Gender Differences in Bladder Cancer Treatment Decision Making

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Purpose/Objectives: To explore gender differences in bladder cancer treatment decision making.

Research Approach: Secondary qualitative analysis of interview transcripts.

Setting: One multidisciplinary genitourinary oncology clinic (Dana–Farber Cancer Institute) and two urology clinics (Brigham and Women's Hospital and Beth Israel Deaconess Medical Center) in Boston, MA.

Participants: As part of the original study, 45 men and 15 women with bladder cancer participated in individual interviews. Participants were primarily Caucasian, and most had at least some college education.

Methodologic Approach: Word frequency reports were used to identify thematic differences between the men's and women's statements. Line-by-line coding of constructs prevalent among women was then performed on all participants in NVivo 9. Coding results were compared between genders using matrix coding queries.

Findings: The role of family in the decision-making process was found to be a dominant theme for women but not for men. Women primarily described family members as facilitators of bladder cancer treatment–related decisions, but men were more likely to describe family in a nonsupportive role.

Conclusions: The results suggest that influences on the decision-making process are different for men and women with bladder cancer. Family may play a particularly important role for women faced with bladder cancer treatment–related decisions.

Interpretation: Clinical nurses who care for individuals with bladder cancer should routinely assess patients' support systems and desired level of family participation in decision making. For some people with bladder cancer, family may serve as a stressor. Nurses should support the decision-making processes of all patients and be familiar with resources that can provide support to patients who do not receive it from family.

Every year in the United States, more than 79,000 individuals are diagnosed with bladder cancer (American Cancer Society [ACS], 2017). Although bladder cancer is more common among men, the mortality rate among women is higher (ACS, 2017), and women are more likely to experience disease recurrence after treatment (Fajkovic et al., 2011). The mechanisms responsible for these gender disparities are not fully understood. Although delayed diagnosis is more common among women, an analysis of Surveillance, Epidemiology, and End Results registries demonstrated that disease stage at diagnosis accounted for only 30% of the excess mortality experienced by women (Scosyrev, Noyes, Feng, & Messing, 2009). Likewise, Siegrist, Savage, Shabsigh, Cronin, and Donat (2010) analyzed a series of bladder cancer cases from 1995–2005 at Memorial Sloan Kettering Cancer Center in New York and concluded that women were less likely to undergo lymph node dissection or

receive a continent urinary diversion than men, even when controlling for confounding disease. Considering these findings, the authors suggested that patient or physician treatment preferences accounted for a significant proportion of the difference between men's and women's bladder cancer–related outcomes.

Little is known about the decision-making processes of women with bladder cancer, and no systematic decision support has been tested for individuals who are making bladder cancer treatment decisions. In addition, women's experiences of shared decision making are suboptimal; women may receive less medical information and less encouragement to participate in decision making from their physicians when compared to men with the same condition (Borkhoff et al., 2013). This is particularly concerning given that patients with bladder cancer have been found to report significantly less positive experiences of decision making when compared to patients with other forms of cancer (El Turabi, Abel, Roland, & Lyratzopoulos, 2013).

Many studies have described the treatment decision-making processes of individuals with cancer, most notably women with breast cancer and men with prostate cancer. However, studies that directly compare the decision-making processes of men and women are limited. Most studies have focused on gender differences in preferred involvement in decision making. For example, in a review of the medical literature, Say, Murtagh, and Thomson (2006) found that women more often prefer to play an active role in medical decision making. This finding was supported in the cancer literature by Jacobs-Lawson, Schumacher, Hughes, and Arnold (2010), whose study of men and women with colorectal cancer found that, although both genders viewed treatment decisions as equally important, women preferred to be actively involved with the decision and men preferred to defer to the surgeon's preference. The men and women in this study also expressed different preferences for the amount and type of information provided to them during the decision-making process. In line with this finding, Wessels et al. (2010) found that having a choice in cancer treatment and a variety of sources of health information was more important to the women in their study than to the men.

