clarity and then from the clarity, the churn and the angst that you feel because you're not sure what you're doing and you're not sure what the right answer is, you're not sure which direction to go in, all of that's removed ... Yes, okay, you've still got tension and you've got a whole range of other emotions but at least you don't have to worry about the 'what do I do next

or what's the right thing to go'? You worry about what's going to happen, but you don't have to focus on all these decisions that you feel that you're unprepared to make. (Family member)

3.2.3.3 Simplifying access to and passage through the health, social and community care systems

Patient participants reported that they often found the complexity of mBC care, the need to consult and receive care from an array of clinicians and allied health workers, and the need to access services across the health, social and community care sectors overwhelming. Most of the patient participants reported that the mBC nurse had played an integral role in helping them to understand and coordinate the different aspects of their care, which directly impacted on the experience and the quality of the care they received.

It didn't occur to me that [my mBC nurse] would be such an integral part of my day-to-day life. (Woman with mBC)

She just makes the whole thing easier to navigate. She navigates for me. She just does it. I can concentrate on my kids, and I don't have to be on the phone, trying to fight with people to get what I need, she does that. I can have quality of life. She does all the hard stuff. (Woman with mBC)

Similarly, family members also spoke about how having access to an mBC nurse helped in navigating care and to feel less confused:

I think without [my mBC nurse], the whole thing would be just so overwhelming and we'd be lost. We'd be in a fog and we'd probably obsess about stuff a lot more than we needed to. We'd probably use a lot more energy on things that we wouldn't know were unimportant. (Family member)

For most of the patient participants, the mBC nurse was their primary point of contact and the go-to person for any care-related questions, with the mBC nurses acting as the intermediary between patients and clinicians, rapid assessment teams and other clinical and support services. Many of the patient participants reported that what they valued was the accessibility and responsiveness of the mBC nurse, the mBC nurses' high-level clinical knowledge and the mBC nurses' network of contacts within and beyond the healthcare system. The mBC nurse was reported to improve access to health professionals and the responsiveness of the healthcare professionals to the needs of women with mBC. Participants reported that mBC nurses used their pre-existing relationships with clinicians and other health professionals to help ensure that patients' diverse needs and goals were responded to.

When I first started on the chemo, with some of my side-effects, [my mBC nurse] has been my first port of call. I had problems with my nose bleeding and not knowing who to tell. Then putting up with it and realising actually, I do need to tell someone, this is more than just putting up with it, I need help with it. I spoke to [my mBC nurse] and then she spoke to one of the oncology registrars, who said, try such and such a cream. That was enough to fix it. But in the meantime, if that cream hadn't worked, she had a referral for me to see an ENT. So, that type of stuff. I guess that circumvents me having to see the oncologist or having to even go to the GP. (Woman with mBC)

You just feel confident contacting [the mBC nurse] because they've come across it all and they just know their stuff. (Woman with mBC)

Patients and their family members also appreciated the involvement of mBC nurses in “simple things like organising scans” and chasing results, as well as in providing more complex and challenging support such as setting up wrap-around services, advocating for limited palliative care services, finding and accessing clinical trials and alternative treatment options, negotiating payment schedules for expensive treatments, facilitating difficult conversations with clinicians and family members, supporting complex decision-making related to treatment and end-of-life and support with clinical care.

... she's been trying to get me onto palliative care caseload, so I can speak to somebody about whatever's happening. So I don't have to go and sit in the hospital emergency [department]. (Woman with mBC)

That you've got all those areas of expertise that you can call on... I don't know that the GP could do that as effectively. [...] It would be left to myself to do a lot of the leg work. (Woman with mBC)

The integral role of the mBC nurse in collaborating and supporting a team approach to cancer care, in particular the close working relationship that many mBC nurses had with medical oncologists, was viewed by women as important.

They collaborate really, really well and [it's the patient] who wins every time. (Woman with mBC)

Having direct access to the nurse via mobile, email or pagers helped to minimise the distress and anxiety experienced by women and their family members. The women and their family members reported that they were encouraged to make contact should they have any concerns about their treatment, when they needed more information about their care, or if they needed emotional support. For example, many women with mBC reported contacting the mBC nurse when they experienced a changing or worsening of symptoms or side-effects, when making difficult decisions (e.g., whether or not to go to the emergency department, when to enter palliative care), when information provided by a clinician was not well understood (particularly regarding treatment and prognosis), and when waiting for results.

So, [the mBC nurse's] knowledge, understanding and our ability to access her through a simple phone call, text or e-mail, it's kept things – it's stopped us building up angst or anxiety, particularly for [my wife]. (Family member)

mBC nurses were reported as being able to make things happen when no one else could. As one patient participant stated, “she really advocates and just pushes until the right outcome is achieved for her patient”. An important area of advocacy was around the financial costs associated with cancer. One of the mBC nurses talked about the work she regularly performed to ensure that patients are well-informed about the hidden financial costs associated with cancer care and treatments, particularly when accessing care through the private healthcare system.

[I've been] advocating a bit lately about asking about your upfront costs because [the patients] think they're going in and the private health fund is going to cover everything. Particularly [now that] we've got a private radiation provider and there's a big out-of-pocket cost for these ladies. So, a big part of our role has been advocating and explaining that to them. (Nurse)

Many of the mBC nurse participants mentioned the high direct financial costs and opportunity costs associated with mBC, and the negative short- and long-term consequences for women and their families. Several of the patients and their family members discussed the support provided by mBC

nurses in helping them to negotiate and navigate the financial complexities associated with living with mBC.

For example one day I needed a CT scan and she just called the CT guys and ... I didn't have to pay for that. [...] it's an extremely expensive venture for me ... I think overall her entire approach is financial, she's got the financial thing constantly on her mind and I think she just always ... thinks about me: how do we do this for the least money possible.
(Woman with mBC)

Many examples were provided by participants of the role mBC nurses played in attending to patients' financial needs including:

- advocating for patients to be bulk-billed;
- securing financial assistance from organisations to help pay bills;
- referring women to organisations that can assist with costs (e.g., for wigs, lymphedema garments, cleaners, gardeners and childcare);
- facilitating access to Centrelink and NDIS payments, superannuation, and life insurance;
- providing referrals to social workers and financial counsellors;
- writing letters to employers in support of flexible or reduced work hours to maintain employment over the longer term.

Overall, participants reported that the work that mBC nurses did to advocate, coordinate and navigate care and to reduce their emotional burden afforded women more time, space and energy to devote to their lives beyond cancer. Women talked about how their mBC nurse had indirectly helped them by making it easier to live a relatively 'normal' life. This included having more energy and time to spend quality time with family, undertake care-giving responsibilities, and continue working, exercising and socialising.

It's just meant that [my wife] can retain interest in other areas rather than having to focus on her treatment, because without [the mBC nurse], we'd have to do a lot more heavy lifting and that would be just not [my wife], it'd be me, it'd be the boys. That would be work that we would have to do to try and figure out what we needed to do or the treatment to give [my wife] the best chance of ensuring she gets the most benefit out of the drug treatment. (Family member)

3.2.4 Potential benefits of the mBC nurse to the healthcare system

In addition to the benefits of mBC nurses for supporting patients living with mBC and their families, participants' accounts indicated that there may potentially be wider benefits to the healthcare system.

