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Dealing with the financial burden of cancer: perspectives of older breast cancer survivors

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Abstract

Purpose—Financial burden among cancer survivors is often overlooked in survivorship care planning. Cancer survivors with limited incomes may be particularly affected. Yet, little data are available to address financial issues among them. Eliciting the survivors' perspectives on how to deal with this financial burden is a first crucial step to identifying the means to provide this supportive care.

Methods—In this pilot study, three Nominal Group Technique (NGT) sessions were conducted with a convenience sample of 23 older breast cancer survivors (age 52 to 83) recruited from a county safety net hospital and a Comprehensive Cancer Center. One single NGT question was posed in these sessions, namely “*What could help women deal with the financial burden that cancer brings to them and their families?*” Survivors responded in an iterative fashion and then ranked the most relevant responses.

Results—The most relevant responses addressed the: (1) need for affordable insurance; (2) need to have prompt information on treatment costs patients will face, insurance coverage, and agencies or programs that provide needed products and services; and (3) need to access social workers, navigators, support groups, or others knowledgeable about available resources. Survivors also suggested that physicians become aware of cancer costs and financial issues faced by patients, and consider costs in their treatment plans.

Conclusions—Older survivors face financial challenges for which there are few available resources. They suggested several avenues to address cancer-related financial issues that may be considered in developing supportive interventions.

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Keywords

survivorship; breast cancer; financial burden; financial toxicity; older women

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Introduction

Recently, several articles in the lay press have highlighted issues related to the cost of cancer treatment and the financial burden, or “toxicity,” of cancer [1–4]. Further, the Institute of Medicine recognizes financial issues among the psychosocial needs of cancer survivors that need to be addressed in a comprehensive approach to cancer care [5]. This need may be particularly salient for survivors with lower incomes who typically pay more out-of-pocket as a proportion of income than survivors with higher incomes [6–9]. Moreover, among breast cancer survivors with low income (<\$40,000), this burden was greatest for racial/ethnic minority survivors, suggesting racial/ethnic disparities even among those with similar income. [9]. This finding is concerning as these financial disparities may lead to disparities in quality of life as well [10–13]. Among the challenges raised by African American medically underserved women (50%, 60 years old and older), concerns about the long term impact of cancer burden on work, on savings, and on ability to pay for other family needs were common [14]. Moreover, low income African American cancer survivors identified financial assistance with paying for medical bills as one of their most pressing needs [15]. Further, among white women with breast and ovarian cancer (30–67 years of age with different income levels), an important theme was worry about spending money for cancer expenses rather than family needs [16]. Women also worried about losing their safety net by using their lifetime savings, cashing in retirement, or building up debt [16]. As a consequence, women reported feeling lost and alone when dealing with these issues [14]. Addressing financial issues associated with cancer is thus a priority to improve the cancer experience and survivorship. Currently, there is little guidance available on how to provide this supportive care to breast cancer survivors, particularly minorities and older survivors.

To guide future efforts to assist women diagnosed with breast cancer with the financial aspects of having this disease, in this pilot study we asked survivors what could be done to help women who are diagnosed with breast cancer deal with the financial challenges breast cancer brings to women and families. Twenty three breast cancer survivors described the financial burden of cancer and offered their perspectives on how to help newly diagnosed women navigate this aspect of the cancer experience.

Methods

The Institutional Review Board of the University of Alabama at Birmingham (UAB) approved this study. We conducted three Nominal Group Technique (NGT) sessions with a convenience sample of women aged 50 and older diagnosed with breast cancer, with no restrictions on time since diagnosis, and recruited from clinical settings serving women with disparate economic backgrounds. The sample was segmented by health care setting first, and then by race.

