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The out of pocket cost of breast cancer survivors: a review

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Abstract

Introduction—Out of pocket (OOP) costs add to the burden facing breast cancer survivors but remain an understudied area of costs. Current turbulent economic climate increases the urgency to better understand this burden. Few studies or systematic reviews focus on OOP costs.

Methods—PubMed search was conducted for articles in English containing: (1) MESH terms breast neoplasms and economics, and (2) words “breast cancer” and “cost” or “costs,” “expenditure,” or “out of pocket.” Limits included: publication dates from January 1, 1980 to December 16, 2009, and populations aged≥45 years old. Articles were excluded based on title, abstract, and full text reviews. Citation searches and searches of reference lists were also conducted. Three articles were selected for this review.

Results—Medical direct OOP costs (e.g., for physician fees) ranged from $300 to $1,180 per month during active treatment, and were about $500 per month 1 year post diagnosis. Non-medical direct OOP costs (e.g., for transportation to doctor’s office, parking etc.) ranged from $137 to $174 per month in the year post diagnosis; and $200–$509 per month 1 year or more after diagnosis. Different types of costs were identified.

Conclusion—OOP costs represent a significant burden for survivors even after initial treatment. The nature and extent of OOP costs need further evaluation.

Implications for cancer survivors—OOP costs are rarely considered. However, as OOP costs affect the well being of cancer survivors, they should be understood more fully and possibly addressed in interventions aimed at improving quality of life.

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Keywords

Economic burden; Cancer survivors; Cost; Out of pocket costs

Introduction

Breast cancer is a costly disease for health care payers and patients. The incremental cost of care for breast cancer survivors compared to the costs of care for women who do not have the disease is considerable even in the years post diagnosis or before death. In the United States, the annual cost of breast cancer paid by Medicare has been estimated to be about $12,500 in 2008 dollars in the first year following breast cancer diagnosis, about $1,400 in each of the following years, and more than $33,000 in the year before death [1]. The cost of breast cancer is not limited to the cost incurred by insurance payers such as Medicare, which has received much attention in the literature [2,3]. Remarkably, the cost incurred by others, including cancer survivors, has received far less attention. For example, there is limited information on the cost incurred out of pocket (OOP) by women with breast cancer during the cancer survivorship experience, defined by the National Cancer Institute as the period from diagnosis and for the remainder of a survivor's life [4]. Developing a better understanding of OOP costs and how they affect quality of life of cancer survivors is important. Recent and current economic conditions result in an even more urgent need for this knowledge. Cancer survivors and their families may be more economically vulnerable to the effects of OOP expenses than are their counterparts without cancer. Such vulnerability may be exacerbated by an increased probability of unemployment within the family and tightening of consumer credit options. Therefore, the purpose of this paper is to: (1) review the literature of studies that reported OOP costs to better understand the nature and extent of these costs during the cancer survivorship experience; and (2) suggest research and methodological implications of future studies of OOP costs with cancer survivors.

Conceptual framework

Out of pocket (OOP) costs are an important part of the larger economic burden of cancer. Brown and Yabroff describe economic burden as the loss of economic resources and opportunities associated with the occurrence of cancer [2]. According to their conceptual model, economic burden is measured by three cost domains: (a) *direct costs*; (b) *indirect costs*; and (c) *psychosocial costs* (Fig. 1) [2].

Direct costs include cost of using resources for the care of cancer and related sequelae. These include medical direct costs such as the costs of physician fees, hospital bills, and other health care services. These costs are paid by a third party payer if survivors have insurance coverage, and OOP by patients and their families (Fig. 1). Non-medical direct costs include those expenses necessary to obtain care such as transportation to hospitals or doctors' offices, parking, and childcare services. They also include other costs related to cancer such as home alterations, special diets or clothing, or expenditures for physical activities. Survivors bear the entire burden of these non-medical direct costs (Fig. 1).

Direct costs also include the cost of time spent by patients to obtain medical care. While this cost may or may not result in an OOP expense, it represents an important component of the burden of cancer. Yabroff and colleagues estimated this cost to vary from $1,206 in the first year after diagnosis to $3,308 in the last year of life for women with breast cancer. In the years between these two extremes, the value was, at most, $72 for all types of cancers [5]. In addition, time lost from work can translate into lost income that may affect decisions about treatment [6].