3.2.4.1 Potential effectiveness and cost-related benefits to the healthcare system

Participants' accounts indicate that the mBC nurse provides a proactive, timely, patient-centred, integrated, and holistic response to care coordination, transitions of care, symptom management and psychosocial support. This in turn could result in direct benefits to the healthcare system while simultaneously ensuring high levels of patient, carer and family satisfaction with the quality of care that they receive.

mBC nurses potentially contribute to increasing productivity and efficiency, resulting in cost saving by:

- reducing unplanned hospital or emergency department admissions

- reducing number of consultations and length of consultation with other treatment team members (e.g. medical oncologist, radiation oncologist, psychologist, surgeon)
- administering intramuscular (e.g. the aromatase inhibitor fluvestrant) and subcutaneous therapies (e.g. the monoclonal antibody denosumab) thereby reducing workload of chemotherapy nurses and GPs
- facilitating shared care with GPs
- supporting self-management in the home.

3.2.4.2 Potential quality-of-care related benefits to the healthcare system

The work of the mBC nurses appeared to be closely related to the quality and experience of care, and potentially the safety of the care delivered to women with mBC. This was achieved through multiple means, including:

- improving adherence to medications, especially oral chemotherapies
- early detection and improved management of disease symptoms
- early detection and improved management of treatment side effects
- making referrals to hospital-based support services, community services and online resources
- facilitating direct-to-ward admissions
- facilitating earlier access to palliative care and other supportive care services
- supporting monitoring and screening processes
- promoting the integration of clinical and supportive care and multidisciplinary teamwork
- improving communication between patients and healthcare professionals, and between health professionals from different settings and sectors, within and outside of the healthcare system
- training and mentoring junior staff in nursing and oncology.

3.3 Establishing and maintaining the mBC nursing role

Key points

- **Treatment advances, improved understanding of the needs of people with mBC and the growing awareness of the value of mBC nurses among clinicians and other health professionals as well as patients themselves, are increasing patient case loads for mBC nurses.**
- **The mBC nurses' success in building referrals and in gaining the trust of clinicians and women with mBC meant that demand for their services has quickly increased.**
- **Some participants expressed concern that as numbers of patients with mBC increase that this might limit the mBC nurses' capacity to deliver the holistic, person-centred support and care that patients and their families reported as valuing so highly.**

This section reports the factors that mBC nurses (n=10) believe contributed to the successful establishment and implementation of the mBC nursing role in their setting, as well as factors that might support the long-term sustainability of their role. The mBC nurses' experiences provide insights into factors that may need to be paid attention to if the role is to develop further, within a particular setting and more generally in Australia.

3.3.1 Establishing the role of mBC nurse

3.3.1.1 A growing awareness of inequities in breast cancer care and patients' unmet supportive care needs

Whilst working as breast care nurses, many of the nurse participants had become increasingly aware that advances in treatment meant women diagnosed with mBC were living longer. They were also aware that the supportive care needs of women with mBC differed from those with eBC, and that these needs, especially their psychosocial needs, often went unrecognised within the breast cancer care system. Many reported that the primary focus of the breast cancer nurse role was to provide support to women with eBC. They believed that the existing breast cancer models of care constrained and restricted their ability and capacity to provide meaningful and effective support to women with mBC. The system seemed to be out-of-step with the needs of this growing patient population.

In the 2000s, we really didn't do a lot with metastatic. But the longevity and the prospects for metastatic also were very different then. I was very aware of a growing number of metastatic patients, who were living longer, who I felt needs weren't being addressed. But the sheer numbers of early breast cancer – and the needs of early breast cancer patients – precluded me from really accessing a lot of those women [with mBC] to support them. (Nurse)

To address this perceived inequity in care, many of the nurse participants had actively advocated within their hospital and healthcare systems for the creation of a new nursing role that would have dedicated time to support women with mBC. A critical first step in establishing the role was educating hospital management and other healthcare staff about the difference in the supportive care needs of those with eBC versus mBC, the increasing size of this patient population, and why the current system did not always meet the needs of this patient group.

I wanted to set this job up here six-and-a-half, seven years ago and people just thought I was from Mars. They were just like whoa, what are you talking about? You don't need a dedicated metastatic breast care nurse, why would you need that? ... So I spent many years trying to talk the powers that be into being a metastatic breast cancer nurse and eventually I got there (Nurse)

3.3.1.2 Factors impacting on the reach and effectiveness of the mBC nurse role

The mBC nurses reported that once funding had been made available and the mBC nurse position created, the reach and effectiveness of their role was determined in part by several key organisational and system-level factors. Factors that nurse participants reported as having influenced the adoption, implementation and maintenance of their role, and therefore the role's reach and effectiveness, included:

- the funding model (e.g., part or wholly funded by McGrath and/or local health district and other third-party funders)
- the location in which the mBC nurse was situated (e.g., BreastScreen, public or private hospital, community setting)
- the visibility of the mBC nurse role within a particular hospital or community setting, particularly awareness of their role among medical oncologists
- the level of understanding among cancer healthcare professionals of how the role of the mBC nurse differs from similar roles (e.g. breast care nurse, care coordinators, patient navigators)

- differences in managerial and other health professional expectations about what the role of mBC nurse entails and sector and regional boundaries which influenced the reach of the mBC nurse.

Source of funding and location of nurse were critical as these determined the role's reach, that is whether all women with mBC within an area were supported or only some, for example those attending a particular public hospital or within a particular local health district. Nurse participants reported that these two factors shaped referral processes, their access to women with mBC, how much time they could spend at different sites, and influenced how they interacted with women with mBC (e.g. predominantly face-to-face or by telephone).

Many of the nurse participants reported that it had taken 12 months for the role to be integrated effectively into the healthcare service, but this varied depending on:

- level of institutional support, awareness and understanding for what the role entails, and local system readiness for the role of mBC nurse, such as established care and referral pathways for women with mBC, review schedules for women with mBC, and clearly defined touchpoints for mBC nurses to meet with patients
- whether the nurse had been working previously as a breast care nurse (or similar role) within the same healthcare service setting and their level of familiarity with the immediate and broader healthcare services in that area
- the existence of pre-existing relationships and contacts with relevant healthcare professionals in that area
- the availability of data on women with mBC serviced by the healthcare service (including the numbers of women with mBC) and access to patients' records
- connections with peak bodies to support training, education and sharing of resources such as Breast Cancer Network Australia's Hope and Hurdles and My Journey resource for people with mBC, and mBC nurse training and support from The McGrath Foundation

3.3.1.3 Key activities undertaken when establishing the mBC nurse role

Two activities were integral to establishment of the mBC nurse role: (1) identifying women with mBC; and (2) generating referrals from healthcare professionals.

Identifying women with mBC

Establishing the mBC nurse role typically started with a service review and service mapping to understand how patients with mBC move through the system (Box 3). mBC nurses also often spent time gathering data to identify the population of women living with mBC in that healthcare setting or region.

