

A comparison of the awareness and utilisation of postoperative health services provided to women with breast cancer in public and private hospitals

JOY CHISHOLM, JUDITH DONOGHUE, KIM DUNN,
FIONA FARMER, ROSEMARY HANNAN, KATE INTRONA,
JENNY O’BAUGH, SUZANNE MITTEN-LEWIS,
JUDITH RICKARD, AND ALISON SZWAJCER.

Joy Chisholm was formerly Nursing Unit Manager, Haematology Oncology Day Care Unit, Kim Dunn and Rosemary Hannan are Clinical Nurse Specialists, Kate Introna is Clinical Nurse Consultant Palliative Care, Jenny O’Baugh is Clinical Nurse Consultant Oncology-Haematology, Suzanne Mitten-Lewis is Research Assistant, Acute Care Nursing Research Unit, Judith Rickard is Nurse Educator, Division of Cancer Services, and Alison Szwajcer was formerly Clinical Nurse Specialist, Haematology-Oncology Day Care Unit, at The St George Hospital. Judith Donoghue is Professor of Acute Care Nursing at The St. George Hospital and The University of Technology, Sydney. Fiona Farmer is Nurse Educator at the NSW College of Nursing.

Abstract

Nurses at a metropolitan Cancer Care Centre (CCC) noted that women who have had recent breast surgery for carcinoma had significantly different levels of knowledge and use of support services depending upon public or private hospitalisation. The public hospital participants were more aware of the range of available services (mean = 3.6) compared to women from the private sector (mean = 2.6). In addition, the public hospital participants were more likely to access a wider range of services post discharge (mean = 2.21) compared to the private hospital women (mean = 0.85). A significant difference was found between younger and older women’s use of services.

Background

The number of women residing within the South Eastern Sydney Area Health Service (SESAHS) and being admitted to public and private hospitals for malignant breast disease surgery is increasing (Inpatient Statistics Collection, 1996–98). The current trend of reduced length of stay for surgical procedures such as biopsies in both private and public hospitals raises concerns about the amount of informational support provided for these women. Traditionally, breast cancer

management is thought to proceed rapidly, with surgery swiftly following diagnosis. However, there may be a substantial delay before the commencement of adjuvant therapy. Ivimey (1994) reminds us of the need for women who progress to adjuvant treatment, be it chemotherapy or radiotherapy, to have made available to them relevant health supports together with accurate and accessible health information. The critical need for support at this time has been articulated by Tobin (1994:102) who states, “as the implications of the diagnosis and the consequences of the treatment begin to be absorbed, women often feel emotionally and physically overwhelmed.”

Aim

In order to determine the informational and support needs of women newly diagnosed with breast cancer, nurses at the CCC designed a prospective survey to assess (1) their awareness and (2) their use of health services during the period between surgery and follow up chemotherapy or radiotherapy. In this study health services are defined as those provided by the specialities of nursing, occupational therapy, physiotherapy, social work, support groups and dietetics that are available in the community.

During the course of the study, it became apparent to the researchers that there were differences in knowledge and utilisation of services of women who had their surgery at private hospitals and those at public hospitals. An extensive search of the literature found no published articles addressing public / private health sector differences in nursing or treatment practices relating to breast surgery.

Method

Design

The study consists of a single group and uses a descriptive survey combining fixed and free response formats. Data were collected in two ways. A questionnaire was used to collect demographic information at their first presentation to the CCC following surgery. Approximately six weeks later, the women were interviewed about their knowledge and use of health services using a set of predetermined questions. Ethics approval to conduct the study was obtained from the Division of Cancer Services and the SESAHS Research Ethics Committee.

Sample

A sample of 104 women was recruited. For any twelve-month period approximately 200 women diagnosed with breast cancer use the treatment services of the CCC. However, only those women who had recently been diagnosed with breast cancer were included in the study, thereby excluding women being treated for recurrent breast cancer. All women who presented to the CCC for treatment and who fulfilled the study criteria were invited to participate. Only those women who gave informed consent were included in the study sample. It took thirteen months to recruit the required number of participants.

Procedure

When women newly diagnosed with breast cancer presented at the CCC they attended a routine educational session, which included a description of available services. Subsequently, a Registered Nurse gave them an information sheet describing the study and inviting their participation. Signed informed consent to participate was obtained. Participants who could speak English were sent a demographic questionnaire to complete and return. Non-English speaking participants used the hospital interpreter service to complete the questionnaire at the CCC. Study participants were interviewed at a later date about their knowledge and use of services.

