

Breast cancer services – a population-based study of service reorganization

Pauline Monaghan, Liam Murray, Michael Donnelly, Peter McCarron, Roy Spence and Anna Gavin

Abstract

Background The Calman-Hine Report in England and Wales and the Campbell Report in Northern Ireland initiated a major reorganization of cancer services with the aim of improving the provision and delivery of care to cancer patients. In this paper, breast cancer patients diagnosed in 1996 and those diagnosed in 2001 are compared in order to examine the extent of service change in Northern Ireland.

Methods Patients living in Northern Ireland with invasive breast cancer diagnosed in either 1996 or 2001 were identified from the Northern Ireland Cancer Registry database. Information relating to the delivery of cancer care to these patients was collected by retrospective review of their case notes.

Results Breast cancer surgery was performed in fewer hospitals (13 versus 21) by fewer surgeons (19 versus 40) with 98 per cent of patients operated on by designated breast surgeons in 2001. Clinically relevant axillary node excision increased with 765 (87 per cent) patients having six or more nodes excised in 2001 compared to 515 (67 per cent) in 1996 ($p < 0.001$). Recording of oestrogen receptor (ER) status improved from 23 per cent in 1996 to 91 per cent in 2001 ($p < 0.001$) and 81 per cent of patients received hormone therapy appropriate to their ER status in 2001 compared with 6 per cent in 1996 ($p < 0.001$). Communication between hospitals and patients and their GPs also improved.

Conclusion A significant change in service provision and delivery has occurred in Northern Ireland in line with the recommendations of the Campbell report. Further work is underway to ascertain the extent to which these changes may have impacted on patient outcomes.

Keywords: breast cancer; cancer services; specialization; service reorganization

Introduction

Cancer is one of the most common diseases in the United Kingdom; one in three people will develop cancer at some point in their life and one in four will die from it. The delivery of care to cancer patients is an important part of the work of the NHS. A major policy and planning review of cancer services was instigated during the 1990s following a number of factors such as expressions of public and professional concern about the existence

of a cancer postcode lottery whereby place of residence determined access to care, potentially affecting the quality of life of patients or their survival. In addition, the patient group Radiotherapy Action Group Exposure (RAGE) exposed deficiencies in radiotherapy.¹ Also, there was mounting evidence that specialization, including centralised treatment,^{2,3} entry into clinical trials,^{2,4} clinician workload⁵ and surgery by specialists⁶ improved quality of care and survival for cancer patients. This evidence together with the comparatively high cancer mortality rate in the United Kingdom⁷ led to recommendations for service changes from the Chief Medical Officers in England and Wales (the Calman-Hine Report, 1995).⁸ The Campbell Report (1996) outlined similar changes for cancer services in Northern Ireland.⁹ The main recommendations of the Campbell report were increased specialization in cancer management, a multidisciplinary team approach, enhanced communication between primary and secondary care, enhanced palliative care and integration of cancer services in four geographically positioned cancer units and one cancer centre. Little information is available on how the delivery of cancer care to patients has changed following the publication of the Calman-Hine and the Campbell Reports. This paper presents the results of a population based comparative study of the processes and service changes relating to the reorganization and delivery of breast cancer care between 1996 and 2001.

¹Northern Ireland Cancer Registry, Department of Epidemiology and Public Health, Queen's University, Belfast BT12 6BJ, UK

²Department of Epidemiology and Public Health, Queen's University, Belfast BT12 6BJ, UK

³Breast Surgery Unit, Belfast City Hospital, Lisburn Road, Belfast BT9 7AB, UK

Pauline Monaghan,¹ Statistician

Liam Murray,¹ Senior Lecturer

Michael Donnelly,² Reader

Peter McCarron,² Senior Lecturer

Roy Spence,³ Consultant Surgeon

Anna Gavin,¹ Director of Northern Ireland Cancer Registry

Address correspondence to P. Monaghan, Northern Ireland Cancer Registry, Mulhouse building, Grosvenor Road, Belfast BT12 6BJ, UK

E-mail: p.monaghan@qub.ac.uk

Methods

Data collection

The Northern Ireland Cancer Registry (NICR) provided a list of all female patients diagnosed with invasive primary breast cancer (ICD-10 codes C50.0-C50.9) in 1996 and in 2001. This list included patients with Paget's disease and patients who had a previous primary of any site or a concurrent primary malignancy of another site. Trained data abstractors examined the medical record of each patient and specific details were extracted using a proforma which was designed in consultation with cancer care professionals. See www.qub.ac.uk/nicr/research for a copy of the proforma.

Data cleaning

The database was subjected to rigorous quality control and consistency checks. For example, consultants names were verified, long delay times were queried and diagnostic methods were cross-checked with details about treatment and investigations. Patients whose diagnosis was based only on a death certificate were excluded as were patients for whom there was insufficient information to permit descriptive analysis.