I started in July and I didn't start seeing people until October. I had three months of literally research, best practice, what is everyone doing? Where are the people with metastatic breast cancer? Because that's the other thing, people don't actually have a log of that. (Nurse)

For women diagnosed with eBC, contact with a breast care nurse typically happens either prior to or shortly after breast surgery. However, women diagnosed with mBC rarely undergo breast surgery.

Therefore, there is no failsafe way of ensuring the breast care nurses are aware of patients diagnosed with mBC. Consequently, the nurses interviewed reported that women with mBC were less 'visible' than women with eBC. As one nurse stated:

One of the biggest gaps was finding out where these people [with mBC] were and where they were going for treatments.
(Nurse)

For women with mBC, points of contact with the healthcare system are highly variable and dependent on their metastatic sites and tumour burden, the symptoms they are experiencing and the type of treatment they are receiving. Few were reportedly admitted as inpatients, with the majority said to receive care as outpatients unless experiencing complications associated with disease progression or treatment side-effects. Women on oral therapies, especially if treated at an oncologist's private rooms, were reported as being particularly challenging to identify and contact.

My access and support to metastatic women was often patient-driven and a bit ad hoc. Because unless they were having chemo, often their touchpoint in the actual hospital is very short. It's not like they get admitted like the early breast cancer patients for surgery and they're there for several days. Some of the metastatic treatments, chemos even, are only for an hour or an hour-and-a-half. Sometimes the reality is, you just can't be everywhere. (Nurse)

I'm spending the first six months in going through and trying to trace all of the people [with mBC]. I'm just looking at the moment through the public clinics and then also the ladies at the private having chemotherapy. But I haven't actually got my head around the number of people that the oncologists see in their private rooms. (Nurse)

Identifying women with mBC was further complicated for nurse participants working across multiple hospital sites or settings, especially if this included a mix of public and private patients or if patients use of services crossed local health districts or other bounded regions, as systems for sharing information across the sector are often limited. Nurse participants expressed concern that poor data collection and sharing and ill-defined referral pathways complicate their job and potentially lead to women with mBC falling between the cracks.

The problem is because there's just so many patients across two hospitals and sometimes a person comes in through emergency and they're admitted, but I don't know. There's no system - and I've talked about it with the palliative care nurses as well. I rely on other people to let me know. So sometimes the generic care co-ordinators might let me know, or one of the doctors might let me know. But a lot of the time I don't know. (Nurse)

Box 3 Strategies reportedly used by nurses to identify women with mBC

Various strategies were used by nurses to overcome the difficulties in identifying patients, including:

- actively identifying patients with mBC from hospital records
- systematically checking who was booked into chemotherapy and oncology clinics in both public and private settings
- asking chemotherapy, surgical and palliative care nurses, and medical and radiation oncologists to help identify mBC patients
- working with the clinical coders at the hospital to develop a sense of potential patient numbers

Networking and relationship building to generate referrals

In addition to making direct contact with women diagnosed with mBC, another critical strategy was generating referrals from clinicians such as medical and radiation oncologists and palliative care physicians.

When establishing the mBC nurse role, it was therefore important that time was invested in developing relationships and being highly visible within the healthcare system. Nurse participants emphasised the importance of 'being known' and that establishing role legitimacy with healthcare professionals and patients involved gaining the respect and trust of both groups. They stressed the need to "get the word out" and the need to continue to educate healthcare professionals and patients on the role of the mBC nurse. By networking widely, the mBC nurse increased awareness amongst healthcare professionals of the size of the mBC population, the unmet needs of these patients, and increased understanding of how the mBC nurse can help to address some of these needs, ultimately driving referrals to the mBC nurse.

So personally, I think it takes a good year to really feel established and part of a team and that everyone knows who you are. I think it's really important to develop the relationships with medical oncology, radiation oncology and palliative care. Very important for everyone to know who you are and what you're doing. Then obviously approaching all the patients, meeting them and seeing if they're happy to accept you being involved in their care is important to start with. Then the main thing really with a patient, is developing those relationships with people so that they always see you, they know who you are, you're always visible, and that takes time to build that sort of relationship up with people, so you just have to take your time with it ... I think if [the doctors] can see the value of what you're doing, then they're much more likely to refer to you and get you to be involved with the patient's care. (Nurse)

Those situated in hospital settings were perceived to have an advantage in establishing referrals over those located in community settings owing to their proximity and visibility to referring clinicians. Highlighting this issue, a community-based mBC nurse stated:

"We physically have not been in there and sometimes when you're not in their faces and [the oncologists] don't see you, they forget" (Nurse).

Concerns were raised that by sitting outside of the hospital setting, the mBC nurses find it harder to identify and support all women with mBC.

The other reason for going out to those hospitals – you know, it might an hour drive to each, but the other reason for going out is just to remind the oncologists that I'm still around because if they don't see you, they don't refer to you. You've got to be – and that's why the nurses that work in hospitals, in my mind, are so lucky because they are there. They are getting the referrals even without having to ask for the referral because they are there and they are seeing the women at the same time as they come to the oncologist whereas I just get – I mean, the oncologists in these secondary hospitals are good. They do refer to me, but I'm sure there's a lot that are still falling through the gap that you're not seeing. (Nurse)

Some nurse participants indicated that establishing role legitimacy often required considerable flexibility and even working outside of their regular hours and/or beyond the scope of their role. Several nurse participants reported making themselves available to sit-in or to observe clinics and specialist appointments and while acknowledging that at times this was beyond what was expected of them,

considered the time invested paid off in the longer term for relationship building and increased exposure to patients with mBC.

When I first started, one of the oncologists suggested that I attend some of the consults with a few different oncologists in two major hospitals here, so that I got to hear the spiel and got to know what they're dealing with and that sort of thing ... They kept calling me their nurse even though they didn't pay me, and I actually attended the Friday clinic on my day off, every week for about a year, without being paid for that ... I learnt a lot but also basically, if I was there, I was getting the referrals so I was able to see the women at the clinic but also follow them up later the next week by telephone. (Nurse)

3.3.2 Ensuring the role remains sustainable

Nurse participants reported that once the role had been established, new challenges emerged that had the potential to impact on the sustainability and growth of the mBC nurse role within a particular setting or service.

3.3.2.1 Coping with increasing patient caseloads

For some nurse participants, the very success of the mBC nurse has generated its own set of challenges. Having effectively identified patients and generated referrals, shown the value of their role, and built authentic healthcare relationships with women with mBC, Nurse participants sometimes found themselves unable to keep pace with the growing demand for their services.

As many of the mBC nurse positions were initially part-time, a typical solution was to request funding for additional days. Consequently, some of the mBC nurses reported that within 2-3 years their role had expanded from 1 day a week to a full-time or almost full-time role or that additional part-time mBC nurses had been recruited to meet the increasing demand for services. However, funding deficits were reported by some as ongoing issues, with a few nurse participants reporting that despite feeling over-stretched they felt pressured to justify and quantify their role.

