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Capturing Treatment Decision Making Among Patients With Solid Tumors and Their Caregivers

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Abstract

Purpose/Objectives—To examine the feasibility and acceptability of using a decision aid with an interactive decision-making process in patients with solid tumors and their caregivers during cancer-related treatment.

Research Approach—A phenomenologic approach was used to analyze qualitative data, with a focus on the meaning of participants' lived experiences. Interviews were conducted by telephone or in person.

Setting—Outpatient clinics at two regional cancer centers.

Participants—160 total individuals; 80 patients with newly diagnosed breast (n = 22), advanced-stage prostate (n = 19), or advanced-stage lung (n = 39) cancer, and their caregivers (n = 80).

Methodologic Approach—Twenty-seven of the 80 pairs engaged in audio recorded interviews that were conducted using a semistructured interview guide. Continuous text immersion revealed themes. Validity of qualitative analysis was achieved by member checking.

Findings—Significant findings included three themes: (a) the decision aid helped patients and caregivers understand treatment decisions better, (b) the decision aid helped patients and caregivers to be more involved in treatment decisions, and (c) frequent contact with the study nurse was valuable.

Conclusions—Decision making was more complex than participants expected. The decision aid helped patients and caregivers make satisfying treatment decisions and become integral in a shared treatment decision-making process.

Interpretation—Decision aids can help patients and their caregivers make difficult treatment decisions affecting quantity and quality of life during cancer treatment. The findings provide valuable information for healthcare providers helping patients and their caregivers make treatment decisions through a shared, informed, decision-making process.

Knowledge Translation—Decision aids can be helpful with treatment choices. Caregivers' understanding about treatment is just as important in the decision-making process as the patients' understanding. Incorporating decision aids that are delivered by healthcare providers or trained personnel has the potential to improve patients' decision satisfaction.

The development of decision aids for patients with cancer has helped to engage patients in decision making. Engaging in a shared decision-making process may reduce decisional conflict when making a choice regarding cancer treatment and may set the stage for more positive outcomes. Decision aids, which prepare patients to participate and share in their

health care, use specific health information related to a particular decision (O'Connor et al., 2003). Decision aids seem most effective when they are interactive, capture values, and are tailored to the individual patient's history, as well as elicited by a shared decision process (O'Connor et al., 2003; Skinner et al., 2002). Shared decisions are the ability to actively understand and influence health status through interaction with healthcare professionals. Shared decision making involves open communication between the patient, their caregiver, and the healthcare provider about the advantages and disadvantages of a particular treatment, taking into account the patient's personal values (Bowen et al., 2006; Jones, Steeves, & Williams, 2010). Visual aids that assist patients to share in decision making can help healthcare providers offer more efficient health care and, potentially, lead to improved quality of life for the patient (Dauer et al., 2011; Hahn et al., 2004).

Although several decision aids for patients with early or localized cancers exist, they provide information only on the disease, generally are not theoretically driven, and are not always interactive (Fiset et al., 2008). Very few decision aids focus on advanced-stage cancers, particularly advanced-stage prostate and lung cancers. The current study examined the feasibility and acceptability of using a decision aid and an interactive decision-making process with patients with solid tumors (newly diagnosed breast cancer, advanced-stage prostate cancer, and advanced-stage lung cancer) attending a regional cancer center with their caregiver during cancer-related treatment.

Background

Breast and prostate cancer are the most commonly diagnosed cancers among women and men, respectively, with lung cancer being the leading cause of cancer deaths for both men and women in the United States (American Cancer Society [ACS], 2012). The ACS (2012) estimated that, in 2012, 226,870 people were diagnosed with breast cancer, 241,740 were diagnosed with prostate cancer, and 226,160 were diagnosed with lung cancer. Breast and prostate cancers are the second-leading cause of cancer-related deaths among women and men, respectively. All three cancers have several factors that should be taken into consideration in making difficult treatment decisions. However, those difficult treatment decisions are not always handled well in clinical practices (Finlay & Casarett, 2009), which highlights the need for evidence-based, tailored care for patients (Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley, 2001; Hofmann et al., 1997; Hughes, 1993; Sinfield, Baker, Agarwal, & Tarrant, 2008).