Instrument

The demographic questionnaire requested information on age, country of birth, language spoken at home, living arrangements, the number of dependent children and health insurance status. Participants were also asked who had informed them of their diagnosis, the name of their surgeon, the place of surgery and their length of hospital stay.

The semi-structured interview consisted of 16 open-ended questions, some of which had several parts. They were asked where they had obtained their information about breast cancer and follow up treatments. Other questions related to the women's awareness and use of services including community nursing, physiotherapy, occupational therapy, social worker, dietician, prosthesis advice and cancer support groups. Women were asked to identify factors preventing their access to these services and to name services that, in hindsight, would have benefited them during this period. Finally they were invited to raise any other pertinent issues regarding the overall service provided.

Pilot study

A pilot group of 10 women completed the demographic questionnaire and participated in open interviews. The pilot identified the need for slight modifications to the questionnaire to enhance understanding. A semi-structured interview format replaced the previous open format as some women found it difficult to respond to a global invitation to talk about their knowledge and use of services. The original plan was to audiotape the interviews in a quiet room in the CCC. However participants expressed a reluctance to speak freely while being taped. Furthermore, the researchers found that transcribing audiotapes was a difficult and costly procedure, which yielded no improvements in data quality. Consequently, data were gathered from written accounts taken during the interviews and from field notes following the interviews.

The data collected were analysed using descriptive statistics for the demographic information and proportions for categorical variables. Content analysis of the interviews was conducted as outlined by Field and Morse (1985). Where necessary, statistical analysis was assisted with the use of the SPSS package (Statistical Package for Social Sciences).

Results

Demographic results

One hundred and two women participated in a semi-structured interview and completed a questionnaire. One participant completed only the questionnaire (N=103), and two women completed the interviews but not the questionnaire (N=104). The mean age of participants was 54 years (range 24 to 83). Australia was the country of birth for 73 women; nine were born in England and five in Greece. Other countries such as Italy and China had one representative. English was the language used at home by 95 (92%) of the women. The country of birth and language was not a significant feature.

Sixty-eight percent of the sample lived with their partner or spouse. Twenty-eight percent had one or more dependants (children under 16 years or dependent friend or relative) at home, but only two of these were single parents. Fifty-two percent of the women with spouses or partners (N=71) reported that no partner or family members were involved in discussions with hospital staff about their cancer. Of those without partners (single, widowed or divorced) 60% reported no family involvement in such discussions.

The study included women from seventeen different hospitals, nine of which were from the private sector. The hospitals were predominantly located within the Sydney Metropolitan area, but also included both public and private hospitals from outlying areas. Median length of hospital stay was 3.0 days, range 1–30. The mean of 4.6 +/- 4.1 days is artificially elevated due to the extended stay of a small number of women who had postoperative complications. The largest proportion of participants in this study was hospitalised from one to three days. None of the demographic variables are significantly correlated with the duration of hospital stay.

Sixty-five women were informed of the diagnosis of breast cancer by the surgeon, 21 were told by their general practitioner, while a doctor at a breast-screening program notified six. Women were provided with the preliminary information regarding their breast cancer by their surgeon (25 responses), by literature provided by the NSW Cancer Council (14 responses), by nurses (12 responses) or by other sources (30 responses). "Other sources" included friends and relatives.

The first aim of the project was to identify women's awareness of the range of services available to them following surgery for breast cancer. Table 1 lists the range of services that are available for women and the percentage of women who were aware of the service.

Awareness scores were derived by summing the number of services of which each participant was aware. The mean and standard deviation of the awareness score is presented in the last row of Table 1. It can be seen that support groups were the best-known service (62% aware). Overall the percentages are disappointingly low.

Table 1: Percentage of awareness of available services for all participants N=104

| Service | Aware |
|----------------------|----------|
| Support Groups | 62% (65) |
| Physiotherapy | 56% (59) |
| Social Worker | 49% (51) |
| Community Nurse | 42%(44) |
| Dietician | 31% (33) |
| Occupational Therapy | 25% (26) |
| Prosthesis | 21% (7) |
| Awareness score* | 2.9+2.3 |

Figure 1: Participants in the public and private sectors and their awareness of services available to women with breast cancer