Differences in decision-making style have been found between men and women. Delaney, Strough, Parker, and de Bruin (2015) analyzed Internet survey responses from 1,075 participants of any health status in RAND's American Life Panel (https://mmicdata.rand.org/alp) and reported that women were more likely to take an interpersonal approach to decision making and men were more likely to make decisions intuitively. This finding is consistent with the results of an Internet survey study of the treatment decision-making processes of men and women with cancer that suggested women are more likely than men to choose to share a treatment decision with a spouse or significant other (Krok-Schoen, Palmer-Wackerly, Dailey, Wojno, & Krieger, 2016). In contrast, the authors found that men were more likely than women to report that the responsibility for decision making had been delegated to or demanded by a family member. Similarly, examples exist in the cancer literature of gender differences in patterns of emotional and practical decision support. In a qualitative study of the social support needs of individuals with cancer, Clarke, Booth, Velikova, and Hewison (2006) found that, although women sought emotional support from multiple sources, men preferred to seek support primarily from their wives.

Despite these findings, little research has been published that examines gender differences in the individual and contextual factors that affect cancer treatment decision making. Given this gap in the literature, additional studies of the process by which men and women make decisions regarding bladder cancer treatment are essential to understanding treatment preferences and reducing the gender disparity in treatment satisfaction and outcomes. Therefore, the purpose of this study was to identify and explore gender differences in the individual and contextual factors that influence bladder cancer treatment decision making.

Methods

The authors conducted a secondary qualitative analysis of 60 individual, semistructured interviews of patients with bladder cancer. The original study was reported by Berry et al. (2015), who recruited 45 men and 15 women with various stages of bladder cancer from urologic and medical oncology practices at a multidisciplinary genitourinary oncology clinic (Dana–Farber Cancer Institute) and two urology clinics (Brigham and Women's Hospital and Beth Israel Deaconess Medical Center) in Boston, Massachusetts. The study was approved by the Dana–Farber/Harvard Cancer Center Institutional Review Board. The recently diagnosed participants primarily were Caucasian, were married, and had at least some college education. Thirty-two interviews were conducted by telephone, and 28 took place in person.

Interviews were recorded, transcribed, and entered into NVivo 9 as part of the original study (Berry et al., 2015). The authors performed a secondary analysis of the interview transcripts using the same dataset and software, beginning with word frequency queries for the male and female participants' interview transcripts. A side-by-side comparison of the results of these queries highlighted thematic differences between the male and female participants' statements. Line-by-line coding of constructs prevalent

Family as Support

"Well, my . . . my youngest daughter did a lot of that. She says, 'OK, this is what you got.' She made appointments with both places."
59-year-old female, stage IV

Family Participation in Treatment Decision

"Well, I talked with my husband quite a bit, and I think that we—he and I—concluded that the first six weeks BCG [Bacillus Calmette-Guérin immunotherapy] was probably the best outcome to me. So, yes. I mean, I talked to my husband, and I have three children. This is my second marriage, so I have the three children from my first marriage, and I talked to my three other. . . . Matter of fact, they did come to a couple of the meetings with a different doctor, and so they were absolutely in the loop."
56-year-old female, stage unknown

Family as Motivating Factor

"The day that I was diagnosed . . . the first thing I wanted to do was crawl under the bed and just stay there forevermore. That's . . . that's it. I'll hide. I don't need to go through this. If I hide under the bed, it will go away, no. My daughter and my daughter-in-law came in that afternoon with their babies, who are a year old now each, and that turned me around. That helped me face the decisions that I've had to face. It's like, 'OK, I can go into this. I can do this 'cause look what I have.'"
59-year-old female, stage IV

Family as Stressor

"Both my parents are in their late 80s, and . . . because my father is gone as far as remembering anything, and my mother's starting to get there, too, so, that makes it a little difficult. But it's just one more problem."
63-year-old male, stage IV

A Choice Not to Share

"In my family, no one knew about it, only my girlfriend and my girlfriend's mom. That's how I got through it for eight months, until my dad came to an appointment . . . and they explained to him, yes, the cancer could come back when I was operated on. She said anything is possible. With that, she told him how serious the cancer I had was."
43-year-old male, stage IV

"It's My Call."

