

The Australian Journal of Cancer Nursing

The Official Journal of the Cancer Nurses Society of Australia

Volume 14 Number 2
November 2013



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Evaluation of the McGrath Foundation's Breast Cancer Nurses Initiative

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Abstract

The McGrath Foundation's Breast Cancer Nurses Initiative (the Initiative) was evaluated in 2012, and found to be an evidence-based model for improving the quality of care for women with breast cancer. The model promotes a patient-centred, multidisciplinary approach to cancer care, improving care coordination between health care professionals in metropolitan and regional cancer centres and is broader than a hospital-specific role. From an economic perspective, the Initiative has had a positive impact on improving patient safety. Stakeholders interviewed believed the Initiative has been able to reduce hospital readmissions and/or unnecessary emergency department visits; reduce the time surgeons, oncologists and allied health staff need to spend with patients; and reduce costs to the mental health system. From a quality of life perspective, women surveyed who had access to a McGrath breast care nurse (BCN) were unequivocal in their view that the McGrath BCN has enhanced their quality of life.

Introduction

The McGrath Foundation was co-founded by Jane McGrath and her cricketing husband Glenn after Jane's personal experience with breast cancer. It was this experience that led her to believe that the McGrath Foundation should raise money to place McGrath breast care nurses (BCNs) in communities right across Australia and to increase breast awareness in young Australian women.

The Commonwealth of Australia is a supporter of the McGrath Foundation and the Breast Cancer Nurses Initiative (the Initiative) was established in 2008 following the execution of a funding agreement between the Department of Health and Ageing (DoHA) and the McGrath Foundation. Under the agreement, DoHA provided funding of approximately \$12.6 million for the recruitment, training and employment of new specialist BCNs across Australia.

The increased burden on women with breast cancer in rural Australia, including lower survival, is well documented¹. A study in 2004 found that when compared to metropolitan areas, people with cancer who lived in remote areas of New South Wales were 35% more likely to die within five years of a diagnosis². Contributing to this is evidence that suggests the quality and availability of breast cancer services directly influence survival rates of people with breast cancer³, demonstrating the importance of the Initiative and the relevance of the McGrath BCN model.

The model adopted by McGrath BCNs is one that promotes a patient-centred, multidisciplinary approach to cancer care. The model provides improved coordination of care between health care professionals in metropolitan and regional cancer centres. It is a community-based role, broader than a hospital-specific one. McGrath BCNs are able to engage at a community level with both health care professionals and patients and they are not restricted to a hospital campus location. McGrath BCNs understand the particular burdens of families in rural Australia experiencing breast cancer and can tailor their delivery of care accordingly.

The aim of the Initiative was to improve the quality of care received by women diagnosed with breast cancer in Australia, with a particular emphasis on those women residing in rural and regional areas.

The objective of the Initiative was to recruit, train and employ 30 new specialist BCNs (23 full-time equivalent positions) throughout Australia over four years, enabling an increased number of women diagnosed with breast cancer, especially those in rural and regional areas, to access nurses with specialist breast care skills and training. While the objective was to employ 30 McGrath BCNs, the Foundation ended up funding 44 using the funding allocated for 23 full-time equivalent McGrath BCN positions.

Methodology

The McGrath Foundation engaged HealthConsult to independently evaluate the Initiative. While the Initiative period

was from June 2008 until January 2014, the evaluation included the period June 2008 to June 2012. The methodology used by HealthConsult to evaluate the Initiative involved six stages:

1. A detailed project planning period. This included receiving an initial briefing; finalising the parameters for the project, including the communication process; establishing stakeholders to be consulted; identification of data and information sources, dates for project meetings and submission of deliverables.
2. A documentation and literature review. This involved reviewing the documentation that related to the Initiative as well as that which described other relevant programmes and projects. Literature on best practice in breast cancer care coordination and its impact on service delivery and patient outcomes and on measuring return on investment for similar initiatives was sourced.
3. An evaluation framework was established. This included defining the key evaluation areas, identifying the required data (qualitative and quantitative) to answer each evaluation question, defining the performance indicators to be generated and the strategies for collecting the necessary data.
4. The development of the data collection infrastructure involved three components:
 - a. A survey to gather supplementary qualitative and quantitative data from McGrath BCNs funded under the Initiative.
 - b. Three service-level case studies were selected where McGrath BCNs were located. The service level case study sites were in Wagga Wagga (NSW), Berri (SA) and Bunbury (WA).
 - c. Six patient-level case study sites were selected. Three patient-level case study sites were where a McGrath BCN was located, Wagga Wagga (NSW), Berri (SA) and Bunbury (WA) and three sites that did not have a McGrath BCN or similar role, Scone (NSW), Pinaroo (SA) and Karratha (WA).
5. Gathering the evaluation data involved the following:
 - a. Distributing an invitation to McGrath BCN incumbents funded under the Initiative to complete an online survey.
 - b. Interviews were conducted with health professionals at the service-level case study sites.
 - c. Interviews with women who had been diagnosed with breast cancer were organised at the patient-level case study sites. Focus groups were also organised. The purpose of the interviews and focus groups was to understand the experiences of women with breast cancer.
 - d. Interviews were conducted with key stakeholder groups from the breast cancer and cancer fields.