In one NGT session, participants were women who received care at a safety net hospital that primarily serves the uninsured population of Jefferson County, AL, and who previously participated in the SURE study, a randomized controlled trial to assess the effectiveness of the American Cancer Society's I Can Cope Program. Following a letter sent by the SURE study principal investigator (MYM), a project recruiter contacted women over the phone and invited them to participate. Of 34 women, 9 agreed to participate, eight African Americans and one white (reflecting the racial composition of the hospital patient population). In the other two NGT sessions, participants were women who received care at a Comprehensive Cancer Center, six African Americans and eight whites (the patient population at the Comprehensive Cancer Center is about 30% African American). Participants were recruited through patient navigators and through word of mouth following a presentation on the economic burden of breast cancer at a support group at the same Comprehensive Cancer Center. Following referrals, the project recruiter contacted women over the phone to invite them to participate. She also elicited further suggestions about survivors who would be interested in the study. Since notification about the study was done through informal networking, the total number of women reached through this effort was not tracked. Given the different financial burden experience of racial/ethnic minorities described in the literature, we segmented this group of participants by race and conducted one NGT session with African American women only, and another with mainly white women (one African American woman recruited later in the process also participated in this group).

Unlike other forms of qualitative interview where multiple questions are posed to participants, NGT is a qualitative method in which a single question (NGT question) is used to elicit responses. The single NGT question was generated by the authors and refined using an informal iterative process with breast cancer survivors and nursing research staff of a breast cancer survivorship study: this process determines whether the question would be understood by survivors and whether it elicited the information we aimed to obtain from them. The final question that was used in the NGT sessions was as follows: *What could help women deal with the financial burden that cancer brings to them and their families?*

The NGT sessions consisted of 1) the silent, written response to the NGT question, 2) the recording of the generated responses in a round robin fashion, 3) the discussion of the responses for clarification, and 4) the voting to prioritize the responses. After completing written informed consent, the moderator explained the NGT procedure and introduced the NGT question. The moderator (RS) is trained in NGT methods and has considerable expertise in conducting these sessions. He was assisted by a female graduate student. Each participant was asked to write down at least one answer. Next, the moderator invited the participants to share their written responses with the group. The moderator compiled a list of all responses, discussed it with the participants, and grouped similar responses together to arrive at a final comprehensive list that included the input of all participants. The moderator then invited each participant to vote by selecting the three top answers that she considered to be the most relevant to help women deal with the financial burden of cancer. Each participant then ranked the chosen responses from the most relevant (score of 3) to the least relevant (score of 1). This process took about 60–90 minutes. At the completion of the NGT

session, the moderator and assistant thanked them and provided compensation for time and travel expenses.

Results

A total of 23 older breast cancer survivors participated in three NGT sessions: of them, 9 were participants who received their cancer care from the safety net hospital, and the remainder from the Comprehensive Cancer Center. Participants ranged in age from 52 to 83 years old, 14 were African American and 9 were white. We report for each NGT session the list of responses selected by participants as most relevant to help women deal with the financial burden of cancer, and for each response, the number of votes received, the votes assigned by participants (3 most relevant, 1 least relevant), and the percent of the sum of all votes.

Participants of the first NGT session were 8 African American women and one white woman who received care from the safety net hospital. They identified 30 distinct responses and voted 16 as the most relevant (Table 1). The most relevant response was “help with finding public agencies that can help finance things (e.g. transportation and co- pays) by providing money or voucher” (20.4% of all votes), with three participants endorsing it as the most relevant way of helping women deal with the financial burden of cancer. The next most relevant response was having less expensive cancer insurance (11.1% of votes) with one participant endorsing this as the most relevant response. The next set of responses, 4 to 8, were each endorsed as most relevant by one participant: these responses were related to i) making psychotherapy available early during the course of treatment, and ii) to what doctors or insurance companies can do to help women deal with the financial burden of cancer. Participants also thought it was important for women to have a social worker who counsels patients about their financial situation (7.4% of votes), to talk to someone with similar problems (5.6% of votes) and, early in the treatment/care process, have information on what cancer costs to expect (5.6% of votes). Moreover, participants thought it was crucial to have laws to ensure that insurance is not denied to cancer survivors (5.6% of votes). This group of participants also recommended that one way to help women was to reassure them that they would be treated “no matter what” (5.6% of votes) and to inform them of where to go for care if their hospital closed (3.7% of votes).

