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Information Seeking and Satisfaction with Information Sources Among Spouses of Men with Newly Diagnosed Local-Stage Prostate Cancer

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Abstract

Information sources about prostate cancer treatment and outcomes are typically designed for patients. Little is known about the availability and utility of information for partners. The objectives of our study were to evaluate information sources used by partners to understand prostate cancer management options, their perceived usefulness, and the relationship between sources used and satisfaction with treatment experience. A longitudinal survey of female partners of men newly diagnosed with local-stage prostate cancer was conducted in three different geographic regions. Partners and associated patients were surveyed at baseline (after patient diagnosis but prior to receiving therapy) and at 12 months following diagnosis. Information sources included provider, literature, friends or family members, Internet websites, books, traditional media, and support groups. Utility of an information source was defined as whether the partner would recommend it to caregivers of other patients with local-stage prostate cancer. Our study cohort included 179 partner-patient pairs. At diagnosis, partners consulted an average of 4.6 information sources. Non-Hispanic white partners were more likely than others to use friends and family as an information source (OR = 2.44, 95% CI (1.04, 5.56)). More educated partners were less likely to use support groups (OR = 0.31, 95% CI (0.14, 0.71)). At 12-month follow-up, partners were less likely to recommend books (OR = 0.23, 95% CI (0.11, 0.49)) compared to baseline. