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Exploring the economic impact of breast cancers during the 18 months following diagnosis.

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# Summary

The economic impact on individuals with breast cancer is not well understood. We sought to identify and describe the direct and indirect economic losses to breast cancer survivors in Australia. A longitudinal, population-based study of 287 women was used to explore economic outcomes (costs and lost income) for women with breast cancer 0-18 months post-diagnosis. Survey methods collected data on out-ofpocket costs, care-giving support, paid and unpaid work reductions, and perceptions from participants on these financial impacts. Bootstrapping was used to estimate 95% confidence intervals around means. Data were sub-grouped by cost type, age category and disease severity. Lost income, health service expenditures and lost unpaid work were the greatest sources of economic burden. Women with positive lymph nodes reported significantly higher costs than those with negative lymph nodes (US\$6,674 versus US\$3,533, p<0.001), and younger women ( $\leq$ 50 years) with positive lymph nodes experienced costs 80% greater than older women (US\$8,880 versus US\$4,937, p<0.001). Economic costs related to breast cancer may continue to affect women 18 months post-diagnosis. Economic research adds an important dimension for understanding the impact of breast cancer, and findings may be used to help improve supportive care services for women and families confronted by this disease.

Keywords: cancer, oncology, breast, economics, costs

#### Introduction

In Australia, the likelihood of a woman being diagnosed with breast cancer is one in 11 before age 75 years(Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR), 2001). The number of new cases of breast cancer increased from 100.4 per 100,000 population in 1991 to 117.2 per 100,000 population in 2001(Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR), 2004). During the same time, mortality declined on average by 2.2% annually (Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR), 2004). Approximately 84% of women diagnosed with breast cancer are expected to survive for at least five years (Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR), 2001). Partly due to these trends of declining mortality and increasing incidence, expenditures for breast cancer treatment from 1993-94 to 2000-01 increased 42% (compared to 24% for all cancers)(Australian Institute of Health and Welfare (AIHW), 2005) and the costs of follow-up medical care, ongoing pharmaceutical needs and recurrences also are predicted to increase(Chirikos, 2001). For women aged 25-64 years, breast cancer had the second highest health system expenditure of all cancers in 2000-01 in Australia (Australian Institute of Health and Welfare (AIHW), 2005).

Although we know from regular monitoring the medical costs to the health system for screening, treatment and diagnosis, there is little information on the economic impact of breast cancer to individuals, families and the broader community. Previous studies on out-of-pocket costs from breast cancer have limited application because they may

not reflect current treatments or health insurance coverage(Butler and Howarth, 1999), have very small convenience samples(Moore, 1998; Butler and Howarth, 1999; Moore, 1999) or included selective breast cancer patients(Moore, 1998; Moore, 1999). However, identified factors that are associated with higher individual out-of-pocket costs include advanced disease and associated medications(Grunfeld et al., 2004), hormone therapy, insurance gap payments, and greater traveling distances to the hospital(Clarke, 1998; Lauzier et al., 2005). When family care-giving was monetized over a 3-month period in an all-cancer sample, the cost of family labor was found to be as much as nursing home care(Stommel et al., 1993).

The literature on breast cancer and the impact on employment and earnings show varying results with positive(Satariano and DeLorenze, 1996; Bradley et al., 2002), neutral(Hensley et al., 2005) and negative consequences(Butler and Howarth, 1999; Bradley et al., 2002; Grunfeld et al., 2004; Maunsell et al., 2004) being reported. Adverse effects on employment and lost income appear short-term, as women resume normal activities over time(Satariano and DeLorenze, 1996; Bradley et al., 2002). However, as a consequence of breast cancer, a small percentage of women report early retirement (≈10%), problematic workplace re-entry(Stewart et al., 2001; Hensley et al., 2005), and/or refusal of insurances(Stewart et al., 2001; Hensley et al., 2005). The interpretation of this literature is limited because of cross-sectional designs, the inability to distinguish effects of ageing and life choices, and limited generalisability because most studies are from the US(Satariano and DeLorenze, 1996; Bradley et al., 2002; Chirikos et al., 2002; Chirikos et al., 2002) where health insurance is linked to employment. Only one study investigated lost household

production(Stommel et al., 1993), while one other compared the broader costs of two rehabilitation programs with a non-intervention group(Gordon et al., 2005).