Two HealthConsult consultants visited each site to conduct the case study interviews. In parallel with this process, meetings were conducted with the agreed key stakeholder groups to gather information about the impact of the Initiative at the health system level.

Throughout the data collection process approximately 60 individuals were consulted. The response rate for the McGrath BCN survey was 93% (41/44). Together these processes produced a comprehensive set of data, which enabled a qualitative assessment of the impact of the Initiative.

6. The evaluation data analysis and final report involved the systematic analysis of the gathered data to identify the evaluation findings.

The evaluation was a qualitative study and the content addressed in this article focuses on the sections of the evaluation that addressed the:

- appropriateness of the Initiative;
- the effectiveness of the Initiative; and
- the efficiency of the Initiative.

Findings

APPROPRIATENESS OF THE INITIATIVE

The appropriateness of the Initiative was assessed by determining whether the Initiative was an appropriate model for improving the quality of care of women diagnosed with breast cancer; whether there were any gaps in the Initiative and whether any improvements could be made.

The appropriateness of the Initiative was assessed by reviewing other BCN models which also aim to improve the quality of care of women diagnosed with breast cancer. The views of key stakeholder groups including Cancer Australia, Westmead Breast Cancer Institute, Breast Cancer Network Australia and the Department of Health and Ageing were also sought.

The evaluation found that while there were similar BCN positions funded in each state and territory, there were a number of differences identified including:

- The Foundation is the only national funder of BCNs.
- The Foundation funds and supports the largest network of BCNs in Australia.
- McGrath BCNs, unlike other BCNs, are not bound by the setting in which they are based.
- McGrath BCNs are annually supported to undertake specialised training and continuing professional development activities.
- All McGrath BCNs attend an annual workshop and/or conference where they share processes and learnings which support the development of a nationally consistent BCN workforce.

From a quality of life perspective it was clear from the health professional and stakeholder consultations that the McGrath BCN role filled a significant gap in health services by supporting patients in a way that has a positive impact on the quality of life of these patients.

Most stakeholders found it difficult to identify gaps in the Initiative, instead suggesting opportunities to extend the Initiative. Suggestions included more McGrath BCNs in the private sector and metropolitan hospitals and in existing locations where McGrath BCNs are located and experiencing an excessive workload. Stakeholders also thought the Foundation should broaden its scope of BCN support and provide opportunities to non-McGrath BCNs to access the support and training provided to Foundation-funded McGrath BCNs. The gaps identified by stakeholders included backfill support to McGrath BCNs and formal provision of emotional support to McGrath BCNs, (particularly the McGrath BCNs located in geographically isolated areas), were found to be being addressed through strategies implemented by the Foundation.

EFFECTIVENESS OF THE INITIATIVE

The effectiveness of the Initiative was assessed by its impact on patients, on the health service and on the health system.

Impact of the Initiative on women diagnosed with breast cancer

The most important component of the evaluation was measuring the impact of the Initiative on women diagnosed with breast cancer. This was measured by patient interviews in locations where patients had access to a McGrath BCN compared to where McGrath BCNs were not located.

The evaluation found that women with access to a McGrath BCN were well supported throughout their entire cancer experience. As McGrath BCNs are connected within the communities in which they work, women with access to a McGrath BCN were more aware of available services compared to women who did not have access to a McGrath BCN.

The McGrath BCN was also key in the provision of emotional support, particularly in regional and rural areas where access to psychologists is either limited or costly.

The McGrath BCN had a strong positive impact on patients' experience and their families and the women surveyed could not imagine how difficult their experience would have been without the McGrath BCN. Women with a McGrath BCN who were interviewed were unequivocal in their view that access to a McGrath BCN has enhanced their quality of life.

Five out of the nine control interviews did not have access to a BCN or McGrath BCN and, in comparison, these women diagnosed with breast cancer had greater difficulty accessing information and support and often utilised more ad hoc

methods including through referral from fellow patients, community members and breast cancer support groups. These women also expressed how they struggled to cope with the emotional burden of cancer, how and where to access services, and the impact of breast cancer on their family. They also felt that there was no one dedicated to helping them through the experience by assessing their needs and referring them to the most appropriate service. Most reported relying on the information packs provided to them when they left hospital, but identified that this did not inform them of the local services and meant the onus was on them to identify services appropriate to their needs.