Data analysis

The number of hospitals performing cancer surgery in each of the 2 years was used as a measure of the centralization of services. Patients were assigned to the consultant leading the surgical team irrespective of whether the consultant personally performed the surgery or it was performed by another surgeon under his/her supervision. In both 1996 and 2001, consultants were designated as breast cancer specialists if they managed more than 30 breast cancer patients in that year. In addition, in the year 2001, breast specialists were defined using the Department of Health, Social Services and Public Safety's directory of breast cancer specialist teams¹⁰ (No such directory existed in 1996).

Patients were assigned to one of two group categories depending on Oestrogen Receptor (ER) status and hormone therapy. Group 1 included patients who had positive ER status and were prescribed hormone therapy and also patients who were ER negative and not prescribed hormone therapy. Group 2 comprised all other patients.

The British Association of Surgical Oncology Guidelines (BASO)¹¹ specifies that four axillary nodes should be sampled in breast cancer patients. The American Joint Committee on Cancer (AJCC)¹² Cancer Staging Manual specifies that six axillary nodes should be sampled. Comparisons were made between the proportion of patients in 1996 and 2001 whose axillary surgery met these criteria and then in terms of who received level three axillary clearance (axillary surgery up to the apex of the axilla).

Descriptive comparisons (frequencies and percentages) and tests of association (chi-square) and differences (*t*-tests) at the 5 per cent level of significance were made between the two years and the variables of interest. Missing values were entered as 'NR'. Each test of association was calculated firstly by including

'NR' values and then by excluding them. Percentage figures in the results section are based on the total number of patients including those for whom values are missing.

Results

The results of the comparative analysis are summarised in Table 1. Data were analysed on 764 patients in 1996 and 881 patients in 2001. There was an increase (by 4 days) in the period of time between referral by GP and being seen for the first time at hospital, but there was no change in median waiting times between being seen at hospital and the date of diagnosis. The number of hospitals at which breast cancer surgery was performed fell from 21 (two private) in 1996 to 13 (one private) in 2001, nine of which were affiliated to cancer units. The number of consultant surgeons performing breast cancer surgery fell from 40 in 1996 to 19 in 2001, 15 of whom were designated breast specialists. These specialists performed 788 (98 per cent) operations for breast cancer in 2001 while four non-specialists performed 13 (2 per cent) operations. In 2001, 84 per cent of patients were operated on by consultants who performed more than 30 operations per year compared to 70 per cent in 1996. Mastectomy was the most common type of operation in both years, its use increased from 31 per cent in 1996 to 36 per cent in 2001. The number of women over 75 years who received surgery increased from 85 (60 per cent) in 1996 to 100 (65 per cent) in 2001 and the proportion of mastectomies in this age group increased from 16 per cent in 1996 to 20 per cent in 2001.

The use of investigative procedures increased in 2001, especially core biopsy which increased by 35 per cent. Almost 90 per cent of patients had their histological grade recorded in 2001 compared to 77 per cent in 1996; 795 (91 per cent) patients had ER status recorded in 2001 compared to 169 (23 per cent) patients in 1996.

The proportion of patients who had four or more nodes or six or more nodes excised increased from 75 per cent and 67 per cent respectively in 1996 to 88 per cent and 87 per cent in 2001. There was a significant increase in the recording of multidisciplinary meetings (MDMs) from 30 (4 per cent) patients in 1996 to 230 (26 per cent) patients (26 per cent) in 2001. The proportion of patients receiving radiotherapy and chemotherapy increased by 19 per cent and 13 per cent, respectively, from 1996 to 2001. The quality of information in discharge letters to GPs improved; diagnosis was recorded for 865 (99 per cent) patients in 2001 compared to 696 (91 per cent) in 1996 and a record that a discussion between a consultant and a patient about diagnosis had occurred was noted for 156 (20 per cent) patients in 1996 and 842 (96 per cent) patients in 2001 (Table 1).