Understanding the economic impact to individuals with breast cancer (and their families) is important for several reasons. Financial distress is a quality-of-life issue and contributes to the context in which a patient makes decisions about treatment and recovery(Moore, 1999). Out-of-pocket costs may potentially cause treatment delays(Moore, 1999; Langa et al., 2004), particularly for women living in areas remote from treatment centres. Treatment processes may incur out-of-pocket costs, and in turn, may affect a woman's ability to continue working; however, these dynamic relationships are not well-understood(Kenny et al., 1999). Additionally, employment effects, lost income and out-of-pocket costs affect the individual, her family and her employer. Prolonged primary and adjuvant treatment for breast cancer may cause greater disruption to workplace activities and earnings, at least within the first year of diagnosis. Clearer information may help those diagnosed with breast cancer plan for anticipated costs while enabling health professionals to identify women who may benefit from referral to social workers and/or government support agencies.

Furthermore, in an attempt to contain costs, hospital systems are shifting the burden of managing many diseases on to patients and families. While there are many benefits from these changes, early discharge and outpatient care are successful only if individuals are adequately supported (physically, psychosocially and financially) by others(Davis et al., 2000). Early discharge following breast surgery is now

commonplace(Burns et al., 2003), and family care-giving is a crucial part of surgical recovery with increasing responsibility and burden on family members(Davis et al., 2000). The burden and social impact of breast cancer therefore is increasingly important to understand for contributing to health and social policies. Finally, economic information for individuals may be useful for investigating cost-effectiveness and other evaluations of health services. Typically, these analyses do not include wider social costs because methods of estimation are controversial, outside of the budget holder's domain, or have simply been overlooked.

The aim of this paper is to report on the direct and indirect costs incurred by women with breast cancer over 0-18 months post-diagnosis and explore these by age and lymph node status (as an indicator for disease severity). Direct costs include breast cancer-related health service expenditure, purchases of garments/aids and hired home services, and indirect costs include reductions in work activities and the use of informal (unpaid) care. In Australia, despite a health care system where universal health insurance is provided to all citizens, and private insurance is optional, this research attempts to highlight the hidden costs associated with having breast cancer that are incurred by individuals.

#### Methods

A longitudinal study, entitled 'Pulling-Through - A Breast Cancer Recovery Study,' was designed to measure the prevalence and severity of upper-body limitations and health-related quality of life during the first 18 months from diagnosis. Physical and subjective measurements of upper-body limitations were collected to establish

patterns of typical recovery and identify possible sub-groups requiring special needs. The target population was English-speaking women recently diagnosed with unilateral breast cancer, aged 20-75 years and who resided within a 100km radius of Brisbane (where approximately 70% of the Queensland population resides). A population-based approach for recruitment utilized data from the Queensland Cancer Registry. All women diagnosed with breast cancer in Queensland have their details sent to this Registry. Random over-sampling of women aged up to 50 years enabled adequate numbers for separate analyses in this subgroup. Following ethical protocols, consent from the treating doctor was received for 417/510 women (82%), and 296 women (71%) agreed to be contacted by the researchers. Of these women, 287 agreed to participate in the study and 272 women remained at the study's end. Staging information is unavailable from Registry records, so lymph node status was abstracted from pathology forms. Relevant ethics and related approvals from the authors' university and the Queensland Cancer Registry were received prior to the project's commencement. Further details on the methods, instruments and primary outcomes of this project have been reported previously (Hayes et al., 2005).

Data collection occurred during 2002-2004 through clinical measurements and self-administered questionnaires. Questionnaires were obtained at five time-points (phases 1 to 5): 6, 9, 12, 15 and 18 months from the date of diagnosis. Pathology records were abstracted to obtain specific breast cancer characteristics (e.g., surgery type, number of nodes removed, and tumor size). The questionnaires covered items on: demographic characteristics; breast cancer treatment; symptoms; usual activities, associated disabilities, and availability of support and assistance; physical activity

levels, general health characteristics, health-related quality of life and economic information.

No standardized or validated instrument was available to assess self-reported economic cost information, and therefore the authors developed these items (Appendix 1). Economic questions included health service expenditure specifically attributable to breast cancer using prompts (e.g., medical practitioner visits, physiotherapist visits, etc.), physical and social support programs undertaken, the use and cost of domestic services, family and other care-giving support, out-of-pocket expenses (e.g., wigs, customized bras, prosthetics, lymphedema sleeve, etc.), paid and unpaid work reductions and associated lost income. The questionnaire was pre-tested among 10 colleagues and 10 breast cancer survivors, and this testing supported the face and content validity of the economic questions.

## Analysis

The analysis was intended to be descriptive and exploratory rather than inferential. The perspective of the survivor was taken for the analysis, and government outlays or third party co-payments were not included. Costs were adjusted for inflation using the Health Price Index (using an annual percentage rate of 2.4%(Australian Institute of Health and Welfare (AIHW), 2001)) and brought forward to 2005 (Australian) dollars. Results have been converted to 2005 US dollars using the purchasing power parity A\$1 = US\$0.75(Organisation for Economic Cooperation and Development, 2006).