It's just not humanly possible to meet the needs of a massive, massive area with one person. (Nurse)

I was completely overloaded with patients I had close to 200 patients which no way I could manage, so the organisation here was really pushing McGrath for another metastatic nurse. The health department had also put in an application for a metastatic nurse sometime earlier and had been rejected. (Nurse)

Even when additional funding was available to increase service capacity, many nurses indicated they found it challenging to keep on top of their workload, particularly returning calls from patients with mBC or their families, and following up with those in the community on oral therapies. Nurse participants reported feeling like they needed to be in multiple places at once, and that they were constantly trying to keep on top of their workload. One of the challenges was that unlike eBC patients, women with mBC were not discharged from the care of the breast care nurse but would remain the responsibility of the mBC nurse potentially for many years. Patient caseloads could therefore quickly expand.

Sometimes you get crazy, like I'll put it in my diary, I'll put it on the Outlook and I go, I haven't rung ... I had to ring her a week ago and I still haven't. So, I'll put it in my diary, and I'll put it in the next day and the next day, and other things take over. (Nurse)

My mantra to myself which is terrible is oh my god, I'm so busy and so behind, it's terrible. But I don't know how you change that because that is the nature of this work. (Nurse)

Redefining the scope of the role as patient numbers increase

The growing demand for their services meant that mbC nurses often had to revisit their role to determine what key elements needed to be retained and what tasks and responsibilities could be dropped or shared with others, such as counsellors, palliative care nurses, support group facilitators, social workers, practice staff or MDT coordinators. Several nurse participants indicated that they were constantly reprioritising and rationalising what they did and when, and to whom they provided support.

Many nurse participants indicated that over time, as their caseload increased, they had to shift their focus from supporting *all* women with mBC to supporting those with the greatest and most immediate needs (Box 4). This typically meant triaging patients according to the complexity of their care, the severity of their disease or treatment side-effects, and the seriousness of their psychosocial needs.

If that gets closer to 200 people [with mBC that I'm looking after], I think the concern is that the support you provide might be spread quite thinly, or that you provide more support to some people maybe because they need it, or maybe because they're the ones that contact you. (Nurse)

Nurse participants also anticipated that as their patient caseloads increase, the role may also shift to focus on providing care only at particular moments in the disease trajectory, that is, initial mBC diagnosis, disease progression, changes in treatment, nearing end of life. However, some reflected that supportive care for women with mBC does not follow a linear trajectory and care pathways and support needs to be responsive and flexible to the needs of individual patients.

You just learn to prioritise. But I just feel that maybe the women that are just going along okay in the community are no longer just getting a call from me to check in with them. I don't know whether that'll change and it's just particularly busy at the moment, or whether this role is just increasing with time? (Nurse)

Nurse participants reflected on the potential impact of the changes to their role on the quality and quantity of care they provide. Concerns were raised by some nurse participants about how to maintain the level of person-centred, holistic care which patients currently valued. Concerns were also

Box 4 Prioritising which mBC patients to support

Increasing mBC patient numbers meant prioritising those with the greatest, most immediate needs, for example:

- inpatient versus outpatient
- point in mBC disease trajectory (e.g. newly diagnosed, disease progression, treatment failure, end-of-life)
- acute versus chronic care needs
- complexity of their treatment regimen
- severity of disease symptoms or treatment side-effects
- the seriousness of their psychosocial needs
- the amount of support available from others (e.g. GPs, community services, family and friends)
- contextual factors such as caring responsibilities (e.g. ageing parents, young children) or financial hardship
- the needs of the family.

expressed about how to maintain the relationships that they had worked hard to develop. Nurse participants commented that: *"in the past we would sit in on oncology appointments, but that's not always possible now"* (Nurse) and how they are sometimes no longer able to call women in the community to check in on them. There was some concern that it would be the patients on the ward with acute clinical issues who would be prioritised, perhaps at the expense of patients with potentially serious and debilitating psychosocial needs. Access to palliative care nurses, pastoral care services or patient navigators might help to ease the load on mBC nurses whose role is becoming dominated with dealing with patients in the last year of their life at the expense of those newly diagnosed or dealing with disease recurrence.

Dealing with the increasing complexity of care coordination

Several nurse participants reported that despite many years of limited services for women with mBC, the number of appropriate services is gradually increasing. This is being driven by the growing awareness of the mBC patient population and their specific supportive care needs by allied professionals such as dietitians, physiotherapists, exercise physiologists, palliative care clinicians, social and pastoral care workers within and beyond the hospital system. Consequently, the mBC nurses' care coordination role is becoming increasingly complex. The complexity of care coordination is further increased by the heterogenous nature of individual needs of the patient and the difficulty in finding appropriate services or competition for limited services. Nurse participants anticipated that the care coordination aspect of their role will continue to grow over time as women with mBC are living longer and more services enter the advanced cancer space.

[Patients with mBC] are never straightforward ... there's so many different providers involved. [For example], I think there was 12 different people working with this lady between the specialists and the nurses and the community teams. It's a real struggle to coordinate all of that, really. I think [the mBC nurse role] is going to be a bit more liaison and coordination because there's more and more services coming along. Particularly in the private sector. [The role] is definitely going to be a lot more coordination as well as patient contact. (Nurse)

Some were concerned that the level and complexity of the care coordination undertaken by mBC nurses sometimes goes unrecognised and undervalued. Nurse participants commented that many aspects of care coordination and associated support (i.e., psychosocial support) that happens simultaneously are hidden from view and not captured accurately in data collection systems:

Well, often, I'm doing everything at the same time so I just put coordinating care, so it doesn't have to capture purely psychological care, but I'm hoping that when I tick coordinated care, they know that that includes psychological care. (Nurse)

3.3.2.2 Getting cover for leave or additional support during busy periods

Nurse participants who worked autonomously, who covered a large geographical area, who had strict role boundaries, or who worked with eBC nurses not experienced in supporting women with mBC reported experiencing difficulties in getting cover during periods of leave or additional support during busy periods. Some nurse participants reported that because they worked so autonomously that there appeared to be little departmental or managerial buy-in when it came to ensuring that their mBC patients continued to receive high-quality care during periods when they were on leave. This left some nurse participants feeling guilty or concerned about the potential backlog they would face on their return to work. One participant with responsibility for both eBC and mBC patients reported that if one of

the other breast care nurses went on leave that her attention shifted to caring for the more immediate and time-critical needs of those with eBC at the expense of her mBC patients.

It's a difficult role, because there is no colleague that I can say listen, I'm really under the weather, I'm stuck on the ward, could you just go and call these five people back. I don't have that luxury. (Nurse)

It is a little bit hard more recently and that's because [name of breast care nurse] my colleague was off for six weeks on leave. Then I found that there's a lot – like I had one of the other breast care nurses came over two days a week. But there was only certain things ... she's relatively new – well newish to the role, so she didn't do any metastatic stuff here. (Nurse)

3.3.2.3 Developing the mBC nursing work force and mentoring new mBC nurses

A potential challenge to the long-term development and sustainment of the mBC nurse role was the relatively limited pool of experienced breast care nurses available to transition into the role of mBC nurse. Related to this was the lack of clear pathways into the mBC nurse role and time it takes to develop the expansive skillset and relationships required for the role of mBC. Concerns were also expressed that those with the level of experience required are reaching retirement age and/or have already been recruited by The McGrath Foundation as mBC nurses:

So what's happened over the years with the McGrath Foundation they pick the cream of the crop, the ones that had the experience and then those wanting to be, like myself, we've aged – there's some us still with experience but a lot have retired. Then a lot of the ones that had experience were also absorbed by the McGrath Foundation. So when new positions were created there hasn't been people – there hasn't been staff that have qualifications that can just step in and run with it. (Nurse)

Nurse participants also mentioned that pathways into mBC nursing are not readily identifiable for potential candidates, and that existing postgraduate nursing qualifications do not adequately cover mBC. Recognisable educational pathways and career transitions were considered important for addressing recruitment shortages and for developing an experienced and sustainable workforce.