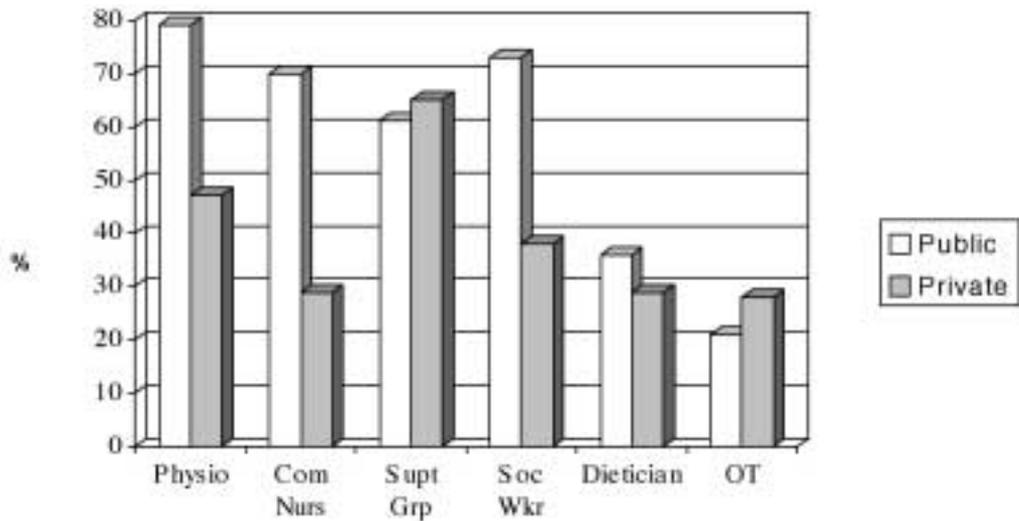


Figure 1 shows that participants treated in the public sector were more aware of services (with the exception of support groups and occupational therapy) than those treated in the private sector. A comparison of their summary scores (Public mean +/- SD = 3.6+-1.9, Private mean +/- SD = 2.6+-2.5) showed differences of borderline significance (p=0.051). Levene's test for equality of variances was also of borderline significance (p=0.057); unequal variances would have yielded a significant result (p=0.034). There were no significant differences between the age groups. It is worth noting that private patients obtained information regarding support groups after discharge and prior to the interview.

The second aim of the study was to identify the usage of services. The findings show that participants were aware of about twice the number of services that they used. The mean and standard deviation usage scores were 1.3+1.4. The usage score was derived by summing the number of the services that each participant used. A significant difference was found between public and private sector usage scores ($P < .000$).

Figure 2: Services used by women with breast cancer treated in the public and private sectors

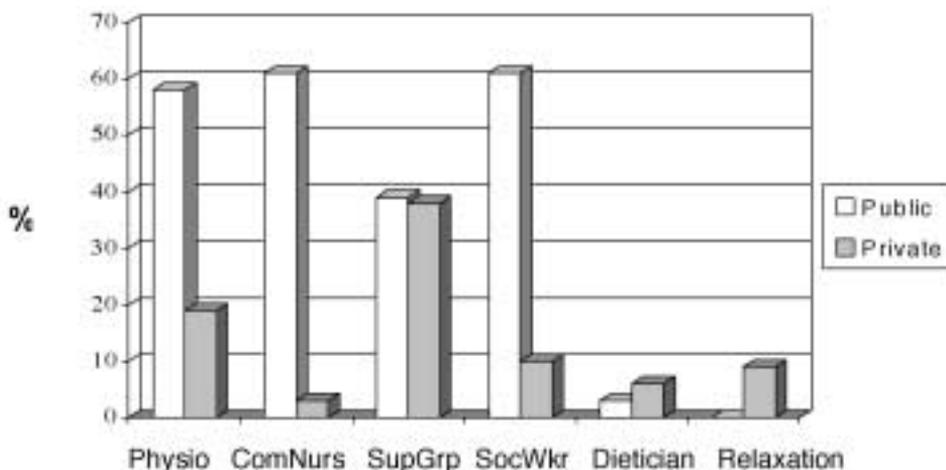


Figure 2 compares the actual utilisation of services by study participants in public and private sectors. Only in the use of a support group and a dietician was the proportion of private patients' usage anywhere near that of the public patients. Neither group used occupational therapy services.

Figures 3 and 4) demonstrate that the participants younger than 50 years old utilised a significantly ($p = .027$) greater number of services (mean \pm 1 SD = 1.7 \pm 1.5) than the participants aged 50 and older (mean \pm 1 SD = 1.0 \pm 1.2). The majority of the older participants either did not access any services (>40%) or accessed one form of service only (30%). There was no significant difference in age between public and private sectors.

Participants' responses about underutilisation of services revealed that 62% of PR women and 36% of PU women ($p < 0.03$) stated that they failed to use some services because they were unaware that the services existed. The participants were also asked if there were any inhibitory factors that affected their ability to utilise the named services. Table 2 demonstrates that 24% of PU and 9% of PR women felt they did not need the services, and for a minority nothing prohibited access. The major inhibitory factor was lack of awareness and/or unsure of access to these services with 39% of the PU women and 68% of the PR women being unaware of services and/or access mechanism. When the responses were collated by age, the overwhelming reason was again lack of awareness of service or route of access.