Discussion

It is important to note that the results presented here are based on a retrospective note review. However, the data was validated

Table 1 Comparing cancer service provision in Northern Ireland: 1996 and 2001

Comparison	1996 <i>n</i> (%)	2001 <i>n</i> (%)	Including NR <i>p</i> -value	Excluding NR <i>p</i> -value
Number of patients removed	13 (2)	16 (2)		
Number of patients included	764 (98)	881 (98)		
Average age	60	60		
Referral from GP: median (average) referral time-days	6 (14)	10 (14)	NA	0.924
Referral from BSU: median (average) referral time-days	6 (7)	6 (8)	NA	0.335
First seen at hospital to diagnosis:				
Median (average) diagnostic delay-days	0 (8)	0 (3)	NA	<0.001
Diagnosis to surgery: median (average) days	8 (16)	10 (15)	NA	0.818
Number of hospitals performing surgery	21	13	NC	NC
Type of procedure: -Mastectomy	236 (31)	316 (36)	<0.001	0.284
Wide local excision	195 (26)	216 (25)	<0.001	0.320
Excision biopsy	110 (14)	47 (5)	<0.001	<0.001
Other	110 (15)	225 (26)	<0.001	<0.001
No procedure	86 (11)	76 (9)	<0.001	0.093
Patients >75 years having surgery	97 (62)	111 (68)	<0.001	<0.001
No. of consultant surgeons performing surgery	40	19	NC	NC
Specialization: patients seen by consultants				
operating on >30 patients	534 (70)	740 (84)	<0.001	<0.001
Investigations: -MM+FNA (triple assessment)	586 (77)	716 (81)	0.007	0.172
Ultrasound	207 (27)	627 (72)	<0.001	<0.001
Core biopsy	54 (7)	370 (42)	<0.001	<0.001
Histological grade recorded:	591 (77)	771 (87)	<0.001	0.023
Node excision: ≥4 nodes excised	574 (75)	773 (88)	<0.001	<0.001
≥6 nodes excised	515 (67)	765 (87)	<0.001	<0.001
Axillary clearance: level 3	108 (14)	490 (56)	<0.001	<0.001
ER status recorded	169 (23)	795 (91)	<0.001	NA
Hormone therapy prescribed	719 (94)	671 (76)	<0.001	<0.001
ER status recorded + hormone therapy prescribed (Group 1)	44 (6)	718 (81)	<0.001	NA
Multidisciplinary team meeting	30 (4)	230 (26)	<0.001	<0.001
[Not recorded]	[81 %]	[72 %]		
Oncology treatment: patients given radiotherapy	431 (56)	648 (74)	<0.001	<0.001
Patients given chemotherapy	196 (26)	344 (40)	<0.001	<0.001
Entered into clinical trial	29 (4)	133 (15)	<0.001	<0.001
Information to GP (discharge letter): diagnosis of patient	696 (91)	865 (99)	<0.001	<0.001
Prognosis of patient	186 (24)	352 (40)	<0.001	0.287
Patient awareness of diagnosis	405 (53)	808 (92)	<0.001	<0.001
Family awareness of diagnosis	199 (26)	403 (46)	<0.001	<0.001
Follow-up plan details	633 (83)	839 (96)	<0.001	<0.001
Patient information recorded in notes:				
Diagnosis discussed with patient	156 (20)	842 (96)	<0.001	0.326
Treatment plan discussed with patient	159 (21)	841 (96)	<0.001	0.334
Follow-up care:				
Seen by breast care nurse in hospital/community	308 (40)	616 (70)	<0.001	<0.001
Community nurse contacted about patient	169 (22)	382 (43)	<0.001	0.174
Information on support groups given to patient	68 (9)	130 (15)	<0.001	<0.001
Review plan organized for patient	573 (75)	826 (94)	<0.001	<0.001

BSU, breast screening unit; FNA, fine needle aspirate; ER status, oestrogen receptor status; level 3 axillary clearance, axillary surgery up to the apex of the axilla; NR, not recorded; NA, not applicable; NC, not calculable.

through presentations and discussion with clinicians and other staff working in breast cancer services, all of whom indicated that the data reflected their experience of service delivery and practice. The same methods were employed in each study year

and the data abstractors followed specific, standardized instructions regarding the collection and interpretation of data contained within patient notes in an attempt to minimize bias. The study took place in 2002 (after both time periods for which

data was collected) and therefore it is highly unlikely that data collection procedures impacted on practice in ways that might influence or bias results. A weakness of retrospective note review is that key information may not be recorded in the notes and this may have been more likely in 1996 than in 2001. Formal statistical tests were performed by including and then excluding missing values in an attempt to utilize the data fully.

Clearly the level of recording in the notes has improved (e.g. the noting of discussions between consultants and patients). Better recording in the notes may, in itself, be viewed as a marker of service improvement.

Evidence that specialization improves survival for breast cancer patients has been demonstrated by Gillis and Hole.⁶ This study has shown that specialization as defined by those who performed >30 operations in a year improved significantly between 1996 and 2001, further work is required to determine the impact on outcome. Recent 5-year survival figures for breast cancer in Northern Ireland indicate significant improvement between 1993–1995 and 1996–1999; 81.5 per cent (95 per cent CI: 79.8 per cent, 83.1 per cent) in 1996–1999 compared to 76.3 per cent (95 per cent CI: 74.2 per cent, 78.8 per cent) in 1993–1995.¹³ The Campbell report and the Calman-Hine report both recommended a team approach to cancer care, which has been shown to improve outcomes.¹⁴ The review of patient charts showed a disappointing lack of change in MDMs. However, subsequent discussions with professionals indicate that MDMs were taking place regularly in 2001 but that they were not being recorded in the patients' notes.