Delays in access to treatment or services were more evident in areas where BCNs were not employed. Four out of the five of these women expressed, "frustration with the time, energy, and, in some cases, cost required to access services such as lymphoedema treatment, garments and prostheses".

Impact of the Initiative on health services

The evaluation sought to determine whether the Initiative had been effective in ensuring McGrath BCNs were seen as a source of knowledge and had expertise in breast cancer care; that McGrath BCNs improved the coordination of care of women with breast cancer, and that McGrath BCNs used evidence-based clinical guidelines and models of care when providing their service to women diagnosed with breast cancer.

The McGrath BCN survey asked McGrath BCNs about the types of services they provided to women with breast cancer and the findings demonstrate that McGrath BCNs provide a range of services that support the patients' emotional and physical wellbeing, including knowledge of their diagnosis, treatment and services available to manage side effects.

The breadth of services provided by McGrath BCNs was also reported by patients, other clinicians and services managers during the site visits. These findings were consistent with the McGrath BCN survey results.

The McGrath BCN survey asked McGrath BCNs whether they follow the specialist breast nurse (SBN) model of care developed by the former National Breast Cancer Centre⁴. The majority of McGrath BCNs, (60%), reported they follow this model with about a third reporting they followed a different clinical pathway model. Geographical location was identified as a factor in the adaptation of the clinical pathway with McGrath BCNs reporting that whilst utilising the pathway as a framework they adapted it to enable them to provide patient-centred care in the context of the location that they were practising in.

Although clinicians and McGrath BCNs consulted recognised the clinical pathway as best evidence-based practice, some felt that the SBN model of care was too rigid and prescriptive, and given it was developed over 10 years ago, most felt it was time

to conduct the research again to ensure it still represents current evidence-based practice.

Multidisciplinary team involvement

McGrath BCNs were asked about their involvement in multidisciplinary teams (MDT). The evaluation found that McGrath BCNs are active participants of MDTs. Table 1 demonstrates that 76% of McGrath BCNs have been active in establishing positive working relationships with MDT members. Seventy-one per cent participated in MDT meetings and 71% built support or referral networks for breast cancer clients via MDTs.

Education

When assessing the knowledge and expertise of McGrath BCNs, the evaluation found the McGrath BCNs funded under the Initiative are highly educated, skilled and knowledgeable professionals dedicated to making a difference to the quality of care received by women diagnosed with breast cancer. This is not surprising given that McGrath BCNs are required to have five years' post-registration experience in oncology or breast cancer, along with a Graduate Certificate in Breast Cancer Nursing. Where nurses do not have qualifications, the Foundation provided funding for nurses to up-skill and complete a Graduate Certificate in Breast Cancer Nursing.

Impact of the Initiative on the health system

The evaluation sought to determine whether the Initiative had increased the capacity of the system to provide women with breast cancer access to a nurse with specialist breast care skills and training, and if the Initiative had an impact on emergency room or hospital admissions.

In most instances, McGrath BCNs funded through the Initiative were located in areas where BCNs previously did not exist. Given this, the Initiative has improved the access of women diagnosed with breast cancer to a BCN. A total of 11,073 women (during the reporting period) had access to a McGrath BCN as a direct result of the Initiative during the evaluation period.

The frequency of McGrath BCN contacts suggests the need for the resource. The evaluation found that, on average, women diagnosed with breast cancer had contact with their McGrath BCN about 12 times across their treatment trajectory, made up of direct and indirect contacts.

Impact on unplanned emergency or hospital admissions

The stakeholders consulted suggested they expected McGrath BCNs would have an impact on reducing hospital admissions or readmissions and/or unplanned emergency department (ED) visits. Unfortunately quantitative data was not available to verify this perception. However, most McGrath BCNs believe the Initiative had either a high (49%) to some (46%) positive impact on reducing hospital readmissions and/or ED visits of their patients. This is further collaborated with most other stakeholders consulted agreeing the Initiative had been able to reduce ED presentations, particularly for those that are postoperative. Again both McGrath BCNs and consulted stakeholders concur this is difficult to measure.

Health professionals identified a range of areas where McGrath BCNs have improved or established cancer networks. Stakeholders reported the McGrath BCN role had been instrumental in developing positive working relationships with a broad range of providers responsible for delivering care to patients diagnosed with breast cancer. The strong collaborative and coordinating components of the role were highlighted as another benefit of the Initiative, with these benefits extended to both the patient and the broader health care system.