Figure 3: Comparison by age group of the most frequently-used services

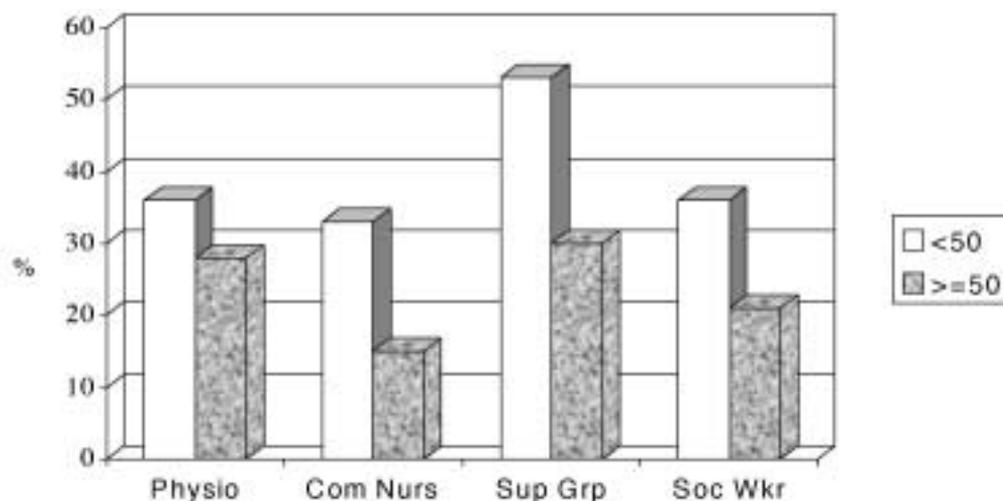


Figure 4: The number of services used by participants aged under and over fifty

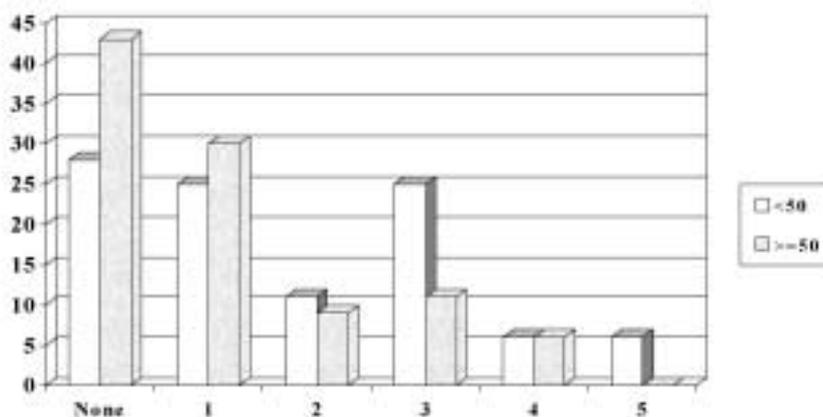


Table 2: Factors inhibiting women from accessing services comparison by public, private and age

| | Public | Private | Age<50 (n=36) | Age>50 (n=66) |
|---|-------------|-------------|---------------|---------------|
| Community nurse unavailable when needed | 0% | 3% (2/68) | 3% | 2% |
| Emotional distress | 0% | 0% | 3% | 0% |
| Not required | 24% (8/33) | 9% (6/68) | 0% | 3% |
| Nothing prevented access | 3% (1/33) | 10% (7/68) | 25% | 39% |
| Unaware of service / unsure of access | 39% (13/33) | 68% (46/68) | 59% | 53% |

Tables 3 and 4 demonstrate services that the women felt would have been of benefit, collated by age and public or private status. The tables show similar patterns. Emotional and/or social worker support featured strongly with 44% of the younger women and 32% of the older women stating this would have been of benefit. The percentages are lower when collated to public (30%) or private status (24%).

Another substantive need was for physiotherapy services and/or information on arm exercises, reported by similar proportions of younger (25%) and older (24%) participants and by 18% of PU and 25% of PR women.

Twenty-two percent of younger and 18% of older women would have liked more information in general (21% PU, 26% PR women).