Cost items were quantified directly from survey responses and may or may not have been abstracted from other sources (e.g., receipts). Direct costs included out-ofpocket expenditure on garments and aids, health services (e.g. co-payments, pharmaceuticals) and paid home services. Indirect costs included the value of lost income, unpaid help, and lost unpaid work. Days of unpaid or paid work lost were self-reported, and for paid work were adjusted for any employer leave benefits. Number of days lost were converted to hours based on a 38-hour week for full-time workers. This conversion was necessary to accommodate part-time or occasional working situations more common among women. The average weekly earnings for women in Queensland were used to value lost income from hours lost from paid employment(Australian Bureau of Statistics, 2003). Unpaid work was categorized into two broad types: production by households for their own consumption (e.g., a family member providing care for another family member), and volunteer, charity or community work provided free of charge to others outside the family. Although the distinctions between unpaid work and leisure are sometimes blurred and certainly debatable, unpaid work was defined here as those activities recognized by the study participants as time-committed and valued activities within their community that otherwise could be purchased from the market sector(Australian Bureau of Statistics, 1997). Examples of unpaid work in our sample included: caring for children and other family members, volunteer work (at schools, hospitals, and caring organizations), office work in a family business and tutoring. The quantities of unpaid work were valued with an hourly estimate using the 'net opportunity cost approach' (Australian Bureau of Statistics, 1997). This estimate was used to reflect the survivors' value of what they could have earned in wages (including employer benefits) had they spent the same amount of time in paid work as expended on unpaid work after allowing for tax and any work-related costs.

Cost data are often skewed, with many participants having zero or minimal values and a small proportion of participants having very high values. Descriptive statistics showing cost distributions (i.e., means, standard deviations, medians, minimums and maximums) and sums are presented. Data are summarized for direct, indirect and total costs and presented separately for all participants and those participants with positive values (i.e., costs were greater than zero). For the complete sample, a zero cost was used for participants who reported a 'no' response to cost questions or failed to respond to that question. This imputation for those with missing data was considered reasonable given the relatively high response rates and proportions of women incurring no cost for any particular item (see Results section). In addition, using the original data, bootstrapped means and 95% confidence intervals (95% CIs) using the bias-corrected-accelerated approach were calculated from re-sampling the data 1,000 times(Efron and Tibshirani, 2003). Bootstrapped means and 95% CIs were produced for each cost type (i.e., health service expenditure, out-of-pocket expenses, home services and productivity lost). Proportions of each cost type to total cost were used to help gauge the relative magnitude of each cost component. Data were stratified by sub-groups of women younger or older than 50 years and by disease severity, defined as local (0 lymph nodes invaded) or regional (≥1 nodes invaded) disease. All bootstrapped means, 95% CIs, and t-tests for significant differences of the mean costs involved data for those participants who reported positive values. The analysis used SPSS Version 13.0 (SPSS, 2000).

Results

Demographic and clinical characteristics were similar between participants and those in the age-stratified random sample of Queensland women from which our sample was recruited (Hayes et al., 2005)(Table 1). However, the women in this study were mainly professionals or had white-collar occupations (69%), tertiary education (44%) and were relatively financially comfortable (i.e., 70% had private health insurance and 33% had annual household incomes over AUS\$52,000)(Table 1). The weighted mean age of the sample was 57 years; this is younger than the most common age group for all Queensland women with breast cancer (65-69 years)(Queensland Cancer Registry and Queensland Cancer Fund, 2005), as expected due to stratified sampling in the study design.

# [Insert Table 1 here]

Response rates for the individual economic survey questions ranged from 85-99% across the five phases. The question on health service expenditure had the lowest response rates at each phase (85-92%) but also had the highest proportions of 'yes' responses for incurring costs (29-54% across all phases). At any one phase, over 50% of the participants incurred no cost for hired help, garments, support programs, paid or unpaid work reductions.

Table 2 presents a summary of overall costs for the time period 0-18 months post-diagnosis. The total value of costs incurred for the 287 women in the study was \$1,322,775 with a weighted median of \$1,781 per person (min \$0, max \$43,727). For 25% of the sample, total economic losses were valued at <\$567 while for the top 5%

of the sample, this figure was >\$18,145. Nearly all women reported some economic loss (92%), while 252 women (88%) reported direct costs (health services or garments/aids or home services) with a median of \$827 and 184 women (64%) reported indirect costs (unpaid or paid work reductions or unpaid help) valued at a median of \$148.

## [Table 2 about here]

Figure 1 illustrates the weighted median costs for each 6-month period for women reporting positive costs. The greatest burden for women was apparent early after diagnosis, particularly during the first six months (total cost median \$1,453, min \$20, max \$31,440); this burden gradually declined over the following months and was substantially lower by 13-18 months (median \$484, min \$6, max \$16,622). Health services expenditure peaked at 7-12 months (median \$420, n= 177) and was higher at 13-18 months (median \$368, n= 145) than at 0-6 months (median \$263, n= 151). Lost income, the most substantial source of cost at each time period, steadily declined in value from a median of \$5,078 (n=73) during 0-6 months to a median of \$1,553 (n=23) during 13-18 months. The value of lost unpaid work also remained relatively high over time but also declined in value, from a median of \$2,380 (n=33) to \$1,433 (n=14) during 0-6 months and 13-18 months, respectively. The cost of purchasing garments and aids peaked at 0-6 months, with a median of \$216 (n=129), and home services costs increased from a median of \$164 (n=57) at 0-6 months to \$208 (n=41) by 13-18 months.

[Figure 1 here]

Bootstrapped means with 95%CIs are provided in Tables 3 and 4. The most substantial costs to women, as a proportion of total costs, included lost income, health service expenditures and lost unpaid work (Table 3). There were significantly higher costs for all items for women ≤50 years than for those >50 years. The mean value of total indirect costs was higher for younger compared to older women, \$3,853 versus \$2,230 (p<0.001), respectively, and similar results were found for direct costs for younger and older women, \$2,099 versus \$1,599 (p<0.001), respectively.

## [Table 3 here]

Women with positive lymph nodes reported nearly twice the costs of women with negative lymph nodes: \$6,674 versus \$3,533 (p<0.001)(Table 4 and Figure 2). Direct costs were more frequently reported than indirect costs for women irrespective of nodal status, but the value of indirect costs were higher. When analyses were stratified by age category and nodal status, younger women with positive nodes had average total costs 80% greater than older women with invaded nodes, \$8,880 versus \$4,937 (p<0.001), respectively. Younger women with negative nodes had average total costs 67% greater than older women with negative nodes, \$4,819 versus \$2,891, p<0.001. Only total direct costs were similar for younger women with negative nodes and older women with positive nodes, \$1,820 versus \$1,797 (p=0.23), respectively.

#### [Table 4 and Figure 2 about here]

#### Discussion

This is the first known study to quantify the economic burden on women with breast cancer over time from a population-based sample and include out-of-pocket expenses, reductions in non-market production and income losses. Furthermore, it is the only study that has investigated personal costs by age category and disease severity. Although there was great variability in the absolute values, most women reported some economic loss by 18 months after their diagnosis. Lost income was the greatest source of financial burden followed by out-of-pocket costs for health services and lost unpaid work. Over time, overall costs for women with breast cancer declined in value. However, as many women began returning to work, and therefore faced reduced losses in income, several sources of costs remained ongoing (i.e., health services, garments/aids and losses in unpaid work).

Health care funding within Australia involves a combination of universal health insurance that is provided to all citizens and optional private insurance. These arrangements are also similar to the Canadian and some European health care systems. In the US, the Medicare and Medicaid programs insure older citizens for health care but no national health service or insurance exists, and health insurance is most often organized through employers. Individuals in both countries also make copayments or out-of-pocket payments for health services, and trends in Australia suggest these contributions are increasing(Australian Institute of Health and Welfare (AIHW), 2004). In the US, it has also been found that older persons with cancer face significant out-of-pocket expenses mainly for medications and home services(Langa et al., 2004). The findings from our study highlight that women are faced with

relatively high proportions of personal health care expenditures and additional hidden costs, despite most being covered by private health insurance. Costs for health services were ongoing for a significant proportion of women up to 18-months after the initial diagnosis, when surveillance ceased, and remained at a level similar to those for 7-12 months.

In our study, women with more severe disease (positive lymph nodes) had significantly higher costs than women with no nodal involvement. Intuitively, women with more advanced disease would likely face greater health service needs and associated costs through greater contacts with doctors, medical tests and routine follow-up care. However, this study also highlights the additional indirect economic burden placed on women with more severe disease to deal with these commitments.

Our study found younger women were especially vulnerable in terms of larger economic burden after breast cancer diagnosis, particularly those with positive nodes. This appeared to be mainly due to larger health service costs and reductions in unpaid work activities (i.e., household production, childcare, school or community volunteer work, etc.). Greater numbers of younger women reported incurring income losses but generally had lower values of these losses than older women. Conversely, for unpaid work reductions, fewer younger women reported losses but the value was higher than their older counterparts. This could be explained by greater numbers of younger women facing part-time work, lower paid jobs and/or greater competing home and children commitments compared to older women. Similarly, a recent study by Hensley *et al.* (2005) found that younger women incurred higher medical costs than

women in general with breast cancer (Hensley et al., 2005). Their sample was comprised of women with stage II disease, all undergoing chemotherapy, and 95% of younger women (<50 years) were found to over-utilize medical practitioner care and follow-up tests after their breast cancer diagnosis (Hensley et al., 2005).

In 2001, 63% of all new cases of breast cancer among Australian women were diagnosed during working ages (<65 years)(Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR), 2004). Lost unpaid work, comprised of household production losses, may be of particular concern because regardless of whether a woman is working or not, household production traditionally falls on women. The results here reflect the extra burden faced by younger (working-age) women. The strain on families to provide care and compensate lost household production by the cancer survivor may be a growing problem given the age demographics of the cancer population (i.e., increasing diagnosis among younger women), the social trend towards smaller households, later childbearing and isolation from family networks (Stommel et al., 1993).

This study highlights the double-edged sword of breast cancer in financial terms, with families facing greater medical and other expenses while at the same time losing household income. Potentially, this may lead to substantial financial strain, particularly if women are casually or self-employed (Butler and Howarth, 1999; Bradley et al., 2002; Grunfeld et al., 2004; Maunsell et al., 2004; Lauzier et al., 2005). A qualitative Canadian study by Lauzier *et al.* (2005) emphasized the financial burden felt by women particularly due to disrupted roles, reduced income and higher medical

costs (Lauzier et al., 2005). The authors stressed that it is not the dollar value *per se* that is of prime concern, but rather, the *perception* of financial strain and coping with an unwanted change in economic circumstances (Lauzier et al., 2005).

This study has some shortcomings. Like previous research in this area, the analysis is exploratory and relies on self-reported survey data with the associated potential for recall bias. Unfortunately these economic data are unavailable from more objective sources (except some health service items via administrative databases), which necessitates survey methods. Balanced against this is the intentional purpose to obtain data from the perspective of the women. Data collection at 3-monthly intervals helped minimize the duration of participant recall, however validation against receipts was considered too onerous to request. Although changes in income and hours of work were directly assessed, other pertinent information on changes in work status, insurance and employment effects were not assessed to further avoid increased participant burden. Furthermore, paid and unpaid productivity has been separately categorized under indirect costs due to conceptual and measurement controversies in this area(Sculpher, 2001). For brevity, travel and accommodation costs were not specifically asked of women, but may have been considered and incorporated in responses to other questions. We did not expect these to be high due to the sample being urban and largely local to their treatment centres. The results of this study may underestimate costs to women with breast cancer living in rural or remote areas and the associated traveling and accommodation expenses that these women incur(Clarke, 1998; Lauzier et al., 2005). Lastly, the results of this study may have limited

generalisability with respect to absolute costs, but the relative proportions in the cost categories may be similar across countries with similar modes of health care.

Treatment for breast cancer has a rippling effect through the community as each woman's life is challenged, with frequent interruptions in her usual (often multiple) role activities, including family functioning, employment and other societal commitments. This paper serves to highlight these hidden and ongoing costs faced by breast cancer survivors, to inform interested parties of the nature and extent of patient costs of breast cancer, and to build on what is currently known about costs to survivors around the time of diagnosis and treatment.

Appendix 1 Economic questions used for data collection

(insert Appendix 1 PDF file here)

## Footnote to Appendix 1:

Please note, the questions within Q21 are limited. These relate to direct expenses for out-of-pocket costs, aids and garments and would be significantly improved in future work if they provided itemised yes/no boxes for each known component, associated quantities and costs per unit quantity. In addition, since this project started, two additional standardised tools for employment and out-of-pocket costs are available:

(1) the Work Productivity and Activity Impairment (Reilly Associates, 2002) survey and (2) the Collection of Indirect and Nonmedical Direct Costs (COIN) form (Sherman et al., 2001).

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Table 1: Characteristics of the sample and target population

| Factor  | Study sample<br>N (%) | Target population |  |
|---|-----------------------|-------------------|--|
| n   | 287                   | 510               |  |
| Age - weighted mean (SD)                        | 57 (9.6)              | 53                |  |
| Younger (≤50 yrs)                               | 108 (38%)             | 42%               |  |
| Older (>50 yrs)                                 | 179 (62%)             | 58%               |  |
| Education <sup>(a)</sup>                        |                       |                   |  |
| Primary   | 28 (10%)              | -                 |  |
| Secondary                                       | 130 (45%)             | -                 |  |
| Tertiary  | 127 (44%)             | -                 |  |
| Occupation group                                |                       |                   |  |
| Professional                                    | 103 (36%)             | -                 |  |
| White collar                                    | 95 (33%)              | -                 |  |
| Blue collar                                     | 11 (4%)               | -                 |  |
| Homemaker                                       | 34 (12%)              | _                 |  |
| Retired/Student                                 | 19 (7%)               | -                 |  |
| Household income                                |                       |                   |  |
| < A\$26,000 p.a.                                | 84 (29%)              | -                 |  |
| A\$26,000 – 51,999 p.a.                         | 73 (25%)              | _                 |  |
| >A\$52,000 p.a.                                 | 94 (33%)              | -                 |  |
| Health insurance                                |                       |                   |  |
| Yes   | 202 (70%)             | -                 |  |
| No  | 84 (29%)              | -                 |  |
| Surgical treatment <sup>(b)</sup>               |                       |                   |  |
| Mastectomy                                      | 78 (27%)              | 28%               |  |
| Breast-conserving                               | 209 (73%)             | 73%               |  |
| Axillary dissection                             | 249 (87%)             | -                 |  |
| Adjuvant therapy <sup>(b)</sup>                 |                       |                   |  |
| Radiation                                       | 205 (71%)             | _                 |  |
| Chemotherapy                                    | 121 (42%)             | _                 |  |
| Hormone therapy                                 | 117 (41%)             | _                 |  |
| Tumor size                                      | 11, (11,0)            |                   |  |
| Median, mm (min, max)                           | 17 (0.5, 140)         | 14 (0.3, 230)     |  |
| Lymph node status <sup>(a)</sup>                | 17 (0.5, 110)         | 11 (0.5, 250)     |  |
| Median, number (min, max)                       | 0 (0-39)              | 0 (0-39)          |  |
| 0 nodes invaded                                 | 158 (55%)             | -                 |  |
| $\geq 1$ nodes invaded <sup>(c)</sup>           | 91 (32%)              |                   |  |
| Z I nodes invaded  Complications <sup>(b)</sup> | 91 (32/0)             | -                 |  |
| _   | 4- (4.60.()           |                   |  |
| Wound or other infection                        | 45 (16%)              | -                 |  |
| Skin/tissue reaction                            | 148 (52%)             | -                 |  |
| Arm swelling                                    | 71 (25%)              | -                 |  |
| Seroma/hematoma                                 | 47 (16%)              |                   |  |

<sup>(</sup>a) Missing data – Health insurance 1 (0.3%); Household income 36 (13%); Occupation group 25 (9%); Education 2 (0.7%); Nodal status 38 (13%) (b) Not mutually exclusive categories (c)This category includes: 1-3 nodes 59 (21%); 4-9 nodes 18 (6%); >10 nodes 14 (5%)

Table 2. Summary of survivor costs related to breast cancer (0-18 months post-diagnosis) by broad cost category (\$US 2005)<sup>(a)</sup>

| Cost Category     | n   | % total n | Mean \$ | Sd \$ | Median \$ | Min \$ | Max \$ | Sum \$    |
|-------------------|-----|-----------|---------|-------|-----------|--------|--------|-----------|
| Direct            |     |           |         |       |           |        |        |           |
| - all women       | 287 | 100       | 1,937   | 3,210 | 827       | -      | 24,338 | 506,411   |
| - women with \$>0 | 252 | 88        | 1,688   | 3,065 | 605       | 4      |        |           |
| Indirect          |     |           |         |       |           |        |        |           |
| - all women       | 287 | 100       | 4,221   | 6,093 | 1,821     | -      | 22.250 | 816,363   |
| - women with \$>0 | 185 | 64        | 2,609   | 5,208 | 148       | 5      | 33,350 |           |
| Total             |     |           |         |       |           |        |        |           |
| - all women       | 287 | 100       | 4,689   | 7,029 | 1,781     | -      | 42.727 | 1 222 775 |
| - women with \$>0 | 265 | 92        | 4,297   | 6,853 | 1,518     | 4      | 43,727 | 1,322,775 |

<sup>(</sup>a) Costs have been weighted to compensate for oversampling of younger women.