The Campbell report also recommended that all patients have early referral to hospital and the BASO guidelines¹¹ recommended that over 80 per cent of urgent referrals were to be seen within five working days of receipt of the referral letter (assume 7 days from date of referral) and 70 per cent of all other referrals were to be seen within 15 working days. Diagnostic delays should also be kept to a minimum.¹⁵ In this study the average time between first being seen at hospital and diagnosis fell significantly between 1996 and 2001, suggesting that specialization has not been at the expense of waiting times.

The use of investigative and diagnostic techniques has increased in line with the recommendations of Campbell and the published evidence advocating triple assessment,¹⁶ ultrasound¹⁷ and core biopsy.¹⁸ Also, despite increased investigations there has been a reduction in delay between patients first being seen at hospital and having their diagnosis established, due in large to the establishment of one-stop breast clinics.

Evidence has shown that limited nodal sampling runs the risk of failure to accurately stage the patient and failure to maintain local control in the axilla.¹⁹ Tumour size and the extent of axillary lymph node involvement are the two most important prognostic factors for breast cancer.²⁰ Our findings showed a significant increase in the number of nodes sampled which suggests a move towards more thorough investigation of the breast cancer patients. This should mean that more patients would be given appropriate treatment.

Evidence of the importance of determining ER status in breast cancer patients has existed for about 30 years,²¹ but its use in routine clinical practice was limited by factors such as reliability and cost. This study demonstrates significantly increased recording of ER status and appropriate prescribing of hormone therapy between the two years but this increase may be largely due to an emerging technology rather than because of policy recommendations.

Evidence available in 1995 suggested that lumpectomy/wide local excision (followed by irradiation) was the treatment of choice for small tumours and when a mastectomy was indicated, breast reconstruction should be offered.²² Despite this, mastectomy was the most common mode of surgical treatment in both years in this study and increased between 1996 and 2001. There are several reasons why mastectomy is appropriate even in patients with a small tumour, e.g. tumour behind nipple, patients choice, family history, Paget's disease, relatively small tumour but small breast. Even though mastectomy was the most common procedure in 2001, results show that a greater percentage was performed on women over 75 years old in 2001 compared to 1996.

One of the problems faced by GPs caring for seriously ill patients in the community was a lack of timely information⁹ and although letters from hospitals to GPs covered clinical topics well, more should include information relating to the social aspects of the patients disease.²³ Information on whether the patient and/or family were aware of the diagnosis was recorded more frequently in 2001. The time frames of the letter to the GP were not examined. A letter which arrives after the patient has been to see the GP is less useful than one that arrives promptly at discharge. The increased information to the GP will allow better follow-up care for the patient and even protect the patient if they do not wish to know their diagnosis or prognosis.

The Campbell Report stated that people with cancer have the right to at least two home visits by an appropriate health professional and information on local support services.⁹ This study showed that there was increased information on support groups and designated follow-up care with breast care nurse and/or community nurses in 2001 in line with this recommendation. These changes probably reflect the availability of these services, however, increased availability of these services was recommended in the Campbell report

Overall, there have been changes in the provision of breast cancer services in Northern Ireland, which, in general, has been in the direction of the recommendations made in the Campbell report. The ideal service model as described in the Campbell report would have been that all patients received the highest level of care, e.g. all patients would have been discussed in a multidisciplinary setting and all patients would be managed by breast specialists, in 2001 the ideal model was not achieved but the changes described in this paper (Table 1) illustrates that service is moving in the direction intended. It is difficult to directly attribute these changes to the Campbell Report, the breast screening service, which was introduced in 1989 and established in all regions throughout Northern Ireland by 1993 played a

vital role through enhanced diagnosis, the BASO guidelines¹¹ also influenced clinical practice, the Calman-Hine report⁸ produced in England and Wales would have influenced clinical practice in Northern Ireland as well as public expectation for better services but the Campbell Report undoubtedly acted as a catalyst to the changes demonstrated in this paper. Further work is required to investigate whether changes in outcomes, e.g. survival has occurred in parallel with the service changes.

What is already known on this topic

Surgeon specialization and multidisciplinary team working are related to measures of effectiveness including, the quality of clinical care and survival.

There is lack of evidence on the effect of breast cancer service reorganization on the processes of cancer care.

What this study adds

A policy change can effect indicators of quality of care including specialization, multidisciplinary team working and communication with primary care.

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