Several nurse participants indicated that mentoring was an important part of building a sustainable workforce of mBC nurses. Mentoring was reported as being particularly important in rural and regional areas where the pool of suitably experienced and qualified nurses for the mBC nurse role is more limited than in metropolitan areas. However, for some nurse participants, mentoring added additional pressure to meeting the demands of their patient caseload.

I'm mentoring the other [metastatic] breast care nurses ... because they're less experienced and have come in with that very early [breast cancer] focus ... Because it's hard enough coming in if you're not all that familiar and having to gain your knowledge and your skills and confidence to care for women with early breast cancer, let alone being thrown into caring for women with metastatic breast cancer because it's quite different. The needs are very, very different. (Nurse)

Yeah, and so they – because in the rural areas because ...some of them some don't have the skills and the knowledge, or they might be quite new to the role, or they might have come in in associate roles where they don't even – previous to becoming a breast care nurse they haven't

had oncology palliative care or anything like that. So they've come in very, very fresh in terms of breast cancer. (Nurse)

3.3.3. Supporting the wellbeing of mBC nurses

Nurse participants expressed a strong sense of job satisfaction in supporting women with mBC. They believed that their role was important and made a difference to their patients and the patient's families. They felt privileged to be able to provide support during this challenging period of the patient and their families lives. The difference they made to patients' experiences of mBC was often acknowledged by patients and their family members, meaning that nurse participants felt valued and respected.

However, despite the positive aspects of the role, nurse participants acknowledged that the intensely emotional and demanding nature of the role could potentially impact on their wellbeing. Several nurse participants expressed a need for greater support to help them to deal with these challenges both in the short and long term.

3.3.3.1 *The emotionality of working in the advanced cancer space*

The role of the mBC nurse was reported to be at times "emotionally fraught" and "emotionally draining" (Box 5). A range of factors were mentioned by nurse participants as increasing the emotionality of working with women living with mBC and their family members in comparison to eBC nursing.

The intensity of the psychosocial support required by many of the women with mBC was commonly reported. Several nurse participants pointed out that this contrasted with the more routinised, practical and tasked-oriented care nurses provided for patients with eBC.

The difference I think, is that early breast cancer is fairly physical and practical and looking at wounds, looking at drains and all of that sort of thing and in metastatic it is much more psychosocial. (Nurse)

Another frequently mentioned challenge was the need to have difficult conversations about topics that people often do not talk about on a day-to-day basis – such as talking with partners and children about the women's life limiting illness, conversations about wills and funerals, when to cease treatment, and when to enter palliative care. Nurse participants were acutely aware that these topics are emotionally

Box 5 An emotionally demanding role

Participants reported many factors that contributed to the emotional nature of their work, including:

- the complexity and depth of the psychosocial support required by patients
- the uncertainty of the diagnosis and disease trajectory, of prognosis, time scales and outcomes
- the intensity of relationships that could span many years
- the frequent need to have difficult conversations with patients and families about emotionally charged matters
- the need to balance patient confidentiality with a family member's desire for information, especially when patients wanted to shield family from the impact of mBC
- the desire to help those patients who themselves had caring responsibilities, e.g. children, elderly parents, or partners with their own health issues

laden topics for patients and family members, and this contributed to elevated emotional responses amongst some nurses themselves.

Talking to patients and their families also involved careful negotiation of patient confidentiality, and the need to balance the emotional and informational needs of women with mBC alongside those of family members. This was particularly difficult when patients were wanting to shield their family members from the lived reality of their cancer experience and the inevitability of their prognosis. At times nurses needed to manage family members who felt frustrated and angry that they were unable to get the information they wanted about their wife's (mother's/daughter's/sister's) prognosis, treatment, side-effects or general wellbeing.

It can also be difficult though if a partner calls, trying to get information and I don't give it. That can make them quite angry, but that's just the way it is. (Nurse)

Several nurse participants commented on the additional emotional burden that they felt when it came to supporting particularly vulnerable patients, such as those with children and women who had little social, emotional, or practical support. Nurse participants were very aware of the unique psychosocial needs of these patients and the relative lack of resources and supportive care services available to meet these needs, resulting in them feeling a greater responsibility towards these patients.

The younger ones are much more distraught. I've got two at the moment who are 35 and they were diagnosed at 30 with their early breast cancers and now it's come back. They've got young children. They've got young husbands. The family is still working. There's the whole loss of income factor. Do we - how do we tell the kids? Who's going to look after the kids? It's a much more traumatic experience for them and it's a much more traumatic experience, what I've seen lately, for the staff looking after them as well. (Nurse)

And finally, as noted in Section 3.3.3, the close and intimate relationships and sometimes friendships that formed with patients could potentially span many years, intensifying feelings of loss, sadness, and grief when the patient died, and creating an additional emotional burden for mBC nurses.

3.3.3.2 Burnout a risk factor for mBC nurses and to patient care

Many nurse participants indicated that there was a real need to minimise the risk of burnout and to help maintain positive wellbeing among mBC nurses over the longer term. Several reported feeling "overwhelmed", "challenged", "stressed" and "tired" due to the emotionality associated with their role, complex and unpredictable nature of their work, pressures in managing scarce time and resources, difficult decision making and prioritising, and feeling like the "meat in the sandwich" between patients and clinicians when advocating. Concern about potential burnout among mBC nurses was raised as an issue not only by the mBC nurses themselves but also by some of the women with mBC who were interviewed.

I do get a bit stressed and I get really tired ... I've actually been thinking about calling the Staff Wellbeing and Support Service where they have counselling for staff. I haven't done it yet because every day I'm just too busy and I never get around to ringing up. But I'm thinking that's what I should do, yeah, because I do feel overwhelmed sometimes. (Nurse)

I know they can be run off their feet at times. Sometimes you wonder how stressful their role is and the demands that are placed on them. (Woman with mBC)

Furthermore, the perception among patients that mBC nurses are overloaded and busy negatively affected nurses' sense of morale and created concern among some of the nurses that patients would hold back contacting them, potentially negatively impacting on patient care (see Parker et al., for discussion on factors which predispose people to burnout).³⁵

3.3.3.3 Strategies for supporting the wellbeing and longevity of mBC nurses

Nurse participants were very aware of the need to protect themselves from burnout and to actively engage in strategies to support their wellbeing. Several mentioned features peculiar to their role that they believed were protective, as well as more general institutional or organisational supports that were available, and personal self-care techniques that they relied upon.

Job sharing, dual roles and shared care

Job sharing, that is working part-time with another mBC nurse, was seen as one way of reducing stress, sharing the emotional load and providing access to appropriate cover for leave and absences. An alternative model reported by a few of the nurse participants was to have all the breast care nurses working within a breast cancer service trained to support both mBC and eBC patients.