"There was no angst, there was no . . . I didn't need to talk to anybody. I'm not married. My kids are grown, you know. My call. And my call was, well, yeah."
59-year-old male, stage III

FIGURE 1. Exemplary Quotes of Family Subthemes

among female participants was then performed on all participants' transcripts. Coding results were then compared between genders using matrix coding queries. The frequencies of thematic codes and the length of narratives were described.

Results

Word frequency queries revealed that words describing family relationships (e.g., "daughter," "parents," "children," "family") appeared more often in the women's transcripts than in the men's. Matrix coding query results revealed that the role of family in the decision-making process was a dominant theme for the women but not for the men. The major subthemes of family that reflected family in a facilitative role were "family as support," "family participation in treatment decision," and "family as motivating factor." More women than men (8 of 15 women versus 18 of 45 men) discussed family as support. Women made proportionally more statements (13:4) and talked at greater length (147% more words) about this theme. Similarly, more women than men (10 of 15 women versus 26 of 45 men) discussed family participation in treatment decision. Women made proportionally more statements (3:2) and talked at greater length (77% more words) about this theme. Family as motivating factor was addressed by more men than women (13 of 45 men versus 3 of 15 women), and, although women made more frequent statements about it (9:5), men talked about this subtheme at greater length (25% more words).

Three subthemes of family portrayed family in a non-supportive role. These themes were "family as stressor," "it's my call," and "a choice not to share." More men than women made statements regarding family as stressor (6 of 45 men versus 1 of 15 women), and men made proportionally more statements (7:6) and spoke at greater length (27% more words) about this subject. Likewise, more men than women (4 of 45 men versus 1 of 15 women) made statements regarding "it's my call," and men made proportionally more statements (4:3) and spoke at greater length (77% more words) about this topic. Two men explained that they made a choice not to share information about their illness with family until treatment was well underway. Exemplary quotes from the six subthemes of family are reported in Figure 1.

Discussion

The women in the current study described family members as practical or emotional support, information gatherers, and direct participants in the decision-making process. Family relationships and responsibilities served as motivating factors for selecting a course of treatment. These findings are consistent with findings from studies of decision making among women with breast cancer, which have described the influence of family and friends on women's breast cancer treatment choices (Gilbar & Gilbar, 2009; Hawley et al., 2009; O'Brien et al., 2008). In addition, the social roles and responsibilities of women in general have been shown to play a role in women's cancer prevention and treatment-related decisions (Howard, Balneaves, Bottorff, & Rodney, 2011).

The finding that the men spoke more often and at greater length about family as motivating factor, family as stressor, "it's my call," and a choice not to share was a contrast with women's descriptions of the treatment decision process in the current study. Similar perspectives have been voiced by men with prostate cancer in that family members facilitated treatment decision making but did not help make the decision (Berry et al., 2003). In a study of men with prostate cancer and their partners, Davison et al. (2002) reported that about half of the men preferred to share responsibility for treatment decision making with their partners and the other half preferred to make the final treatment decision on their own. In a qualitative study of men with prostate cancer, Shaw, Scott, and Ferrante (2013) observed that, although many men were willing to yield to family pressure in the context of screening decisions, most men preferred to retain control over treatment decision making. These findings may reflect that men carry a sense of obligation to protect their families from emotional or practical burdens. Symes et al. (2015) found that 81% of partners of men with prostate cancer reported themselves as being involved in their partner's decision-making process. However, the perceptions of patients' partners may be different from those of patients themselves.