In the second NGT session, participants were five African American women who received care from the Comprehensive Cancer Center. They identified 25 distinct responses, then selected 10 as those relatively more relevant (Table 2). The response receiving the highest percent of all votes (20%) was “Make sure that the patients are informed about their coverage and what services are available to them prior to surgery.” Two participants endorsed this as most relevant. The next set of responses that received 13.3% of the votes indicated that participants felt it was important that “physicians work together to develop a treatment plan that considers financial consequences,” and that financial grants for things not covered by insurance and complementary alternative medicine be made available to cancer patients. Participants also expressed that patients have access to social workers knowledgeable about benevolent funds at various hospitals (10% of votes) (Table 2).

Eight white survivors and one African American survivor who received care from the Comprehensive Cancer Center participated in the third NGT session, but one white survivor did not have the opportunity to participate in voting. Participants identified 36 unique responses, and then selected 11 as the relatively most relevant to help women deal with the financial burden of cancer (Table 3). The two most important ways to help women (18.7% of votes each) were 1) better insurance policies with low copayments and deductibles, and 2) the program “Look Good, Feel Better” by the American Cancer Society which provides complementary goods to survivors such as make up, hats and wigs. Four participants identified support groups as the second or third most relevant way of helping women by providing information and help (14.6% of votes). Two women endorsed Cancer Care/New Beginning groups (10.4% of votes) for gaining information and for support, and the use of a good navigator to help with financial issues (10.4% of votes) as the most or second most relevant way of helping women with financial issues.

Discussion

Hearing the voices of cancer survivors is fundamental to inform meaningful interventions to improve their quality of life. In this study, we asked breast cancer survivors the following question: “*What could help women deal with the financial burden that cancer brings to them and their families?*” Our group of African American and white participants identified several distinct avenues. They recommended better and more affordable insurance with lower deductibles and copayments, and emphasized the need for women to be informed prior to cancer treatment about the cancer-related costs they were going to face along with the services, agencies or programs that may be available to support them or to provide needed products and services. Related to this point, participants, in particular African Americans from both recruitment sites delineated a role for physicians to help with costs and access to resources. All participants also voiced the need to access social workers, navigators, support groups, or others knowledgeable about available resources. Some differences across the NGT sessions were noted: for example, the participants recruited from the safety net hospital recommended mental health care to be provided soon after diagnosis as a way to help with the financial burden of cancer.

Cancer imposes a number of costs on survivors, ranging from losses in quality of life and productivity, to out-of-pocket costs related to medical care and achieving wellbeing [17, 18]. Out-of-pocket costs and financial concerns may be substantial even when the survivors have health insurance coverage [9, 19–21]. Across diverse studies, more than one third of survivors report concerns paying for medical care, financial hardship, or having had financial problems related to cancer [19, 21, 22]. Moreover, concerns are not unique to survivors in the United States. Survivors in countries that have different health care systems face similar challenges [23–25]. The burden may be disproportionate for minorities [9, 22]. Out-of-pocket costs were a considerable burden representing as much as 31% of monthly income, the highest burden being for racial/ethnic minority breast cancer survivors with lower incomes [9]. This disparity relates to the fact that while survivors have some latitude in some cancer related expenses, they do not have latitude in other expenses, and thus, these unavoidable expenses are bound to burden survivors with the lowest incomes [23]. Such financial “toxicity” has consequences for the care of survivors, potentially leading to lower

adherence to prescribed medications, forgone medical care, or reduced spending on basics such as food or clothing [22, 26]. In one study, Canadian survivors also reported lengthening time between follow-up visits, or choosing inpatient care to save some of the expenses related to their care, while their providers also reported shortening the duration of some treatments to reduce expenses for their patients [27].

The inability of predicting out-of-pocket costs is frustrating to cancer patients [28]. This may explain the weight given by our participants to the need of having information upfront about costs and resources available to deal with them. For example, for Medicare beneficiaries, copayments are about 20% of Medicare allowable charges; however, how much the allowable charge is for radiation or chemotherapy that is likely not known until the patient has treatment. Similar to our study, more than two thirds of surveyed patients from one academic oncology practice reported preferring to know costs before treatment, and more than half reported wanting the physician to discuss costs with them [29]. Our participants also mentioned that physicians should discuss costs of treatment. Their views have important implications for practicing physicians and their relationships with cancer patients. Ideally, physicians would have a more active role and be aware of patients' needs and financial concerns, by providing comprehensive treatment plans that considered costs. Yet, in a very busy and time-limited practice setting, the responsibility for attending to patients' financial concerns should not be placed on the shoulders of physicians. Rather, a broader comprehensive approach that includes nurses, social workers, lay navigator, financial consultants, and other cancer survivors, who may intervene with accurate financial information, may be more realistic. In fact, interventions that included social workers to address financial and legal challenges had an important effect on the quality of life of patients under active treatment [30]. Our participants also mentioned that this information could come from support groups, other survivors, or social workers, similar to another study in which surveyed cancer patients reported being amenable to discuss costs with someone other than the physician [29].

Participants recommended that more affordable insurance would be beneficial for cancer patients. Provisions of the Affordable Care Act may make this more achievable. The new health care law ends higher charges for people who are sick, eliminates lifetime benefits limits, requires health plans to cover cancer treatment and follow-up care, limits amounts paid for out-of-pocket costs and deductibles, and provides for coverage of persons with pre-existing conditions, effectively guaranteeing that people with cancer can get insurance [31]. However, our participants also noted the importance of the need for assistance in dealing with insurance companies. This is not unique to this group of participants. Other breast cancer survivors on managed care, for example, reported stress and frustration related to the considerable challenges in dealing with their insurance companies during and after treatment [28]. Challenges were related to understanding written information, obtaining authorizations for care or assistance with insurance-related tasks, paying bills that kept coming, as well as planning for the cost of their care. These challenges in planning led women to feel unable to plan for their families' future and to fear being unable to "leave something behind" for their loved ones [28].

One of the ways to help women with financial challenges voted by the participants from the safety net hospital was providing help with emotional issues and stress. Mental health issues are not uncommon for low income minority survivors. For our participants, the precarious situation of the safety net hospital at the time of this study, also contributed to their mental health status by provoking feelings of vulnerability and some anxiety about the availability of medical care: participants voiced the need to be reassured that they would be treated “no matter what,” and to be informed of where to go for care if their safety net hospital closed. In another study, the need for emotional support and counseling services was clearly identified by African American survivors and caregivers from low-income neighborhoods, and a group of professionals providing care for that population [15]. Similarly, another group of African American medically underserved survivors thought that providing emotional support was an important role for patient navigators, as survivors reported difficulty dealing especially with depression [32]. In our study, however, the means by which mental health and financial issues were connected was not clear. It may be that mental health was one of the needs that brought significant financial burden, or that seeking care for mental health concerns was not within reach without significant financial burden. Alternatively, these participants may have thought that financial concerns were secondary to other more pressing concerns such as mental health, or that financial concerns contributed to poorer mental health

Results need to be interpreted in light of some limitations. First, we do not have information that may better characterize participants and offer additional insight into their responses, such as personal income, cancer stage or time since diagnosis. However, we intentionally achieved racial and socioeconomic variation across the three groups, as we were able to recruit African American and white women, the main racial groups in our state, from medical settings that serve populations from different socioeconomic backgrounds. This variation allowed us to represent the views of diverse cancer survivors on this topic. Second, in part due to the limited funds for this pilot study, we only conducted three NGT sessions. However, given the similarity of topics brought up by the group, we believe saturation may have been reached. Third, participants were from one city and may not represent survivors in the US. Fourth, we only included breast cancer survivors, and we do not know if survivors of other cancers would identify the same means to help with financial challenges. Fifth, we did not limit NGT sessions to discussions of financial burden during a specified phase of care, either during treatment or after. This may have caused some dilution of issues and responses, but yielded rich data showing the interplay of financial burden with other social and familial challenges in survivorship.

Despite these limitations, the data remain compelling in light of the scarce information available for addressing financial burden and out-of-pocket costs. Based on the suggestions provided by our participants, one intervention beneficial to new patients may be providing assistance to estimate the financial consequences of treatment recommendations. Certainly with modern technology, it is conceivable that insurance and cost information can be linked to create personalized medical plans that include cost information. The challenge rests in creating applications that are easily accessible to patients of all socioeconomic backgrounds. Moreover, women suggested that the help of other survivors may be beneficial. Peer support interventions are generally well received by cancer patients who gain informational and

emotional support [33, 34]. The extent to which these interventions have addressed financial challenges is unclear: future research should investigate what role survivors may play in mentoring new patients about the financial challenges of cancer.

In addition to the main findings, our study highlights two areas for further study. One is measuring the costs for each of the items identified in the NGT sessions. Participants thought comprehensively about their needs, mentioning, for example, alternative treatments for side effects, mental health, and various items needed like bras, lymphedema sleeves, nutrition counseling, reconstruction surgery. Research should expand to consider the costs of cancer that affect survivors beyond direct medical costs, and that are usually not included in the estimation of the overall cost of cancer. Recently, a study among breast cancer patients in Canada reported on a wide range of out-of-pocket costs that women incur in the first year of diagnosis, including those for alternative and complementary treatments [35]. The second area for further study is the use of NGTs for future qualitative studies. To our knowledge, this is the first time that NGT has been reported in the exploration of issues concerning cancer survivors. The enthusiasm and support received by the participants and their active role in identifying the most pressing concerns were clearly apparent.

Conclusions

Breast cancer survivors of different racial and economic backgrounds identified several avenues to help patients deal with the financial burden of cancer. These patient-driven recommendations, including affordable insurance, increased awareness of potential costs, and access to a variety of health providers to deliver pertinent information, are realistic and the potential base for dealing with one of the burdens that cancer brings to patients and families.

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References

1. Fox M. Medical bills drive many U.S. women into debt, report finds. 2012 [NBCNews.com](http://www.nbcnews.com).
2. Bach P, Saltz LS, Wittes RE. In Cancer Care, Cost Matters. The New York Times. 2012
3. Lewis Dolan P. Oncologists confront "financial toxicity" of cancer care. American Medical News. 2011 ([amednews.com](http://www.amednews.com)).
4. Pollack A. Doctors blast cost of cancer treatment. The Boston Globe. 2013
5. National Research Council. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. Washington, DC: The National Academies Press; 2008.
6. Arozullah AM, Calhoun EA, Wolf M, Finley DK, Fitzner KA, Heckinger EA, Gorby NS, Schumock GT, Bennett CL. The financial burden of cancer: estimates from a study of insured women with breast cancer. J Support Oncol. 2004; 2(3):271–278. [PubMed: 15328826]
7. Finkelstein EA, Tangka FK, Trogdon JG, Sabatino SA, Richardson LC. The personal financial burden of cancer for the working-aged population. Am J Manag Care. 2009; 15(11):801–806. [PubMed: 19895184]

8. Langa KM, Fendrick AM, Chernew ME, Kabeto MU, Paisley KL, Hayman JA. Out-of-pocket health-care expenditures among older Americans with cancer. *Value Health*. 2004; 7(2):186–194. [PubMed: 15164808]
9. Pisu M, Azuero A, Meneses K, Burkhardt J, McNees P. Out of Pocket Cost Comparison Between Caucasian and Minority Breast Cancer Survivors in the Breast Cancer Education Intervention (BCEI). *Breast Cancer Research and Treatment*. 2010 In press.
10. Coons SJ, Chongpison Y, Wendel CS, Grant M, Krouse RS. Overall quality of life and difficulty paying for ostomy supplies in the Veterans Affairs ostomy health-related quality of life study: an exploratory analysis. *Med Care*. 2007; 45(9):891–895. 00005650-200709000-00012 [pii]. [PubMed: 17712260]
11. Ell K, Xie B, Wells A, Nedjat-Haiem F, Lee PJ, Vourlekis B. Economic stress among low-income women with cancer: effects on quality of life. *Cancer*. 2008; 112(3):616–625. [PubMed: 18085642]
12. Institute of Medicine. *From Cancer Patient to Cancer Survivor: Lost in transition*. Washington, DC: National Academy Press; 2005.
13. Baider L, Andritsch E, Uziely B, Ever-Hadani P, Goldzweig G, Hofmann G, Samonigg H. Do different cultural settings affect the psychological distress of women with breast cancer? A randomized study. *Eur J Cancer Care (Engl)*. 2003; 12(3):263–273. doi:412 [pii]. [PubMed: 12919306]
14. Darby K, Davis C, Likes W, Bell J. Exploring the financial impact of breast cancer for African American medically underserved women: a qualitative study. *J Health Care Poor Underserved*. 2009; 20(3):721–728. [PubMed: 19648700]
15. Mosavel M, Sanders K. Needs of low-income african american cancer survivors: multifaceted and practical. *Journal of cancer education : the official journal of the American Association for Cancer Education*. 2011; 26(4):717–723. [PubMed: 21706193]
16. Sherwood PR, Donovan HS, Rosenzweig M, Hamilton R, Bender CM. A house of cards: the impact of treatment costs on women with breast and ovarian cancer. *Cancer Nurs*. 2008; 31(6):470–477. 00002820-200811000-00010 [pii]. [PubMed: 18987515]
17. Pisu M, Azuero A, McNees P, Burkhardt J, Benz R, Meneses K. The out of pocket cost of breast cancer survivors: a review. *J Cancer Surviv*. 2010
18. Brown, ML.; Yabroff, KR. Economic Impact of Cancer in the United States. In: Schottenfeld, D.; Fraumeni, JF., editors. *Cancer Epidemiology and Prevention* 3rd edn. New York (NY): Oxford University Press; 2006.
19. Stump TK, Eghan N, Egleston BL, Hamilton O, Pirollo M, Schwartz JS, Armstrong K, Beck JR, Meropol NJ, Wong YN. Cost concerns of patients with cancer. *Journal of oncology practice / American Society of Clinical Oncology*. 2013; 9(5):251–257. [PubMed: 23943901]
20. Davidoff AJ, Erten M, Shaffer T, Shoemaker JS, Zuckerman IH, Pandya N, Tai MH, Ke X, Stuart B. Out-of-pocket health care expenditure burden for Medicare beneficiaries with cancer. *Cancer*. 2013; 119(6):1257–1265. doi:10.1002/cncr.27848. [PubMed: 23225522]
21. Shankaran V, Jolly S, Blough D, Ramsey SD. Risk factors for financial hardship in patients receiving adjuvant chemotherapy for colon cancer: a population-based exploratory analysis. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2012; 30(14):1608–1614. [PubMed: 22412136]
22. Kent EE, Forsythe LP, Yabroff KR, Weaver KE, de Moor JS, Rodriguez JL, Rowland JH. Are survivors who report cancer-related financial problems more likely to forgo or delay medical care? *Cancer*. 2013; 119(20):3710–3717. [PubMed: 23907958]
23. Lauzier S, Maunsell E, De Koninck M, Drolet M, Hebert-Croteau N, Robert J. Conceptualization and sources of costs from breast cancer: findings from patient and caregiver focus groups. *Psychooncology*. 2005; 14(5):351–360. [PubMed: 15386763]
24. Timmons A, Gooberman-Hill R, Sharp L. It's at a time in your life when you are most vulnerable": a qualitative exploration of the financial impact of a cancer diagnosis and implications for financial protection in health. *PloS one*. 2013; 8(11):e77549. [PubMed: 24244279]
25. Timmons A, Gooberman-Hill R, Sharp L. The multidimensional nature of the financial and economic burden of a cancer diagnosis on patients and their families: qualitative findings from a

- country with a mixed public-private healthcare system. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2013; 21(1):107–117. [PubMed: 22987093]
26. Zafar SY, Abernethy AP. Financial toxicity, Part I: a new name for a growing problem. *Oncology*. 2013; 27(2):80–81. 149. [PubMed: 23530397]
  27. Mathews M, Buehler S, West R. Perceptions of health care providers concerning patient and health care provider strategies to limit out-of-pocket costs for cancer care. *Current oncology*. 2009; 16(4): 3–8. [PubMed: 19672419]
  28. Klimmek R, Snow D, Wenzel J. Insurance-related and financial challenges reported by managed care enrollees with breast cancer. *Clinical journal of oncology nursing*. 2010; 14(5):598–606. [PubMed: 20880817]
  29. Bullock AJ, Hofstatter EW, Yushak ML, Buss MK. Understanding patients' attitudes toward communication about the cost of cancer care. *Journal of oncology practice / American Society of Clinical Oncology*. 2012; 8(4):e50–e58. [PubMed: 23180999]
  30. Miller JJ, Frost MH, Rummans TA, Huschka M, Atherton P, Brown P, Gamble G, Richardson J, Hanson J, Sloan JA, Clark MM. Role of a medical social worker in improving quality of life for patients with advanced cancer with a structured multidisciplinary intervention. *Journal of psychosocial oncology*. 2007; 25(4):105–119. [PubMed: 18032268]
  31. American Cancer Society. Atlanta GA: The Affordable Care Act: How it helps people with cancer and their families. Accessed April 25 2013 from <http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-026864.pdf>.
  32. Davis C, Darby K, Likes W, Bell J. Social workers as patient navigators for breast cancer survivors: what do African-American medically underserved women think of this idea? *Social work in health care*. 2009; 48(6):561–578. [PubMed: 19860292]
  33. Hoey LM, Ieropoli SC, White VM, Jefford M. Systematic review of peer-support programs for people with cancer. *Patient education and counseling*. 2008; 70(3):315–337. [PubMed: 18191527]
  34. Macvean ML, White VM, Sanson-Fisher R. One-to-one volunteer support programs for people with cancer: a review of the literature. *Patient education and counseling*. 2008; 70(1):10–24. [PubMed: 17904782]
  35. Lauzier S, Levesque P, Mondor M, Drolet M, Coyle D, Brisson J, Masse B, Provencher L, Robidoux A, Maunsell E. Out-of-pocket costs in the year after early breast cancer among Canadian women and spouses. *Journal of the National Cancer Institute*. 2013; 105(4):280–292. [PubMed: 23349250]

Table 1

Most Relevant Responses of Nominal Group Technique (NGT) session 1, with participants who received care from a county safety net hospital.

Responses ^a	Votes ^b		
	N	Assigned	Sum %
1 Help us find public agencies that can help finance things (e.g. transportation and co- pays) by providing money or voucher	4	3,3,3,2	11 20.4
2 Make better cancer insurance available with lower premium cost	3	3,2,1	6 11.1
3 Make social workers available to counsel patients about their financial situation	3	2,1,1	4 7.4
4 Make psychotherapy available as soon as you are diagnosed	1	3	3 5.6
5 Getting reassurance that you will get treated -- no matter what	1	3	3 5.6
6 Have the oncologist ask about how will you pay for medications and make more free medications available	1	3	3 5.6
7 Make sure doctor listens to patients about what they are telling him about their needs and passes on information that may help -- not just standard information because every patient is different	1	3	3 5.6
8 Add a rider to insurance policies because of women's important role in the family	1	3	3 5.6
9 Provide information about costs patients can expect when they are diagnosed with cancer	2	2,1	3 5.6
10 Talk to someone who has had the same problems as you	2	2,1	3 5.6
11 Pass a law to make sure that people who have cancer can get life and other types of insurance	2	2,1	3 5.6
12 Provide help to deal with emotional issues when needed	2	1,1	2 3.7
13 Provide free or more affordable therapy to deal with stress	1	2	2 3.7
14 Tell us what to do if <HOSPITAL> closes down	1	2	2 3.7
15 Encourage patients to contact and get information from American Cancer Society	1	2	2 3.7
16 Have case worker or social worker send someone to help me with my homecare	1	1	1 1.8

^aEight African American survivors and one white survivor who received care at a county safety net hospital participated in this NGT session... A total of 30 responses were generated. The full list of responses is available from the authors upon request.

^bEach participant voted by selecting three responses as the most relevant to help women and families deal with the financial burden of cancer. N indicates the number of participants voting that response, Assigned votes indicate the rank assigned to the selected response with 3 indicating the most relevant, and 1 the least relevant response. The sum refers to the sum of the votes assigned to that response, and the percent refers to the percent of total votes given for all responses (54).

Table 2

Most Relevant Responses of Nominal Group Technique (NGT) session 2, with African American participants who received care at the Comprehensive Cancer Center

Responses ^a	Votes ^b		
	N	Assigned	Sum %
1 Make sure that the patient is informed about their coverage and what services are available to them prior to surgery	2	3,3	6 20.0
2 Make financial grants available to help patients pay for things not covered by insurance	2	3,1	4 13.3
3 Make all physicians involved in the treatment team work together to develop a coherent plan that considers the financial issues related to their treatment recommendations	2	3,1	4 13.3
4 Make complimentary alternative medicine available to patients to help them deal with side effects they experience	2	2,2	4 13.3
5 Provide access to a social worker who knows about "benevolent funds" at various hospitals	2	2,1	3 10.0
6 Provide some financial assistance for someone to help in preparing meals	1	3	3 10.0
7 Make cancer insurance more affordable	1	2	2 6.67
8 Assist patients in dealing with insurance companies when they do not cover specific prescription ordered by the doctor and instead ask you to take another medicine	1	2	2 6.67
9 Help patients pay for someone to help with basic housekeeping tasks	1	1	1 3.33
10 Provide a support group for new patients to inform them about financial issues and how they can be addressed	1	1	1 3.33

^aFive African American survivors who received care at the Comprehensive Cancer Center participated in this NGT session. A total of 25 responses were generated. The full list of responses is available from the authors upon request.

^bEach participant voted by selecting three responses as the most relevant to help women and families deal with the financial burden of cancer. N indicates the number of participants voting that response, Assigned votes indicate the rank assigned to the selected response with 3 indicating the most relevant, and 1 the least relevant response. The sum refers to the sum of the votes assigned to that response, and the percent refers to the percent of total votes given for all responses (30).

Table 3

Most Relevant Responses of Nominal Group Technique (NGT) session 3, with mostly white participants who received care at the Comprehensive Cancer Center

Responses ^a	Votes ^b		
	N	Assigned	Sum %
1 Provide help to get better insurance policy with lower deductible and co-pays	4	3,3,2,1	9 18.7
2 "Look Good Feel Better" program by American Cancer Society help provide the patients with free makeup, hats and wigs at workshops	4	3,3,2,1	9 18.7
3 Support groups to help gain information and help each other out	4	2,2,2,1	7 14.6
4 Cancer Care/ New Beginnings meetings to learn about help with co-pays	2	3,2	5 10.4
5 A good navigator who has knowledge about where to go to get all the information to help out with financial issues	2	3,2	5 10.4
6 Don't get caught without a cancer policy	2	3,1	4 8.3
7 Pray that God would give you peace under stress	1	3	3 6.2
8 Ask friends to drive you to appointments not just doctors	2	2	2 4.2
9 Provide caregivers who can assist the patients while they are going through care	1	2	2 4.2
10 Ask your oncologist if a former patient could act as mentor for you	1	1	1 2.1
11 Get family members to help out if they live nearby	1	1	1 2.1

^aOne African American and eight white survivors who received care at a Comprehensive Cancer Center participated in this NGT session. One white survivor did not participate in voting. A total of 36 responses were generated. The full list of responses is available from the authors upon request.

^bEach participant voted by selecting three responses as the most relevant to help women and families deal with the financial burden of cancer. N indicates the number of participants voting that response, Assigned votes indicate the rank assigned to the selected response with 3 indicating the most relevant, and 1 the least relevant response. The sum refers to the sum of the votes assigned to that response, and the percent refers to the percent of total votes given for all responses (48).