Table 3: Services identified that, in hindsight, would have been beneficial, comparison by age. (Responses collated from open and closed response format questions)

| | Age <50 (n=36) | Age ≥50 (n=66) |
|------------------------------------|----------------|----------------|
| Analgesia | 1 (3%) | 0 |
| Community nurse | 4 (11%) | 6 (9%) |
| Counselling/support/ social worker | 16 (44%) | 21 (32%) |
| Dietician | 2 (6%) | 4 (6%) |
| Home help | 2 (6%) | 2 (3%) |
| Longer hospital stay | 0 | 3 (4%) |
| More information | 8 (22%) | 12 (18%) |
| Physiotherapy | 9 (25%) | 16 (24%) |
| Prosthesis advice | 2 (6%) | 0 |
| Relaxation | 1 (3%) | 1 (2%) |
| Wound care | 1 (3%) | 2 (3%) |

Table 4: Other services that might have been beneficial, by Public and Private hospitals

| | Public (n=33) | Private (n=68) |
|---------------------------------------|---------------|----------------|
| Dietician | 3% (1) | 6% (4) |
| Family involvement | 6% (2) | 7% (5) |
| Longer stay in hospital | 6% (2) | 1.5% (1) |
| More information in general | 21% (7) | 26% (18) |
| No response | 9% (3) | 18% (12) |
| Nothing else needed | 30% (10) | 22% (15) |
| Physiotherapy / info on arm exercises | 18% (6) | 25% (16) |
| Relaxation techniques | 6% (2) | 1.5% (1) |
| Social worker / emotional support | 30% (10) | 24% (16) |

As demonstrated in table 5, the women either had no further issues to raise (40% of both public and private participants) or they felt that additional information would have been of benefit. Twenty-one percent of the PU women and 29% of the PR women would have liked more information (includes verbal form). Emotional support was an issue cited by 19% of all participants, the percentages being equal between the two groups.

Table 5: Additional issues raised by the women in public and private hospitals

| | Public (n=33) | Private (n=68) |
|---|---------------|----------------|
| More info on arm exercises/ physiotherapy | 6% (2) | 12% (8) |
| Needed verbal information | 12% (4) | 6% (4) |
| Needed more information (in total) | 21% (7) | 29% (20) |
| Needed someone to talk to / emotional support | 18% (6) | 19% (13) |
| No other issues | 42% (14) | 38% (26) |

Discussion

This prospective study aimed to identify the awareness and utilisation of ancillary services by women who have undergone breast surgery. It did not intend to discriminate between the public and private health sectors but aimed to highlight any variation in knowledge that existed. The sample size was small but significant differences in the knowledge base of the PR compared to PU women are apparent. The major inhibiting factor to service utilisation designated by both PU and PR women was lack of awareness and/or unsure of access to services. This reason was cited by 68% of the women from private hospitals and 39% of those from public hospitals. In addition to the lack of awareness, the need for more information featured highly throughout the survey. This is potentially explained by the reduced time available by health professionals for information sharing resulting from reductions in length of stay. PU women tended to stay in hospital an average of one day longer than PR women (PU mean +/- SD = 5.3+-5.1 days with median = 4 days, PR mean +/- SD = 4.3+-3.9 days with median = 3 days), but this difference was not significant ($p=.38$).

Over 60% of participants were aware of support groups, but as PR women obtained this information in the post-discharge phase it leads one to question the source of their information and why awareness was not gained in the acute phase of their illness. Use of support groups was approximately 40% in both PR and PU women. The knowledge of and subsequent utilisation of allied health services was significantly greater in the PU participants with over 50% of the PU women using the physiotherapist and social worker compared to 20% of the PR women accessing the physiotherapist and 10% the social worker.

Disparity of awareness and utilisation of community nursing services between the two groups is particularly noteworthy. This raises the issue whether (and why) liaison between the community nursing sector and hospitals is greater in the public sector.

Although the majority of women did not perceive a longer hospitalisation (in hindsight) to be of benefit, 36% identified the need for more counselling and support services. It could therefore be assumed that this additional support was required after discharge.

The lower use of services by the older women requires additional exploration, particularly as it is universally accepted that the older person consumes the greater proportion of health services. The study did not aim to identify personal circumstances and therefore can not explain whether the older women participating in this study had increased need of any services.

References

Field, P.A. and Morse, J.M. 1985. *Nursing research: application of qualitative approaches*. Rockville, Maryland: Aspen.

Inpatient Statistics Collection; Clinical Services Policy and Planning Unit, SESAHS; Flowinfo Version 3.

Ivimey, B. 1994. The role of the nurse counselor in the management of patients with breast cancer. *Cancer Forum*. 18(3):171–172.

Tobin, M. 1994. Rehabilitation and support issues for women with breast cancer. *Cancer Forum*. 18(2):102–103.