Cancer-related decisions can be difficult because of problems in communicating complex information about prognosis and the modest benefits of available treatments with some types of cancers (O'Brien et al., 2009). Often, a key difficulty in decision making is when the physician counsels discontinuation of cancer-directed therapy, and that course of action is difficult for the patient or family to accept, which may bring about conflict. Janis and Mann's (1977, 1982) Conflict Model of Decision-Making underpins the decision aid used in this study. The basis of the theory is that stress negatively affects decision making, and high-level cognitive processes are needed for decision making. Preconditions precipitate a degree of stress, affecting the decision-making style individuals select, including the amount of risk from consequences, the hope of finding a better solution, and time pressure to make a serious decision (Janis & Mann, 1977, 1982). The decision-making style chosen results in quality or nonquality decision making with decisional regret or satisfaction as the outcome.

Since 2002, the development of decision aids for patients with cancer has helped engage patients in decisions about their health (O'Connor et al., 2009). The decision aid used in this article focuses on weighing the pros and cons of the treatment to help arrive at a potential choice discussed later with a healthcare provider. This decision aid may not only help

communication between healthcare providers and patients, but also patients and their caregivers in arriving at a shared decision and easing any conflict.

Methods

Design

A mixed-methods design was used in the overall study to determine the feasibility and acceptability of implementing a short, clinic-based decision aid for patients with cancer and their caregivers. The decision aid intervention, titled DecisionKEYS for Balancing Choices: Cancer Care, has the following objectives: (a) to improve decision-making skills when two complex and stressful choices exist, (b) to help with a specific decision, and (c) to provide structured time for support by healthcare providers for decision making as a means of reducing decisional conflict. This decision aid intervention, developed by Hollen et al. (2012), includes a series of common decisions related to care for each of the cancers (prostate, breast, and lung), such as type of breast surgery and changing chemotherapy. This series of decision aids is a comprehensive decision skills program that teaches or reviews a psychological theory related to quality decision making as an easy-recall method during decision situations. It also provides application of the theory using a tailored decisional balance sheet for values clarification regarding cancer treatment options. Finally, the decision aid provides information about the cancer or treatment. Unique features of this decision aid include the presentation of the theory to the patient and the inclusion of the effect of the decision on others.

The interactive decision aid intervention contains balance sheets for weighing difficult decisions. The components are presented by content elements and processes in Hollen et al. (2012). The decision aid intervention consists of seven components: (a) disease-specific patient education pamphlets; (b) decision theory description; (c) a disease-specific, paper formatted decision balance sheet that weighs benefits and risks of a treatment decision; (d) structured time with healthcare providers; (e) treatment decision collaboration with the patient's caregiver; (f) patient's preference level of participation in the treatment decision; and (g) audio CDs that provide the context of what others in similar cancer treatment situations have done. In the development of the decision balance sheets, a panel of healthcare professionals, a patient, and a caregiver were used to reach consensus for content validity on the four components (title, instructions, preamble, and benefit and risk statements) of an initial draft of the balance sheets. The authors used the balance sheet format by Janis and Mann (1977,1982) and then developed the content within each balance sheet, followed by validation by a panel of experts in decision making or solid tumors (physicians, nurses, a patient, and a caregiver) as well as the theorist, Leon Mann, PhD, of the University of Melbourne, who helped identify which parts of the underpinning theory were pertinent for patients with cancer.

For the quantitative approach, a pre-/post-test design was used to measure four decisions (e.g., type of surgery, starting cancer treatment, changing cancer treatment, and stopping cancer treatment) during the course of treatment. For the qualitative method, the focus of this article, a phenomenologic approach was used to capture the experiences of patients and caregivers. A hermeneutic, phenomenologic approach involves interpreting text to explore and describe areas of experience that are not fully understood because of complexity (Cohen, Kahn, & Steeves, 2000). Participants were asked to share their experiences in narrative form and to explain in detail their experiences and the meaning of those experiences. This article reports the qualitative findings; the quantitative findings have been reported in Hollen et al. (2012).

Sample and Setting

Of the 160 total participants, 80 were patients with solid tumors (newly diagnosed breast cancer, advanced-stage prostate cancer, and advanced-stage lung cancer) and 80 were their chosen caregivers, resulting in 22 pairs in the newly diagnosed breast cancer group, 19 pairs in the advanced-stage prostate cancer group, and 39 pairs in the advanced-stage lung cancer group. The sampling plan included serially screening the clinic appointment roster for eligible patients, with eligibility determined by the physician and study nurse. Inclusion criteria for patients with cancer were pathologically or cytologically determined disease, being aged 18 years or older, participation of a caregiver (defined as any family member or concerned other who consistently provides emotional or physical support), and the patient and caregiver being able to understand English. Breast cancer required some separate eligibility criteria because of specific issues related to this malignancy. First, the decision making around breast-conserving surgery would only be relevant for women with a certain size primary tumor (thus appropriate for this surgical procedure). This fact dictated a specific eligibility for breast cancer. Second, many patients with breast cancer will require adjuvant therapy, which is very commonly advised in patients with breast cancer, involving patients without prior chemotherapy or hormone therapy. Here too, specific eligibility criteria were needed. Some patients with advanced-stage lung cancer with brain metastasis did not qualify because of the additional eligibility criterion of being three weeks post-whole brain radiation. The one exclusion criterion across all subgroups was documented severe psychiatric problems that could prevent full study participation. Verbal and written consent was obtained from patients and caregivers prior to beginning the study. The setting included two cancer centers, the University of Virginia Emily Couric Cancer Center in Charlottesville and Memorial Sloan-Kettering Cancer Center in New York, NY.

Interview Guide and Procedures

The study was approved by the institutional review boards at both institutions. The study nurses were invited to a face-to-face orientation session that consisted of a three-hour meeting to discuss the goals and objectives of the study, to understand the study protocol, and to discuss how to administer the decision aid intervention as an interactive process with the patient and caregiver while in a clinic setting. After the patient and caregiver had used the decision aid and helped make the treatment decisions, the participants were interviewed by telephone and audio recorded with permission. A semi-structured interview guide created by the authors contained both open-ended and closed questions designed to obtain patients' and caregivers' narratives about the experience of using the decision aid. Specifically, at the last clinic visit, the study nurse scheduled the time for the follow-up telephone call (about one or two weeks after completion of the study) to address study closure with the patient and caregiver. An exit interview guide was sent home with the pair in preparation for the telephone call. Using the exit interview guide, one of the researchers (who had not seen the pair before) first asked permission to record the interview, asked some joint questions, and then asked questions to each participant separately. Telephone calls lasted about one hour. The rationale for this approach was that collecting data by telephone reduced patient and caregiver burden by limiting travel time to the regional cancer center.

Analysis

Each interview was audio recorded and then transcribed verbatim. All transcribed interviews and demographic forms were organized, coded, and placed in categories. Thick and rich descriptions were captured from the participants about their complex experiences during the treatment decision-making process (Myers et al., 1996). Participants' narratives were carefully reviewed by the authors using an iterative approach to better understand the participants' experiences. The authors continually revisited the data and narratives, then the categories were narrowed and arranged to form themes to express the experiences of

participants. From this iterative comparative analysis, the first author proposed the themes and the three other authors reviewed the transcripts to make sure that the themes accurately represented the narratives, reviewed the dependability of extracting the themes, and reviewed the confirmability of the findings by consensus. Descriptive statistics were calculated to understand the characteristics of the sample. Descriptive data were analyzed using statistical procedures in SPSS[®], version 19.

Results

A total of 80 pairs (patients and caregivers) with solid tumors enrolled in three feasibility substudies for patients with newly diagnosed breast cancer, advanced-stage prostate cancer, and advanced-stage lung cancer. Not all participants were able to follow through with interviews at the completion of the study; however, 27 pairs (7 pairs with newly diagnosed breast cancer, 13 pairs with advanced-stage prostate cancer, and 7 pairs with advanced-stage lung cancer) engaged in audio recorded interviews. The pairs that were not included in the interviews were either too sick to complete the interviews, withdrew from the study, or a member of the pair died and the living member did not want to participate in the interview. Sample characteristics are typical of patients with solid tumors seeking treatment in these catchment areas (see Table 1). The three major themes were: (a) the decision aid helped to understand treatment decisions, (b) the decision aid helped the patient and caregiver to be more involved in the treatment decisions, and (c) frequent contact with the study nurse was valuable.

The Decision Aid Helped Patients and Caregivers Understand Treatment Decisions Better

Participants newly diagnosed with breast cancer were not just positive, but often enthusiastic about the overall helpfulness of the decision aid. One participant said she appreciated “information on what she was going to go through and how to handle it and how to deal with it.” Another participant said that the study supplied “information that I would not have been able to necessarily accumulate in such a short period of time on my own.” According to one woman newly diagnosed with breast cancer,

Other than I think it’s a really good tool and that I’m glad somebody investigated and put out the theory, I wouldn’t have thought about it. I would have just been flying by the seat of my pants.

Some patients with breast cancer singled out specific aspects of the process that were particularly helpful. Some said it “opened their eyes” to decisions they would be facing. For others, finding out what kind of decision maker they were was valuable. The product at the end of the process was most important to some participants as well. They felt that they were helped to arrive at the “correct decision” or a decision they “could live with.” The decision-making process the patients and caregivers learned helped them communicate with healthcare professionals.

Similarly, patients with advanced-stage prostate cancer and their caregivers felt that the decision aid was quite helpful as they considered decisions about treatments. The patients and caregivers believed the decision aid provided more insight into the progression of the disease and the treatment and provided them more independence to decide on a treatment that was right for them. According to one patient with advanced-stage prostate cancer who was deciding whether to start chemotherapy,

I would tell others it’s a helpful decision aid; they should, you know, try it. It certainly makes you think of all of the ramifications of the decision and what you need to consider before making a decision. I think it would be quite helpful to anyone in this condition.

The man's wife, his caregiver, mentioned that her husband began to think about important issues that he had never thought about before.

I think [the decisional balance sheets] were helpful. I can recall my husband being a little surprised at some of the things that the balance sheet mentioned ... things he hadn't really thought about when beginning to discuss the chemotherapy or the ramifications of it. I think it made him look at what we were getting into a little bit more.

The wife (caregiver) of a man who had advanced-stage lung cancer and had died said,

The balance sheets were helpful and he listened to all of the tapes. He said he wanted to figure out how his body was doing. He would have wanted [me] to do the exit interview; he wanted to help others. It was almost two years exactly that he died after being diagnosed, just as the doctor had said.

According to a woman with advanced-stage lung cancer,

My sister from New Jersey was there; she was normally with me for most of my treatment. They gave me CDs to listen to ... they made me aware of what goes into making a good quality decision. I didn't know that the decision was going to be so huge. It really helped me slow down, gave me an awareness of not just blurting out an answer. The CDs were very methodical, which was what I needed. The voice was good. Everything else was going so fast. The CDs were slow and helped me slow down. They helped answer a lot of questions in my head. They help relieve some of the fear and help prepare you. I didn't realize how helpful [the CDs] were to go to the next step ... they helped me be prepared. I would promote the CDs a bit more.

The participants in the study clearly found that the decision aid was helpful in trying to make a decision about their health care. The decisional balance sheet was used to discuss the treatment risks and benefits throughout the interactive decision-making process. In addition, because both patient and caregiver used the balance sheet, the participants began to feel that they were understanding one another better through the process.

The Decision Aid Helped Patients and Caregivers to Be More Involved in Treatment Decisions

In addition to the patients' and caregivers' feeling that the decision aid intervention assisted them in making a treatment decision, it also helped them have a more active role with their healthcare provider. The process of using balance sheets to examine a decision's pros and cons with a nurse or physician and listening to audio files about making decisions appeared to have helped patients obtain more insight about choosing the next step for their treatment. As one woman with newly diagnosed breast cancer said,

No, there wasn't anything that wasn't helpful in the process. I'm grateful that I was included in the study because, even though I am a collaborative decision maker, as that would have been defined, I needed to know that I could be comfortable with the decision that I was making.... I don't know, but, at the time, even though the decision that I made was to have the double mastectomy, if the doctors had fought me on that and I had gone with a lesser or a different treatment, I don't know that I would have been settled with it because what was important to me, really, was defined through that decision-making process. I think that it also helped to communicate with the doctor what was important to me, whereas I may not have had the clarity to express those values to my doctor.

One participant with advanced-stage prostate cancer said,

[The decision aid and balance sheet] made me have more involvement in the decision making on my health care ... this really put me in a position to be better educated ... to know how to go about things. It gave me some avenues that I had never thought about, like more involvement and more discussion with the physicians themselves. [The decision aid] kept stressing you had to be a partner with your healthcare team. It made me more comfortable with asking questions [to the healthcare team].

Decision making can be an overwhelming process and patients with cancer may not feel comfortable taking the initiative or playing an active role in the decision making with their healthcare provider. One patient with advanced-stage prostate cancer was very impressed by the increased involvement of his wife because of the process of the study. He saw a change in his wife that he much appreciated.

Just very recently my wife was saying how very helpful this [decision aid] was to her because as she's, even though we've been together for 53 years and we talk about things, she was never quite as involved. And, because of this, now I just depend on her like crazy when we go to our regular physician.

The wife of a patient with advanced-stage lung cancer said,

The decision-making tools were helpful.... I would say some of his balance sheets helped me understand what he was thinking. He was worried about me too.

Both patients and caregivers wanted to be more involved with healthcare decisions for patients. The caregivers felt that the decisions that had to be made should be shared and they wanted to be a part of the decision-making process.

Frequent Contact With the Study Nurse Was Valuable

Throughout the study, participants enjoyed having the study nurse contact them on a routine basis to follow up on their care, answer any questions they had about the study and serve as an extra line of support. The participants appreciated having the study nurse available by phone and seeing this nurse at each clinic visit. As a woman with newly diagnosed breast cancer said,

But I do know that ... [the study nurse] was very easy to talk to. Her communication skills were very good. As I said, I was one of those that was scared to death when I found out I had cancer and talking with her was very helpful.

Another woman with breast cancer said,

I had to go to an MRI [magnetic resonance imaging], and [the study nurse] went to the MRI. She worked really well with me because we were driving such a distance. That was really great because time was so valuable. We have a six-hour drive, for us.... So she worked some after-hours and some later times, and it worked out really well for us to be able to have her be that flexible with me.

The wife of a patient with advanced-stage prostate cancer said,

To me, [the study nurse] was the most beneficial part of the study ... you know, just calling and being very supportive.... [The study nurse] was an advocate for us on all levels. So, I think you need both [balance sheets and a nurse], as some [patients] ... they've never been faced with something like this before.

A patient with advanced-stage prostate cancer struggled with lung damage from his chemotherapy regimen and was feeling isolated. He wanted to speak to someone who might have had a similar issue to see how he dealt with the issue and possibly as a form of support.

We [patient and caregiver] enjoyed talking to her but, as I say, it was a difficult time.... Fifty percent of the people who get on this chemotherapy, it damages their lungs, and I was in that group. So I asked ... [the study nurse] if she could find for me somebody who had been through the same thing and their lungs had been damaged. And she got me a name of somebody and I've tried to make contact with him.... I think if somebody had been through the very same thing I had, I would love to talk to somebody who had been through the same thing.

A woman with advanced-stage lung cancer said,

I really got into the study ... enjoyed having someone else following my care. [The study nurse] is a ball of energy. Dealing with [the study nurse] was uplifting and gave me someone else to talk to besides my family and friends. She gave me a good outlet to discuss my feelings and thoughts.

Participants felt that having another line of support that they could call on for assistance, to speak to about different issues, or just see a familiar face at the clinic visit was an added value. The study nurse was a non-intimidating resource in the cancer center, and this made participants feel more at ease.

Discussion

This decision aid for patients with cancer and their caregivers was perceived as important and helpful by all three diagnostic groups. The majority of the patients in these small feasibility studies were married and their spouse was their caregiver. Participants, particularly individuals diagnosed with an advanced-stage cancer, often stressed during discussions the value they placed on quality of life as opposed to quantity of life. They also stressed the importance of using a decision aid, such as the one used in this study, to help make important treatment decisions and have more interactions with the healthcare provider. The patients seemed to think more about the process of treatment decision making and what was right for them by using the decision aid instead of making a decision based solely on the healthcare provider's recommendation. Patients took time to digest the information that was given to them by the healthcare provider, discussed the issues in depth, and felt more satisfied with their treatment decision.

Caregivers also thought that the patients began to "open up" to a point that there was more understanding between the patient and caregiver while using the decision aid. As presented by Janis and Mann (1977, 1982) in their Conflict Model of Decision Making, most people faced with a difficult decision will discuss their preference with people who they expect to support their decision first. Clearly this applies to patients facing cancer treatment as patients are rarely alone in the decision-making process and they often communicate with a family member or caregiver who can help patients cope better (Jones et al., 2008). Many of these caregivers mentioned that the patients might not have spoken so openly about the stresses they had experienced from the disease if they had not used the decision aid. The decision aid helped the patient to begin a dialogue not only with the healthcare provider, but also with their caregiver.

Recognizing that, in many cases, guidelines for intervention are available based on the patient's tumor characteristics, most of those who participated in the audio recorded telephone interviews reported making decisions about care that were congruent with the recommendations of their physicians. For the subgroup of newly diagnosed patients with breast cancer, most participants reported that the physicians presented options, but the participants said they knew what their physician thought was the best option, and the patient, caregiver, and physician decided on that option. However, they said that they believed they had shared in the process or had made the decision. Similarly, many of the men with

prostate cancer thought that the decision aid made them think through the decision they were facing and ask more questions to better understand the treatment and help them play a more active role. Interestingly, in one interview from the lung cancer subgroup, a patient and his caregiver (wife) said they had discussed treatment with their physician and had been ready to stop several months before, but they waited until the oncologist was ready as well because they respected the oncologist.

Limitations

A limitation within this study was the sample characteristics. The majority of the sample had an annual income of more than \$40,000 per year and at least a high school diploma. A lack of information still exists about individuals who are at a lower socioeconomic status, and future studies should be expanded to include a larger range of socioeconomic classes to ensure more representation. Another limitation to this study was the small sample size within each disease. Because of the progressive nature of the disease and the three-year time span for the study, several participants either died or were too sick to have an interview completed toward the end of the study. A future study should address the timing of the interview to ensure interviews while patients are in better health. Lastly, although this study provided useful information on how participants viewed the decision aid and the decision-making process regarding treatment, most of the sample resided in central Virginia and they may not be representative of the population throughout the United States. Future studies need to include multiple sites and multiple cultural backgrounds and ethnicities to ensure greater generalizability.

Conclusion

Complex decisions must be made when facing cancer; however, few decision aids have focused on advanced stages of cancer, specifically prostate cancer and lung cancer. Despite the study limitations, the themes that emerged from this study provide important insights into decision making, not only in the newly diagnosed but also those facing advanced-stage cancer treatment. The findings provide initial evidence that patients and their caregivers are willing to use decision aids and believe that they benefit from using decision aids; therefore, the decision aid was found to be feasible and acceptable to patients and their caregivers. Patients and their caregivers strongly reported that they appreciated the support of a nurse who helped them use the decision aid and followed-up with them throughout treatment as an advocate. In addition, the study nurses, who were oncology nurses, found the decision aid feasible and acceptable.

The importance of open communication between patients, caregivers, and healthcare providers was apparent in this sample of patients with solid tumors. Open communication and shared decision making can have an impact on some dimensions of health-related quality of life. Indeed, healthcare providers should continue to recognize the needs of patients, particularly as it relates to including supportive family members or friends in the decision-making process. Also, providing the patient and caregiver with information and resources to help make an informed treatment decision is vitally important to allow absorption of new information over time. In addition, creating a welcoming environment in the clinic to help patients and their caregivers feel comfortable so that trusting relationships can be formed with healthcare providers is crucial (Earl, Alegria, Mendieta, & Linhart, 2011; Krothe & Clendon, 2006).

Implications for Nursing

Although additional study is needed, the Decision-KEYS for Balancing Choices in Cancer Care decision aid may enhance informed, shared decision making between patients,

caregivers, and healthcare professionals. It fosters a collaborative process to support decision making among healthcare professionals. Of six physicians participating in this study, all found the interactive format to be feasible and acceptable in a busy clinical setting (Hollen et al., 2012). This feasibility was in the context of having the help of a nurse who led the interactive process for the decisional balance sheet. All four oncology nurses serving as study nurses in this study found the process to be a viable role for nurses in addition to traditional roles, such as helping with symptom management.

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Table 1

Presenting Characteristics of Patients and Their Caregivers (N = 160)

| Characteristic | Newly Diagnosed Breast Cancer | | Advanced-Stage Prostate Cancer | | Advanced-Stage Lung Cancer | |
|---------------------------------|-------------------------------|---------------------|--------------------------------|---------------------|----------------------------|---------------------|
| | Patients (n = 22) | Caregivers (n = 22) | Patients (n = 19) | Caregivers (n = 19) | Patients (n = 39) | Caregivers (n = 39) |
| | Median | Median | Median | Median | Median | Median |
| Age (years) | 55 | 55 | 72 | 60 | 62 | 56 |
| Education (years) | 15 | 15 | 16 | 16 | 12 | 12 |
| Characteristic | n | n | n | n | n | n |
| Gender | | | | | | |
| Female | 22 | 15 | - | 17 | 24 | 32 |
| Male | - | 7 | 19 | 2 | 15 | 7 |
| Married | 17 | 20 | 15 | 15 | 30 | 32 |
| Income (\$) ^a | | | | | | |
| Less than 40,000 | 5 | 5 | 10 | 7 | 14 | 13 |
| 40,001–80,000 | 10 | 9 | 3 | 5 | 8 | 9 |
| 80,001 or more | 7 | 8 | 6 | 7 | 14 | 13 |

^aThree patients and four caregivers from the lung cancer group did not report income levels.