Table 3. Summary of survivor costs of breast cancer (0-18 months post-diagnosis) among all participants and separately by age category<sup>a</sup> (\$US 2005)

|                                       | N   | Median <sup>b</sup> | Mean <sup>b</sup> | Lower<br>95%CI <sup>b</sup> | Upper<br>95%CI <sup>b</sup> |
|---------------------------------------|-----|---------------------|-------------------|-----------------------------|-----------------------------|
| All participants (N=265) <sup>b</sup> |     |                     |                   |                             |                             |
| Health services                       | 214 | 1,317               | 1,329             | 1,016                       | 1,679                       |
| Garments/aids                         | 162 | 245                 | 245               | 200                         | 292                         |
| Paid home services                    | 85  | 186                 | 191               | 112                         | 291                         |
| Total direct costs                    | 252 | 1,760               | 1,762             | 1,416                       | 2,111                       |
| Unpaid help                           | 138 | 329                 | 332               | 208                         | 446                         |
| Lost income                           | 92  | 1,891               | 1,901             | 1,369                       | 2,435                       |
| Lost unpaid work                      | 52  | 614                 | 625               | 358                         | 890                         |
| Total indirect costs                  | 185 | 2,821               | 2,845             | 2,300                       | 3,509                       |
| Total costs                           | 265 | 4,575               | 4,595             | 3,815                       | 5,474                       |
| Age <sup>c</sup>                      |     |                     |                   |                             |                             |
| ≤50 years (N=103)                     |     |                     |                   |                             |                             |
| Health services                       | 90  | 1,526               | 1,531             | 1,048                       | 1,992                       |
| Garments/aids                         | 62  | 276                 | 278               | 201                         | 365                         |
| Paid home services                    | 34  | 269                 | 281               | 110                         | 491                         |
| Total direct costs                    | 98  | 2,091               | 2,099             | 1,570                       | 2,635                       |
| Unpaid help                           | 58  | 415                 | 429               | 217                         | 667                         |
| Lost income                           | 52  | 2,483               | 2,503             | 1,727                       | 3,346                       |
| Lost unpaid work                      | 20  | 919                 | 938               | 311                         | 1,547                       |
| Total indirect costs                  | 82  | 3,851               | 3,853             | 2,700                       | 4,991                       |
| Total costs                           | 103 | 5,924               | 5,951             | 4,622                       | 7,395                       |
| >50 years (N=162)                     |     |                     |                   |                             |                             |
| Health services                       | 124 | 1,205               | 1,216             | 772                         | 1,632                       |
| Garments/aids                         | 100 | 222                 | 224               | 177                         | 278                         |
| Paid home services                    | 51  | 134                 | 135               | 70                          | 209                         |
| Total direct costs                    | 154 | 1,553               | 1,566             | 1,130                       | 2,038                       |
| Unpaid help                           | 80  | 269                 | 275               | 155                         | 401                         |
| Lost income                           | 40  | 1,499               | 1,522             | 914                         | 2,196                       |
| Lost unpaid work                      | 32  | 423                 | 427               | 251                         | 616                         |
| Total indirect costs                  | 103 | 2,229               | 2,230             | 1,504                       | 2,956                       |
| Total costs                           | 162 | 3,781               | 3,815             | 2,855                       | 4,826                       |

a. Results weighted to compensate for over-sampling of younger women.

b. Participants reporting values >\$0.

c. Mean costs were significantly different (p<0.001) between age  $\leq$ 50 versus age >50 for all itemized costs for participants who reported a positive value

Table 4. Direct, indirect and total costs by status of lymph node involvement overall<sup>a</sup> and stratified by age category (\$US 2005)