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The economic burden of cancer also includes indirect costs and psychosocial costs (Fig. 1). Indirect costs, namely the value of time spent with disease, represent time that cannot be dedicated to usual activities and are considered a loss of productivity for the survivor and society. Receiving a diagnosis of cancer also affects the decision to work or retire, thus altering individuals' economic opportunities [7]. Indirect costs may also refer to other lost opportunities such as using retirement savings, postponing schooling plans or vacations, and/or relocating to more affordable housing [2,8].

Psychosocial costs refer to the loss of quality of life associated with having cancer. Women with breast cancer incur such costs in the psychosocial domain of quality of life. These costs are related to: anxiety, depression, cancer burden, marital discord, negative changes in social and family relationships, and uncertainty over the future [9].

The three domains of economic burden can affect the lives of cancer survivors and their families. However, these domains and the types of costs within each domain have not received the same degree of scrutiny. For example, much attention has been given to direct medical costs paid by third party payers such as Medicare [1]. Other costs, in particular, OOP medical and non-medical costs, are less understood [10]. Thus, in this review, we examined published information on OOP direct costs reported by breast cancer survivors.

Methods

To identify articles on direct OOP costs of breast cancer survivors we first conducted a PubMed search for articles in the English language that contained the MESH terms breast neoplasms and economics. We then conducted a text search with words "breast cancer" and "cost" or "costs," "expenditure," or "out of pocket." We excluded articles with the following keywords: screening, prevention, mammography, mammogram, Phase 1, genetic, child, childhood or children in the title. We then excluded papers that were either reviews, comments, letters, or did not have an abstract. We limited the publication date from Jan 1, 1980 to December 16, 2009. We then limited the search to articles in the English language on populations aged 45 years old and older.

The searches yielded 1,182 articles. We reviewed the titles for first level screening. We identified 208 articles that were potentially relevant. We reviewed their abstracts and eliminated 79 articles that were studies conducted with a non-US population. We limited to studies of breast cancer survivors in the US because data on OOP costs are not easy to compare across countries. Each country has different health care and social systems that affect treatment and follow-up patterns and reimbursed services, and, thus, affect the type and amount of OOP costs [10].

Next, we eliminated nine papers that were cost studies conducted from the perspective of a third party payer, 12 that did not report cost information but focused on treatment preferences, quality of life, or survival, 10 that focused only on specific side effects, and 5 that were review papers, letters, comments, or qualitative studies.

With the remaining 33 studies, we examined the full text articles. We found that 18 were cost-effectiveness studies of which two were conducted using a non-US population; eight reported costs from a third party payer perspective; eight included time costs and travel costs that were estimated based on assumptions rather than participant self-report. Further, one was a case report study, two were reviews, three were conducted from a third party payer perspective, and one was conducted with a non-US population. Of the remaining eight, we eliminated five because the authors reported on indirect costs of breast cancer and not OOP expenses [11–15]. The remaining three articles are discussed in this review [7,16,17].

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Citation searches for these articles and searches of review articles' reference lists did not yield additional articles of interest.

All costs reported in the three articles were adjusted to 2008 dollars using the Consumer Price Index (all items, all urban consumers). Average costs and standard deviations (SD) were reported separately based on the time since diagnosis. In this study, survivorship is considered to be the time from diagnosis to the rest of the life of a woman diagnosed with breast cancer [4].

Results

Direct medical costs

Table 1 summarizes studies that reported various categories of OOP costs related to breast cancer. Given and colleagues reported results of 62 women receiving treatment for a new or recurrent diagnosis of breast cancer [16]. Women were recruited from community cancer treatment centers, were between the ages of 20 and 80, mostly white and middle class. Investigators used a telephone interview and mailed questionnaire to collect information on OOP costs (i.e., non-reimbursed expenses for breast cancer related care) for the 3 months before the interview. They included nine categories of costs: hospital and physician services, medications, purchases of special equipment, supplies, foods and supplements, nursing homes, visiting nurses, and home health aides. Investigators found that women who survived more than 6 months after participating in the survey, reported average OOP costs of $902 [SD=842] (2008 US dollars) or about $300 per month in 3 months preceding the interview. Women who did not survive as long spent on average $1,853 [SD=1,282] (2008 US dollars), or about $600 per month.

Arozullah and colleagues reported OOP expenses of 156 women within 2 years of breast cancer diagnosis recruited from one cancer center. The majority were white, between the ages of 29 and 64, within 1 year of diagnosis, and with private insurance [7]. The authors considered OOP, or non-reimbursed expenses, for a wide array of health care. Similar to Given et al., the authors included expenditures for hospital bills, doctor visits, medicines, special equipment, medical supplies, and supplements. They also included expenditures for prosthesis, second opinion visits, nursing care, alternative therapies, counseling, nutrition counseling, physical or speech therapy, and experimental treatment. They collected data using an in-person interview and a written questionnaire. The authors found that the OOP cost amounted to $655 per month in the 3 months before the interview. Costs varied depending on time since diagnosis with the lowest being $504 per month (2008 US dollars) for women who were more than 1 year from diagnosis (Table 1). These costs were particularly burdensome for poor women. Costs represented 75% of total income for women who earned less than $30,000 per year ($39,000 in 2008 dollars) and 8% for those who earned more than $60,000 ($77,000 in 2008 dollars) [7].

Direct non-medical costs

Direct non-medical costs examined by Arozullah et al. included costs for transportation (reported by 78% of women), restaurant meals (51%), telephone calls (36%), housekeeping and laundry services (16%), childcare (7%), and hotel stays (4%) [7]. These expenses amounted to $169 on average per month, with the highest monthly costs (about $200) incurred by women who were 1 year post diagnosis. These costs represented 6% of income for women earning at the time less than $30,000 per year, and only 2% for those earning $60,000 or more [7].

Moore reported on a small but more diverse population composed of 30 breast cancer patients who were between 13 to 120 months since first diagnosis and were undergoing

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chemotherapy [17]. Women were on average 52 years old, 53% were black, 20% were on Medicaid, 10% on Medicare, and the rest on HMO or other private insurance. Data were collected in person by an interviewer using a modified version of the Cost Interview Questionnaire originally created to collect data on the costs of terminal care for childhood cancer [18], and adapted by the author to adult cancer patients [19].

Overall, direct non-medical costs reported by Moore were higher than those reported by Arozullah for women who were more than 1 year from diagnosis. However, the women interviewed by Moore were undergoing chemotherapy treatment [7,17]. The amount spent OOP in 1 month was about $509 in 2008 dollars (range $51 to $1,730) and included cost for travel to the chemotherapy facility, parking, overnight stays, and meals away from home. While only one participant had OOP expenses for overnight stays (3%), 70% reported expenses for meals and snacks for a mean cost of $48 (range $4–$283) (2008 dollars) [17]. Eighty three percent reported other expenses related to side effects of treatment such as clothing, food and supplements, and medications.

One particular OOP identified as personally important was the expenditure for wigs which was reported by 70% of women for an average cost of $263 (2008 dollars) and a range of $20 to $800 [17]. Moreover, 27% of women bought gifts for themselves or others who helped them during treatment: the costs of these gifts ranged from $14 to $706 (2008 dollars) [17]. Women also spent on household improvements such as purchasing appliances to reduce household work (13% for an average cost of $268), distractions and counseling (10% of women for an average cost of $612), housekeeping (3% of women with an average cost of $71) [17], and administrative type costs such as increased health insurance premiums (30% of women with an average cost of $220) and increased phone bills (57% of women with an average cost of $62) (2008 dollars) [17].

Discussion

Recent economic conditions have created an urgent need to understand how a diagnosis of cancer affects the economic well being of cancer patients and their families. We identified only three studies that reported OOP costs for breast cancer survivors in the US and only one published in the last 10 years. This highlights the scarce attention being paid to this topic and the need to better understand what the cost of cancer survivorship is. In these studies, we found that OOP costs incurred by breast cancer survivors are considerable even for survivors with insurance coverage [7,16,17]. In addition, they constitute a substantial burden even for survivors 1 year post diagnosis [7]. For example, survivors who were 1 year post diagnosis and completed treatment had OOP monthly expenditures of $500 in direct medical costs and an additional $200 in non-medical direct costs [7]. Within 1 year post diagnosis, direct medical costs were as high as about $1,180 per month [7,16]

These studies highlight types of expenditures that are rarely taken into account when considering the economic burden of cancer. OOP costs that are important to survivors include expenditures for wigs, meals out of the house, gifts to caregivers, housekeeping, and telephone bills [7,16,17]. In focus groups including Canadian breast cancer survivors and their caregivers, Lauzier et al. found that costs considered important were those for treatment of side effects, prosthesis, or other equipment that helped women feel comfortable after surgery [20]. Other costs included those for wigs, creams, bandages, clothes, bras, hats, scarves, makeup, and new clothes to adjust for weight changes [20].

Depending on financial means, the types of expenditures may vary. Breast cancer survivors participating in focus group discussions made a distinction between costs that were not avoidable, such as those costs related to getting to and from treatment or costs related to job

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changes, and costs that were avoidable and were incurred by those who were able to pay, for example costs of house cleaning and treats for caregivers [20]. Thus, cancer survivors with limited financial means who avoid some expenses may be giving up some services that could help to ameliorate their quality of life. However, even when avoiding some expenses, lower income women remain disproportionally affected by the burden of OOP costs [7]. Langa et al. found similar results when considering OOP direct medical costs for individuals 70 years old and older participating in the Health and Retirement Study in 1993 [21]. In their study, OOP direct costs amounted to 23% of income for survivors not on treatment, 27% for survivors on treatment and only 17% for non-cancer survivors in the bottom quartile of the income distribution. However, the costs were 5%, 7% and 5% for individuals in the top income quartile [21]. Guidry and colleagues reported on OOP costs for chemotherapy and radiation treatment visits and found that a higher proportion of Hispanics had expenses greater than $200 (or $298 in 2008 dollars) than black or white patients [6]. Therefore, minority patients with limited resources may be disproportionally burdened economically.

The economic burden of cancer as illustrated in Fig. 1 is not limited to OOP costs, but includes several other considerations of lost opportunities for patients and often families. For example, in order to distract themselves from cancer, breast cancer survivors may engage in activities they would not have engaged in if they did not have cancer [20]. Moore reports expenses for distractions and counseling for 10% of the women in her study, for an average cost of $612 [17]. Families often make sacrifices in the form of abandoning, changing, or cutting back projects or other activities of family members, or using savings and retirement funds [8,20].

Breast cancer is not the only cancer to impose significant burdens on those affected, and may not be the most costly. In general, large surveys report that, compared to respondents without cancer experience, cancer survivors have higher OOP costs even when not receiving cancer related treatment. Langa et al. found a mean annual OOP cost that was about $2,204 if cancer survivors were not on treatment and $2,967 if on treatment (2008 dollars). These amounts were considerably higher than the $1,935 (2008 dollars) spent by respondents without cancer history [21]. The costs reported by Langa and colleagues included OOP for hospital and nursing home stays, outpatient services, home care or similar community based services, and prescription medications. Finkelstein et al. analyzed data from the Medical Expenditure Panel Survey (MEPS) for the working age population [22]. They found that the mean OOP medical expenditure (copayments, deductibles, and payments for non-covered medical services) was $596 in 2008 dollars for respondents with no evidence of cancer, $948 (2008 dollars) for cancer survivors with no cancer care in the survey year, $1,301 (2008 dollars) for cancer survivors with follow-up cancer care, and $1,907 (2008 dollars) for those with one or more claims for cancer care in the survey year [22]. In a convenience sample of 20 cancer patients on chemotherapy (of whom 11 had breast cancer), Moore found that the average OOP (for clinic visits, symptoms and side effects, support/assistance, administrative, and quality of life) was about $1,045 in 1 month, with a maximum of $4,422 (2008 dollars) [19]. This cost was higher than the cost reported by the same author for the breast cancer group alone (Table 1) [17].

The type and amount of OOP expenses differ for breast cancer survivors in non-US countries as the health care and social systems may cover more or different services than the US. Direct medical OOP costs in Australian breast cancer survivors were similar in magnitude to costs reported in Table 1. Gordon and colleagues reported that survivors incurred expenses for health services (copayments and prescriptions), garment/aids, and paid home services for an average of about $1,860 in the 18 months following diagnosis, or about $100 per month (in 2008 US dollars) [23]. In this study, expenditures for copayments and prescriptions varied little in the three 6-month periods from diagnosis, with the highest

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median cost ($462) being in months 7–12 from diagnosis [23]. Median costs of purchasing garments and aids in Australian women were highest at $238 in months 0–6, while those for home services were highest ($220) in the later survivorship period (months 13–18 post diagnosis) [23]. Even if the magnitude of the OOP cost is similar for Australian and American survivors, its impact on the quality of life may not be the same because of different support services available. Furthermore, in a group of Canadian survivors of breast, lung, colorectal, and prostate cancer undergoing initial treatment, Longo and colleagues found that travel costs were higher ($234) than OOP costs for drugs, homecare, homemaking, alternative medicines, vitamins/supplements, family care, accommodations/meals, devices, and other ($160) (in 2008 US dollars) [24].