It's not ideal, I think, to have just one full-time [mBC nurse]. I think, ideally, it's good to have it as a part-time role or a job share role. (Nurse)

Similarly, some viewed it beneficial for the eBC and mBC nurses to work together as a team, as it facilitated decision making and referrals, and created familiarity across the patient cohort, which helped the nurses to cover for each other when on leave. It was also mentioned that having some exposure to supporting women with mBC when working as a breast care nurse helped breast care nurses develop the experience needed for transitioning into the mBC nurse role.

The early breast care nurse and myself work very closely; we sit next to each other basically ... Like today, I'm covering for her, for example. Patients get to know both of us by sight if you know what I mean, because we help each other out and look after our patients together if one of us is off. So, yeah, we work very much together but independent. Our jobs are obviously very different, but we're seen as a team basically. (Nurse)

However, other nurse participants indicated that they believed that the advantages of working closely with eBC nurses were outweighed by the disadvantages, specifically that it impacted on the quality of care given to people with mBC. These nurse participants stressed the importance of maintaining clear boundaries and working independently of the eBC nurses to ensure the needs of women with mBC are met. There were reports that the needs of women with mBC may not be prioritised when working in a dual role owing to the high volume of women with eBC, the physical care needs of women with eBC taking priority over the psychosocial needs of women with mBC, and the greater visibility of women with eBC in the hospital setting.

This is the whole point of why this role was set up here because the early breast care nurse identified that she could not get to the metastatic patients because you're so busy with all the early breast cancer patients. There's no way she could provide ongoing support for all the metastatic people. (Nurse)

Appreciation was also expressed for women with mBC participating in support groups or seeing psychologists or counsellors, as it helped lessen the psychosocial load on the nurses when patients and

their family members received support from a wider support network. Shared care or integrated care models that linked the patient into other healthcare services and providers, such as general practitioners and palliative care professionals, helped to lighten the load and reduce the emotional burden that some of the nurse participants felt in relation to supporting women with mBC. Commenting on how a shared care model helped to maintain longevity in the role one participant stated:

I think for me, I don't think I could have stuck it out this long without the shared care [i.e., working with other health professionals and services]. I think [sustainability is about] making sure that it's not a standalone role, that it works in with all the other services. Especially palliative care and that. You couldn't do this role on your own if you were trying to do the job of all the other services instead of actually linking in with them. (Nurse)

Being part of a community of practice

Feeling connected to a larger community of practice was important for many of the nurse participants. Participants spoke highly of events that fostered a sense of peer support and camaraderie, that facilitated reflective practice and that provided opportunities to work through issues with peers. Conferences, networking with other mBC nurses and attending MDTs enabled mBC nurses to connect with other mBC nurses and other health professionals, particularly oncologists, social workers and palliative care workers on a personal as well as a professional level. Informal opportunities for connection and peer support were also valued, such as discussions in hospital corridors and lunchrooms, however it was noted that not all nurses have these opportunities, even less during the Covid-19 pandemic:

The other thing that is really good is the network of McGrath metastatic nurses. We do have Zoom meetings – not often, but just every couple of months... Yeah, so I think that connecting with other metastatic nurses is really important from my point of view. (Nurse)

I didn't really know a lot of [the other mBC nurses] and I just felt so comfortable because we all had this common thing, we were all really passionate about. (Nurse)

Some of the nurse participants who worked outside of the hospital setting commented that they felt that they missed out by not having easy access to opportunities for informal support from their peers, and that they missed having colleagues with whom they could bounce ideas off.

Maintaining boundaries around one's role and relationships

Maintaining boundaries was viewed as important for longevity in the role of mBC nurse. However, role ambiguity and gaps in the system contributed to the blurring of boundaries for some nurse participants, particularly those expressing perfectionist traits:

I find with this job, especially if people are out in the community, you just end up being the person that just kind of takes things on ... I can't really work out like should I be doing this, should the GP be doing this, should I get a community social worker and I guess sometimes, I take the attitude, which is probably not correct, where it's just rather than finding out the answer to that, it's just easier for me – I'm a bit of a martyr, it's just easier for me to get it done. So I just do it. (Nurse)

A lack of awareness among other health professionals about how the role of mBC nurse differs from the traditional role of breast care nurses also posed difficulties for some nurses in establishing clear role boundaries.

This happens sometimes, [the mBC nurses] are pulled and pushed and expected to do this and that. So I'm kind of trying to keep my boundary about what I can do because - and [the early breast care nurses] are not helping me. So I've got to do my work. So I've got to focus on my patient cohort and [the early breast care nurses] do theirs. That's just the way I've done it from the start because that's how I was told my role should be. (Nurse)

Furthermore, nurse participants indicated boundaries for the role of mBC nurses are not clear cut or fixed, and instead vary based on setting and in response to patient caseloads, level of psychosocial support provided, status of the mBC nurse within the sector, as well as the individual mBC nurse's level of experience and capabilities. Nurse participants indicated boundary management is learnt over time and comes with experience on the job, developed in response to individual workloads, capabilities, and relationships. At times boundaries between personal and professional life blurred (e.g., working back, taking work home, managing stress and grief), as did boundaries with patients (e.g., buying gifts for patients' children, dropping off medications at home, developing friendships).

I'm kind of quite big on boundaries now and I think I've had to learn that. So I used to when I started, I think I was just really nice and I just wanted to please everybody and I've just realised that you can't. (Nurse)

I really think my years of experience of nursing, not just breast care nursing, but just my life experience and nursing experience, helps me manage that load. I'm very strict. I pretty much work 7:30 until 4:00 or 4:30. My message says I work until 4:00. I give them 15-20 minutes and then I switch my phone off. We're not an emergency service. There's other numbers they can ring out of hours. I think being in such an autonomous role, I have to set the boundaries like that, because you've got to have a turn-off point. (Nurse)

Clinical supervision and psychological support

There was widespread support amongst nurse participants for formalised, structured support systems and supervision, both as a preventive approach and in times of need. However, there were differences in the types and availability of support for nurses. Only a few had access to organisational or institutional support, and some indicated this support was inadequate or not appropriate to their needs (e.g. support provided through Employee Assistance Programs):

But then everyone went well, we're not really sure who to give you for clinical supervision because we don't have anyone who works in the sphere that does the same sort of thing. I now get clinical supervision from one of the [name of service] counsellors who has no idea what I do [laughs]. Still doesn't to this day. To me, that's a little bit ineffective, to be honest but it - that's kind of [name of service] feels that that's filling their obligation as well to look after my mental health. (Nurse)

Nurse participants acknowledged that unlike those working in psychology, formalised, routinised clinical supervision or support has not traditionally been part of their role, but would be helpful, given the level of psychosocial support provided by mBC nurses, intensity of the healthcare relationship, and their repeated exposure to death and dying.

Traditionally, boundary management was a way for nurses to manage the emotionality associated with their role, but with women with mBC living longer, relationships are changing, accompanied by different boundaries. Discussing the emotional load of working with women with mBC and need for supervision, one participant stated:

In the first couple of weeks, I sat with my manager and I said, I want to cement into the role ... clinical supervision. Because, I said, it's a demanding role. Breast cancer - there's something about breast cancer patients. Other oncology nurses will tell you too, breast cancer, the patients - it's very emotional. It's very intense. Whether it's because it's mainly women and they're carers, they're mothers, they're organisers....it's really emotionally draining. (Nurse)

Self-care strategies

Some nurse participants reported they used their own self-care strategies to manage the challenges, demands and grief that come with working in the mBC space. Strategies included attending funerals, sending a card or lighting a candle to acknowledge the death of a patient and to help with closure.

I'm quite strict; I don't - I've become quite strict. I don't go to funerals at all. I light a candle at home, kind of acknowledge every loss because I think the day that I don't acknowledge a loss is the day that I'm burnt out. (Nurse)

Other strategies included engaging in physical activity, mindfulness, meditation, hobbies and spending time with family and friends.

...a more practical thing it's knowing how you can destress and debrief. For me it's walking, it's talking to friends not about work, it might be going to the movies, it might be reading. I think everyone has their own different coping mechanisms that work for them. Because otherwise you'll find that people go out of oncology reasonably quickly after a few years if they haven't got those kind of coping strategies because otherwise there is the chance, they'll burn out absolutely. (Nurse)

However, some nurse participants indicated that these strategies were not always helpful and they continued to feel stressed and tired, and concerned about burn out.

I try to take care of myself, exercise and eat well and all those sorts of things. But look, I do get a bit stressed and I get really tired. I had a couple of weeks off a few weeks ago and about three days before I was due to come back, I started getting really stressed...That really worried me about this anxiety building up when I'm on a break. (Nurse)

These comments by nurse participants reflect what has been reported more widely by others working in oncology and in the healthcare sector generally.³⁶ Health professional burnout is increasingly being recognised as an issue needing to be addressed, with the issue worsening since the start of the COVID 19 pandemic.³⁷

5. SUMMARY

This study examined the perceptions and experiences of the mBCN role, scope of care and support, and opportunities for future role development. In line with the project aims, this study advances our understanding of mBC experiences in the Australian health context, where gaps in supportive care for those with metastatic cancer are known to exist. In particular this study increases our understanding of the contribution the specialised mBC nurse (or an appropriately trained and experienced general breast care nurse) can make to the care received by people living with mBC. Those with mBC are a diverse population with significant unmet needs in areas such as symptom and side-effect management, psychosocial support and access to appropriate health services. This knowledge is directly relevant to key end-users such as patients, advocacy organisations, policy makers, hospital administrators and nurse and clinical oncology practitioners in the advanced cancer space.

The mBC nurse role was shown to be a valued addition to the field of clinical and supportive care for people living with mBC and their families through the provision of person-centered, holistic care and support. While there was some heterogeneity in the role of the mBC nurse across different settings and institutions, in terms of scope, funding, and inter/cross-professional collegiality, patterns were present across the perspectives of women with mBC, family members and mBC nurses.

The mBC nurse provided a vital first point of contact for women and their family members at all stages of the illness trajectory, providing an integral and continuous link across clinical, supportive, and palliative care. In addition to complex care coordination and system navigation, the mBC nurse managed a wide range of disease symptoms and treatment side-effects, provided high-level emotional and practical support to patients and family members, and acted as a patient advocate to ensure the patient received the care they needed. Nurses not only played a critical role in reducing the care burden on patients and family members, but they also improved the way in which the patient moved through the system.

Importantly, the mBC nurses were integral to improving the experience of care for women with mBC and their families. Of particular importance to patients and family members was the mBC nurse's support through critical and often highly stressful transitions, such as initial mBC diagnosis, disease progression, changes in treatment, end-of-life planning and palliative care, including determining goals of care. In part this was because the nurse was reportedly one of the few healthcare professionals who fully understood the impact of the diagnosis and the complex, often highly psychosocial, supportive care needs of these patients. A defining characteristic of the role was the quality of the healthcare relationship that developed between the mBC nurse and the person with mBC, a consequence of the length and depth of the nurse's engagement with the patient. Crucially, mBC nurses reportedly helped patients with mBC to feel cared for and their needs validated in a system that has historically been designed primarily to meet the supportive care needs of those with eBC.⁹

Success in the role reflected the nurses' commitment to those with mBC, their high-level clinical and healthcare system knowledge, their connections to other healthcare professionals within and beyond the hospital setting, and the high levels of respect and recognition with which they were held by other staff within the healthcare system. Critical to this success were the years of accumulated experience as an oncology or breast care nurse combined with in-depth knowledge of other disciplines such as palliative care, psychosocial care and counselling. Given the relative scarcity of appropriate supportive care or survivorship services for those with advanced cancer, the role of the mBC nurse was viewed as filling an important supportive care gap in oncology care in Australia today.

6. RECOMMENDATIONS

1. Given the potential benefits to patients, families and the healthcare system, the specialised metastatic nurse role should be considered as a standardised option in healthcare settings for people with mBC.
2. Access and equity issues need to be addressed to ensure anyone living with mBC has the support of an mBC nurse.
3. Many aspects of the mBC nurse role are likely to be generalisable beyond mBC. The potential applicability of this role to people living long-term with a metastatic or advanced cancer diagnosis should be considered.
4. To optimise scalability and long-term sustainability of the mBC nurse role, core elements of the role most valued by people diagnosed and living with mBC and their families need to be identified. This would allow identification of tasks and responsibilities that could potentially be provided by others such as administrative or healthcare staff (e.g. social workers, counsellors, psychologists, palliative care professionals, patient navigators or care coordinators)
5. Part of the mBC nurse role (including the funding model for the mBC nurse positions) should include succession planning and staff development to ensure appropriately trained staff are available to meet current and future demand for these positions.
6. Set-up and establishment of the mBC nurse role requires time to establish effective integration into the healthcare setting. Adequate time should be allowed for set-up and establishment of the mBC nurse service prior to the mBC nurse seeing patients, with a focus on:
 - a. identifying people recently diagnosed and those living with mBC
 - b. establish relationships with the healthcare professionals who will potentially be referring patients to the mBC nurse.
7. For newly established mBC nurse roles and services, education and awareness at the hospital management and executive level are key to establishing and ensuring ongoing support for mBC nurse roles.
8. mBC nurse roles would benefit from formally institutionalised support structures to manage wellbeing and prevent burnout, such as additional clinical supervision.
9. Defining the scope and patient load for an mBC service is key to manage best practice care and staff wellbeing. Establishing triage and alternative referral pathways along with referral capacity limits should be considered.
10. Professional development is critical to allow mBC nurses to keep abreast of advances in mBC treatment and supportive care; furthermore:
 - a. investment should be prioritised in order to maintain and develop the clinical knowledge of current and future mBC nurses
 - b. consideration should be given to upskilling other nurses to enable backfill and succession planning
 - c. representatives from multiple sectors, including peak cancer nursing organisations and researchers from the university sector, need to be included in discussions regarding formal training requirements for specialised metastatic and advanced cancer nurses.
11. Relationship management, communication with other healthcare professionals and ongoing advocacy are key to ensuring patients with mBC receive the best care; it is therefore essential that:
 - a. mBC nurses receive training to support development of communication and advocacy skills and resources to assist in building effective relationships.
12. MDT engagement from an mBC nurse, where one is available, should be considered as this has the potential to improve quality of patient care.

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8. APPENDICES

Appendix A: Interview guide for mBC nurses

Appendix B: Interview guide for women with mBC

Appendix C: Interview guide for family members of women with mBC

Appendix A Interview guide: mBC nurses

Introduction

Researcher introduces themselves and briefly describes the purpose of the study, the voluntary nature of participation, and the interview process. First, I have some questions about your nursing experience in general and then we will focus on your experiences of the providing supportive care to women with metastatic breast cancer. I will ask you a few questions, but feel free to also talk about the things that are important to you. Before we get started, do you have any questions?

During the course of the interview, ensure the following demographic information is captured

Age, qualifications and experience (e.g. nursing/cancer/breast cancer/palliative care/counselling); setting (community; private vs public; metro/regional/rural); employer; years in current position; FT or PT; mBC only or mBC and eBC (if so, dedicated days for different pt groups?); job-share?; approx. nurse to patient ratio (e.g. 1 FTE per 100pts)

Broad questions

Can you tell me about your involvement in breast cancer care?

Can you tell me how your role is set up at [name of service]?

What would you say are your key responsibilities?

Can you tell me whether your practice is informed by any particular models of care?

How well do the current models of care meet the needs of women with mBC?

What types of supportive care do women with mBC need?

What do you consider are the key priorities / greatest needs of women and families living with metastatic breast cancer?

What do you think are the gaps in supportive care for women with mBC?

How do you think the mBC nurse role helps to meet some of the (unmet) needs of women with mBC?

What is it about the role that you believe women with mBC most value?

What do their families most value?

BCN: breast care nurse; eBC: early breast cancer; mBC: metastatic breast cancer; HCPs: healthcare providers.

Appendix B Interview guide: women with mBC

Introduction

Researcher introduces themselves and briefly describes the purpose of the study, the voluntary nature of participation, and the interview process. First, I have some questions about you and your diagnosis and then we will focus on your experiences you have had with your breast cancer nurse. I will ask you a few questions, but feel free to also talk about the things that are important to you. Before we get started, do you have any questions?

During the course of the interview, ensure the following demographic/disease status information is captured

Age, date of primary breast cancer diagnosis (if applicable); date of metastatic breast cancer diagnosis; metastatic sites (bones vs visceral); education; current employment status; marital status; children (ages), public vs private medical care.

Broad questions

Can you tell me about when you were first diagnosed with mBC?

Can you tell me a little bit about your disease trajectory – for example, have you had periods in which you've been relatively stable or periods of disease progression and treatment failure?

Can you tell me about the breast care nurses who have been involved in your care since being diagnosed with mBC?

What events or circumstances have triggered you contacting the BCN or the BCN becoming involved in your care?

Can you tell me about your experiences with a BCN? How has this involvement from a BCN been helpful? (was this involvement in any way unhelpful?) ?

What do you think about the amount and type of contact or care you have from your BCN?

What ideally would you have wanted, that you didn't receive from the BCN?

Can you tell me a little about any unmet needs you might have in relation to your diagnosis of mBC and the day-to-day living with mBC?

In what ways has your BCN helped in meeting these needs?

How has the breast care nurse contributed to your understanding of mBC (and about what the future holds for you)?

In what ways has this helped you in making decisions relating to your mBC? Was there anything that was not helpful? Or anything else that would have been helpful?

What about In increasing your understanding of your diagnosis (treatment / prognosis / health and supportive care available)?

In what ways was the support provided helpful with dealing with physical symptoms, either of the mBC itself or of treatment-related side-effects? Was there anything which wasn't helpful, or anything else you needed?

In what ways has the BCN helped in providing practical support, e.g. about financial, childcare, work, travel issues? Was there anything which wasn't helpful, or anything else you needed?

Can you tell me if you've ever experienced any anxiety or distress since being diagnosed with mBC?

What is this anxiety or distress related to? In what ways was the BCN helpful in dealing with this anxiety or distress? Was there anything which wasn't helpful, or anything else you needed?

What sort of emotional support does your BCN provide you with?

Summing up, can you tell me what is the most important difference the BCN has made to you or your family?

If you didn't have access to a BCN, who do you think would fill that role for you?

BCN: breast care nurse; eBC: early breast cancer; mBC: metastatic breast cancer; HCPs: healthcare providers.

Appendix C Interview guide: Family members of women with mBC

Introduction

Researcher introduces themselves and briefly describes the purpose of the study, the voluntary nature of participation, and the interview process. First, I have some questions about you and [patient's name] diagnosis and then we will focus on the experiences with breast cancer nurses that you and [patient's name] have had. I will ask you a few questions, but feel free to also talk about the things that are important to you. Before we get started, do you have any questions?

During the course of the interview, ensure the following demographic/disease status information is captured

Age, relationship to woman with mBC; education; current employment status.

Broad questions

Can you tell me about when [patient's name] was first diagnosed with mBC?

Can you tell me a little bit about [patient's name] disease trajectory – for example, have you there been periods in which her disease has been relatively stable or periods of disease progression and treatment failure?

Can you tell me about the BCN who have been involved in [patient's name] care since being diagnosed with mBC? What events or circumstances would trigger you or [patient's name] contacting the BCN or the BCN becoming involved in [patient's name] care?

Can you tell me about your experiences with a BCN? What has been helpful/unhelpful? What ideally would you have wanted, that you didn't receive from the BCN? What do you think about the amount and type of contact or care [patient's name] has received from the BCN?

Can you tell me a little about any unmet needs [patient's name] or you might have in relation to [patient's name] diagnosis of mBC and how you cope day-to-day living with mBC?

Can you tell me in what ways the BCN has helped in providing information about mBC? Anything else you can think of which would have been helpful? In increasing your understanding of [patient's name] diagnosis (treatment / prognosis / health and supportive care available)?

In what ways has the breast care nurse contributed to [patient's name] and your understanding of mBC (and about what the future holds for you both)? How has this helped both of you in making decisions relating to your mBC?

In what ways did the BCN help with dealing with physical symptoms that [patient's name] has experienced, either of the mBC itself or of treatment-related side-effects? Anything else which would have been helpful?

In what ways was the BCN helpful in providing practical support, e.g. about financial, childcare, work, travel issues? What else would be helpful?

Can you tell me if [patient's name] or you have experienced any anxiety or distress since being diagnosed [patient's name] was diagnosed with mBC? What is this anxiety or distress related to? How has the BCN helped [patient's name] or you in dealing with this anxiety or distress?

In what ways does the BCN provide emotional support to [patient's name] or you?

Some women have reported feeling 'excluded' from the breast cancer community. In what ways does your BCN help [patient's name] and you to feel acknowledged and connected to the breast cancer community?

Can you tell me how the BCN has been involved in supporting you and the family?

Summing up, can you tell me what is the most important difference the BCN has made to you or your family?

If you didn't have access to a BCN, who do you think would fill that role for you?

BCN: breast care nurse; eBC: early breast cancer; mBC: metastatic breast cancer; HCPs: healthcare providers.



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