|  |         |                     |                   | <b>T</b>                    | T.T.                        |  |  |
|--|---------|---------------------|-------------------|-----------------------------|-----------------------------|--|--|
|  | N       | Median <sup>b</sup> | Mean <sup>b</sup> | Lower<br>95%CI <sup>b</sup> | Upper<br>95%CI <sup>b</sup> |  |  |
| All women <sup>c</sup>                 |         |                     |                   |                             |                             |  |  |
| Local - $0$ invaded nodes ( $N=143$ )  |         |                     |                   |                             |                             |  |  |
| Total direct costs                     | 138     | 1,440               | 1,450             | 1,090                       | 1,820                       |  |  |
| Total indirect costs                   | 93      | 2,061               | 2,072             | 1,379                       | 2,856                       |  |  |
| Total costs                            | 143     | 3,486               | 3,533             | 2,667                       | 4,591                       |  |  |
| Regional - $\geq 1$ invaded r          | nodes ( | N=85)               |                   |                             |                             |  |  |
| Total direct costs                     | 80      | 2,363               | 2,387             | 1,710                       | 3,155                       |  |  |
| Total indirect costs                   | 68      | 4,331               | 4,354             | 3,007                       | 5,718                       |  |  |
| Total costs                            | 85      | 6,640               | 6,674             | 5,136                       | 8,515                       |  |  |
| Younger women <sup>d</sup>             |         |                     |                   |                             |                             |  |  |
| Local - 0 invaded nodes                | (N=48)  | 3)                  |                   |                             |                             |  |  |
| Total direct costs                     | 46      | 1,800               | 1,820             | 1,130                       | 2,534                       |  |  |
| Total indirect costs                   | 35      | 3,022               | 3,066             | 1,565                       | 4,628                       |  |  |
| Total costs                            | 48      | 4,755               | 4,819             | 3,219                       | 6,986                       |  |  |
| Regional $\geq 1$ invaded no           | des (N  | =40)                |                   |                             |                             |  |  |
| Total direct costs                     | 39      | 3,117               | 3,138             | 2,120                       | 4,203                       |  |  |
| Total indirect costs                   | 36      | 5,706               | 5,728             | 3,864                       | 7,775                       |  |  |
| Total costs                            | 40      | 8,843               | 8,880             | 6,701                       | 11,204                      |  |  |
| Older women <sup>d</sup>               |         |                     |                   |                             |                             |  |  |
| Local - $0$ invaded nodes ( $N=95$ )   |         |                     |                   |                             |                             |  |  |
| Total direct costs                     | 92      | 1,256               | 1,259             | 872                         | 1,730                       |  |  |
| Total indirect costs                   | 58      | 1,580               | 1,613             | 965                         | 2,432                       |  |  |
| Total costs                            | 95      | 2,867               | 2,891             | 1,961                       | 3,870                       |  |  |
| Regional $\geq 1$ invaded nodes (N=45) |         |                     |                   |                             |                             |  |  |
| Total direct costs                     | 41      | 1,747               | 1,797             | 830                         | 2,649                       |  |  |
| Total indirect costs                   | 32      | 3,120               | 3,173             | 1,443                       | 4,919                       |  |  |
| Total costs                            | 45      | 4,868               | 4,937             | 2,482                       | 7,177                       |  |  |

a. Nodal status is known for 246 women; 38 women did not have nodes removed and 3 had nodes removed but status is unknown.

b. Participants reporting values >\$0. All results weighted to compensate for over-sampling of younger women.

c. Mean costs were significantly different between local and regional disease groups for all costs (p<0.001).

d. Mean costs were significantly different between younger and older women within local disease groups and within regional disease groups for all costs (p<0.001)

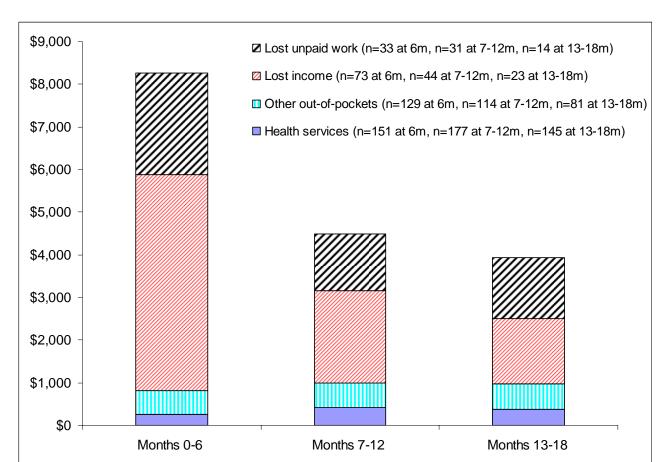


Figure 1. Median costs<sup>1</sup> by main source<sup>2</sup> in each 6-month period for the first 18 months post diagnosis (\$US 2005)

- 1. Participants reporting values >\$0. Figures are weighted to account for over-sampling of younger women.
- 2. 'Other out-of-pocket expenses' include unpaid help, garments/aids, and domestic help expenses.

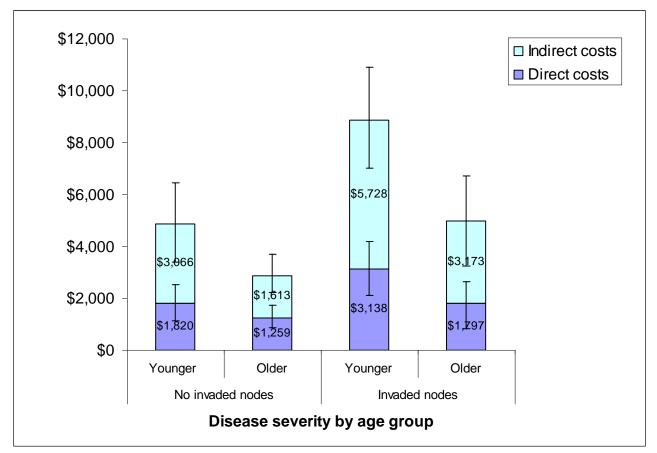


Figure 2. Mean costs¹ and 95%CIs by age category and lymph node status (younger women ≤50 yrs and older women >50 yrs) (USD 2005)

1. Participants reporting values >\$0.