EFFICIENCY OF THE INITIATIVE

The evaluation sought to determine the extent to which the Initiative duplicates other BCN Initiatives and whether the Initiative is cost beneficial.

Initiative seen as a complementary one

Whilst BCN positions existed prior to the Initiative, the evaluation found the Initiative to be complementary and not duplicative as

Table 1: Role of McGrath BCNs in promoting multidisciplinary care within their local health care organisation

Region	Assist in the development of MDT meetings	Participate in MDT meetings	Establish working relationships with MDT members across the continuum of care	Building referral/support networks for breast cancer clients via MDTs	Ensuring that outcomes from MDT meetings are incorporated into patient care plans	Ensuring that outcomes from MDT meetings are discussed with patients and their carers
Metropolitan	43%	86%	86%	71%	43%	57%
Regional	47%	93%	93%	87%	67%	60%
Rural	42%	47%	58%	58%	37%	42%
Total (average)	44%	71%	76%	71%	49%	51%

Source: HealthConsult McGrath BCN survey. Note: Patients identified as 'regional' accessed a McGrath BCN in either an 'inner regional' or 'outer regional' location as defined by the ABS Remoteness Area Classification. Patients identified as 'rural' accessed a McGrath BCN from a 'remote' or 'very remote' location.

Table 2: Number of women receiving support from the McGrath BCN by location type

Region	Measure	2008-09	2009-10	2010-11	2011-12	Total
Metropolitan	Total contacts by McGrath BCNs ^β	485	6,589	8,696	10,862	26,632
	Total patients seen by McGrath BCNs ^β	172	774	658	694	2,298
Regional & rural	Total contacts by McGrath BCNs ^β	2,028	21,488	38,225	42,110	103,851
	Total patients seen by McGrath BCNs ^β	702	2,522	2,764	2,787	8,775
National	Total contacts by McGrath BCNs ^β	2,513	28,077	46,921	52,972	130,483
	Total patients seen by McGrath BCNs ^β	874	3,296	3,422	3,481	11,073
	Ave McGrath BCN contacts per patient	2.9	8.5	13.7	15.2	11.8

Source: McGrath BCN contacts database developed by the Foundation. Note: The number of contacts was not reported until the 4th quarter of 2008-09; therefore, contacts made in this financial year have been multiplied by four. ^β McGrath BCN contacts database developed by the Foundation.

there remains a demand for more McGrath BCNs. Under the Initiative, McGrath BCNs provided a service in a location where there was either no service, or a need for increased services. This allowed for increased capacity of service provision, supporting a demonstrated need consistent with the increasing incidence in breast cancer.

McGrath BCNs were viewed by patients as a central point of contact that proactively provided information and referral services such as psycho-social support, rehabilitation services, lymphoedema management and breast cancer programmes.

The economic benefit

Whether the Initiative has been cost beneficial was a challenging question to answer without the required quantitative data. Qualitatively, McGrath BCNs, health service managers, other clinicians and cancer peak bodies believe the investment in the Initiative has produced positive results for women who have had access to their services. Although baseline data was not available to undertake a cost/benefit analysis some indicators have been produced on the cost of delivering some of the Initiative outputs. Table 3 shows that based on 11,073 women that had access to a McGrath BCN funded by the Initiative, the average cost per contact with the McGrath BCN is \$94 and the average cost per patient is \$844.

As a means of assessing whether the Initiative has been efficient, it would have been valuable to compare the Initiative's outputs to the outputs of other initiatives. A literature review to identify such outputs was unsuccessful due to the lack of economic evaluation of similar initiatives.

Table 3: Total initiative cost per patient with breast cancer, 2008-09 to 2011-12

Measure	2008-09	2009-10	2010-11	2011-12	Total
Total cost of the Initiative ^α	\$734,902	\$2,803,167	\$2,798,316	\$3,008,662	\$9,345,047
Total patients seen by McGrath BCNs ^β	874	3,296	3,422	3,481	11,073 ^π
Total number of direct patient contacts ^β	2,513	27,412	32,305	37,369	99,599
Initiative cost per new patient seen	\$841	\$850	\$818	\$864	\$844
Initiative per direct patient contact	\$292	\$102	\$87	\$81	\$94

Source: ^α Consolidated progress reports produced by the Foundation and ^β McGrath BCN contacts database developed by the Foundation. Note: ^π Foundation's 8th progress report cites a slightly lower number (10,669 unique patients) due to timing differences in the submission of reports by McGrath BCNs.