The results of the current study highlighted a distinction between family as support and family participation in treatment decision. This is consistent with previously published literature that distinguishes between the emotional, informational, and practical support that significant others provide and their actual participation in the medical decision (Laidsaar-Powell et al., 2013; Shaw et al., 2013). In a study of men with prostate cancer conducted by Ihrig et al. (2011), all of the participants discussed treatment options with family but attributed the strongest influence on decision making to physician advice and advice provided by other patients. In contrast, studies of women with breast cancer portray family members as playing an active role in making the final decision. For example, Gilbar and Gilbar (2009) found that 89% of women with breast cancer felt that their husband agreeing with the final treatment decision was important. Likewise, Kreling, Figueiredo, Sheppard, and Mandelblatt (2006) found that decisions regarding adjuvant chemotherapy for breast cancer were often made by both the patient and her husband.

Only two other studies known to the authors have directly compared the role of family in men's and women's cancer treatment decision making. In an analysis of online cancer support group discussions, Seale (2005) found that discussions among men with prostate cancer emphasized the patient's obligation to be decisive and use information derived from medical sources rather than from personal contacts, and discussions among women with breast cancer emphasized the importance of discussing the decision with family and friends. In a comparison of men and women with colorectal and breast cancer, Stiggelbout et al. (2007) found that women placed more importance on the opinion of their partner, children, and family than men did. Additional research is warranted to explore the extent and implications of these gender differences in decision making. If women are more likely than men to make cancer treatment decisions in collaboration with others, education and decision support must target not only the patients but also their significant others.

Knowledge Translation

- Influences on the decision-making process may be different for men and women with bladder cancer.
- Women with bladder cancer often view family members as participants in the decision-making process.
- Nurses should routinely assess patients' family support systems and desired level of family participation.

Limitations

The current study is limited in three ways. First, the authors conducted a secondary analysis and were unable to add more participants to further explore study themes. Second, most participants were well educated and Caucasian, precluding generalization to more diverse populations. Third, as with all interview studies, the results may have been influenced by individual and gender-specific differences in communication style. Participants who are less forthcoming are likely to make fewer statements and use fewer words than other participants discussing the same themes.

Of note, the degree to which family members are involved in treatment decision making may vary not only between men and women, but also among members of the same gender. Numerous studies have found that family involvement in health decisions varies by culture, with family playing a particularly important role in some Latin American (Maly, Umezawa, Ratliff, & Leake, 2006) and Asian (Back & Huak, 2005; Lee & Knobf, 2015; Shin et al., 2013) cultures. In addition, individuals' preferences for participation in decision making may vary over time and by decision point (Mallinger et al., 2006; Shaw et al., 2013).

Implications for Nursing

The findings suggest that family members play an important role in the decision-making processes

of women with bladder cancer. Clinical nurses who care for this population may wish to routinely assess patients' family support systems and desired level of family participation in decision making. Patients who view family members as partners in the decision-making process should be offered a family meeting with key care providers prior to making a choice. Likewise, nurses and other healthcare providers should prepare to discuss the way in which family members may be affected by care decisions, particularly with patients who view family as a motivating factor for choosing a particular treatment.

Importantly, the findings of the current study also serve as a reminder that not all patients wish to share health decisions with family. For some patients with cancer—perhaps more often for men—family serves as a stressor. Although the authors identified topics that are important for nurses to discuss with women who have bladder cancer, the importance of individualized care cannot be understated. Nurses should support the decision-making processes of all patients and be familiar with resources that can provide support to patients who do not receive it from family.

Conclusion

The results of this analysis suggest that influences on the decision-making process are different for men and women with bladder cancer. Family may play a particularly important role for women faced with bladder cancer treatment–related decisions. The influence of family on the decision-making process is not always facilitative. Although little is known overall about the decision-making processes of women, the current findings highlight the need for clinicians, health educators, and decision aid developers to consider likely gender-related differences in decision making and that family members and family issues may considerably influence the treatment-related decisions of women with bladder cancer.

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