The paucity of studies on OOP costs for cancer survivors is troublesome as these costs may have a profound effect on survivors [3,8,25–27]. However, it is not surprising. Collecting these costs is not straightforward as instruments to collect them are not available [28]. Therefore, opportunities to collect OOP costs from participants of clinical trials of survivorship interventions or from larger populations of survivors are missed. Moreover, studies rely on patients' recall of their expenditures and often ask them to recall expenditures over a number of months before the interview. Efforts to collect these costs as patients go through treatment and periodically during survivorship may provide a better estimate of these costs.

Collecting OOP cost information would be beneficial on several fronts. A better understanding of OOP costs and their effects on the well being of cancer survivors can provide useful information on planning interventions to improve the life of survivors, especially for minorities and poor women [3,29]. For example, given that medical direct costs are the major component of OOP expenditures (Table 1), interventions may be designed to enroll survivors in programs that provide drugs for free or at a reduced cost, or to implement payment plans for health care services with affordable monthly payments, or to waive copayments for follow-up cancer procedures. Moreover, survivors may be guided to use available community resources that may reduce the costs of transportation or meals away from home. Studies also need to understand if and how OOP costs affect decisions concerning access to health care services and, thus, survivors' future health outcomes. Continuing cancer surveillance care, treatment for other medical conditions, even the ability to afford health insurance coverage, could all be affected by the magnitude and types of OOP costs explored in this review [3]. Studies that investigate how the burden of OOP costs affect decisions to access medical care and other services are needed in larger and more diverse populations of survivors across the US.

Additional studies that collect OOP costs information are useful to conduct economic evaluations of interventions for cancer survivors from a broader perspective than that of a health care payer. Not including these costs may lead economic evaluations to underestimate the benefit of interventions, as the full cost of disease cannot be considered. Moreover, economic evaluations may find cost-effective interventions that shifts costs from third party payers to survivors, i.e., to interventions that are less expensive for third party payers but that may end up being too burdensome for survivors.

Information on OOP costs will help plan the evaluation of intervention studies that may include an assessment of the effect of the intervention on OOP costs. A reliable estimate of the standard deviation of OOP is needed, in order to determine the sample size required to statistically detect a relevant difference of interest. The few studies available in the literature provide a wide range of standard deviations that would result in a wide range of estimated sample sizes. Such uncertainty makes it difficult to plan and implement a study. Systematic examinations of OOP are required to better understand their distribution and patterns of

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variability (both cross-sectionally and over time) in the population of US breast cancer survivors, before attempts are made to ameliorate the economic burden on survivorship.

Limitations of the review should be noted. First, there are only a few studies that have reported OOP costs from breast cancer survivors. These studies have measured different items of OOP costs and at different stages of survivorship. This makes it difficult to compare dollar amounts across studies. Moreover, they have included small samples of survivors (30–156 women) and thus their generalizability to larger populations of breast cancer survivors is limited. Caution must be used when updating costs to 2008 dollar values as these figures may not reflect the current cost of goods and services. As these costs change over the years, expenditures for buying the same goods in the same quantities may be different than the updated dollar figures.

Implications for cancer survivors

Cancer OOP costs include various types of expenses that are rarely measured but still burden survivors and families even after treatment is completed. Not understanding this burden may lead researchers to ignore an important factor that affects the quality of life and long term outcomes of survivors. Studies in larger and more diverse populations are needed to quantify the OOP burden especially for poor and minority survivors. It is also necessary to understand how potential OOP costs affect decisions about accessing health care and other services that may help survivors improve their quality of life. Furthermore, not understanding the burden of OOP costs may also limit researchers' ability to design and evaluate appropriate interventions. It is important that studies better understand what constitute the economic burden of cancer and how it affects the lives of cancer survivors especially in current economic conditions.

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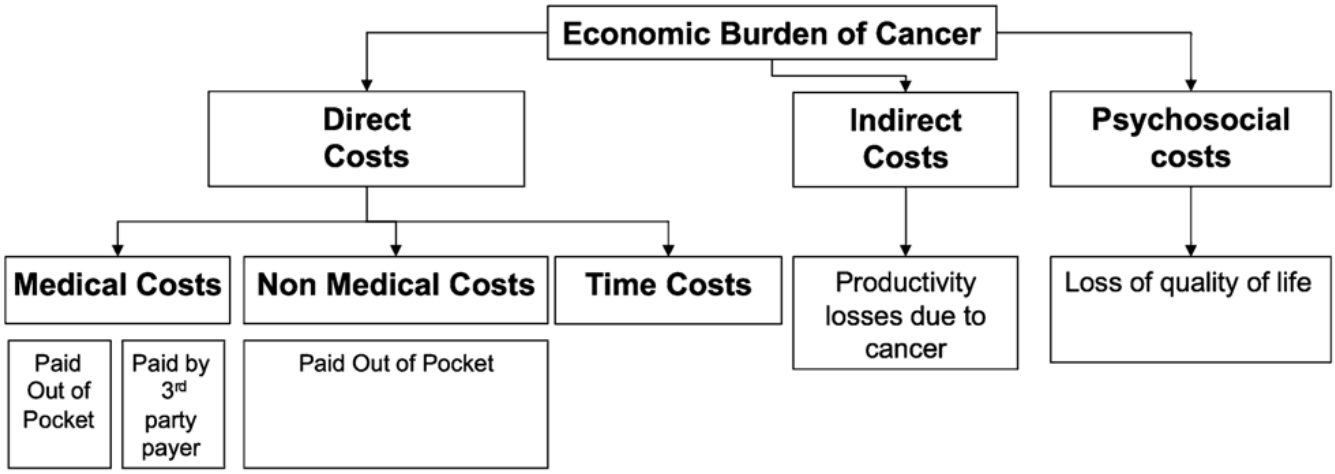

Figure 1.
Economic burden of cancer: adapted from Brown and Yabroff 2006.

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Table 1

Summary of studies that have reported direct medical and non-medical costs for breast cancer survivors, costs in 2008 US dollars

	Sample	Direct		Timing	Notes
		Medical	Non medical		Specific cost items
Within one year of diagnosis					
Given 1994 [16]	Women who survived≥6 months after the interview	$902 (SD 842)	No	3 month costs during treatment	**Questionnaire on out-of-pocket costs for the following non-reimbursed expenses (telephone interviews plus mailed questionnaire): Direct Medical:** Hospital and MD, nursing home, meds, visiting nurse, home health aide, special equipment, supplies, and foods and supplements
Given 1994 [16]	Women who did not survive	$1,853 (SD 1,282)	No	3 month costs during treatment	
Arozullah 2004 [7]	Women on month 0–5 from diagnosis	$629 (SD 865)	$174 (SD 252)	Monthly cost for the 3 months before interview	**Questionnaire on out-of pocket costs for the following non-reimbursed expenses (in person interview and written questionnaire): Direct Medical**: Hospital bills, doctor visits, medicines, prosthesis, second opinion visits, supplements, nursing care, alternative therapies, counseling, nutrition counseling, medical supplies, physical or speech therapy, special equipment, and experimental treatment. **Direct Non-medical**: Cost of childcare, transportation, housekeeping, restaurant meals, telephone bills, and hotel stays
Arozullah 2004 [7]	Women on month 6–12 from diagnosis	$1,179 (SD 1,809)	$137 (SD 295)	Monthly cost for the 3 months before interview	
More than one year post diagnosis					
Moore 1999 [17]	Women on month 13–120 from diagnosis and receiving chemotherapy for recurrent cancer	No	$509 (SD 489)	One month during chemotherapy	**60 item questionnaire on the following expenses (administered in person): Direct Non-medical:** Transport, parking, overnight, meals, clothing, food and supplements, medications, housekeeping, meals out, counseling, household improvements, phone bill, and insurance premiums
Arozullah 2004 [7]	Women on month 13–24 from diagnosis	$504 (SD 685)	$200 (SD 372)	Monthly cost for the 3 months before interview	**Questionnaire on out-of pocket costs for the following non-reimbursed expenses: Direct Medical**: Hospital bills, doctor visits, medicines, prosthesis, second opinion visits, supplements, nursing care, alternative therapies, counseling, nutrition counseling, medical supplies, physical or speech therapy, special equipment, and experimental treatment. **Direct Non-medical**: Cost of childcare, transportation, housekeeping, restaurant meals, telephone bills, and hotel stays