The role of McGrath BCNs providing support to patients was also noted by a number of stakeholders as important in reducing costs to the mental health system. Although it is not possible without the required data to measure the impact of McGrath BCNs on improving patient quality of life, anecdotal evidence gathered during the evaluation suggested that McGrath BCNs and patients believe the role has made a positive impact in this regard.

Further, qualitative evidence gathered from surgeons, oncologists, allied health professionals and community nurses indicated that McGrath BCNs save them direct patient contact time as well as logistics and administration time. Hard evidence such as a measure of the amount of time saved could not be generated within the time and resources available for this study. However, time saved by clinicians as a result of the McGrath BCNs is an important finding and would certainly allow time for clinicians to see additional patients, thereby improving access.

To put a value on this saving, the data recently published by the Independent Hospital Pricing Authority (IHPA)⁵ on the prices (which equal the arithmetic average cost) to be used to fund public hospitals for outpatient services under activity-based funding was used. The average of the published prices for medically led outpatient breast surgery, medical oncology and radiation oncology consultations is \$258. In this study it was estimated that the cost per McGrath BCN contact is \$94. So, conservatively for the 11,073 patients who have accessed a McGrath BCN since the Initiative began there has been a benefit (in terms of medical time saved only) of \$2,856,834. This saving alone recovers 31% of the total funds allocated.

Conclusion

The evaluation of the Initiative was a qualitative one and sufficient data was gathered to show that the Initiative has had a positive impact on women diagnosed with breast cancer that have had access to a McGrath BCN; on health services where McGrath BCNs have been located and on the health system.

The Initiative was recognised as an evidence-based model for improving the quality of care of women diagnosed with breast cancer. Since the model is evidence-based and similar models exist in Australia and overseas, it is considered to be an appropriate model for improving the quality of care of women diagnosed with breast cancer.

The evaluation found the Initiative was effective in terms of outcomes. The McGrath BCN role has filled a significant gap in health services supporting patients in a way that has had a positive impact on their quality of life.

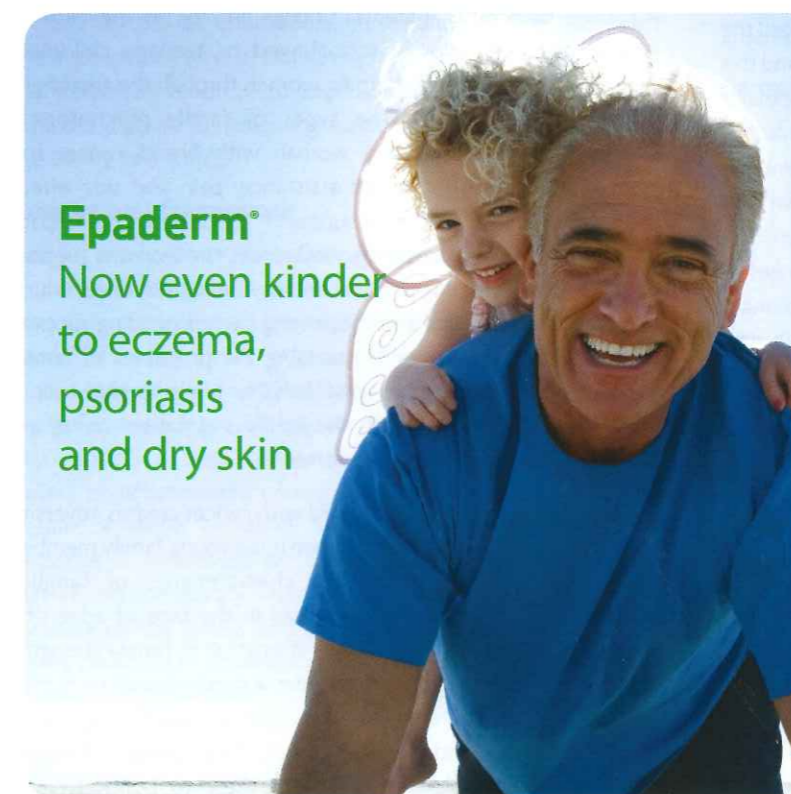
The Initiative was efficient as it was considered complementary and not duplicative of other BCN initiatives; however, there remains a demand for more McGrath BCNs throughout Australia.

The qualitative evidence gathered through the evaluation suggests the Initiative has produced economic benefits; however, qualitative data would quantify the economic benefits of the Initiative.

Future evaluations of the Initiative would benefit from gathering quantitative and qualitative data before a McGrath BCN is funded and then after the position has been funded for two to three years. Collection of this data would enable a more precise measure of the impact of the McGrath BCN. These concepts are currently being implemented by the Foundation.

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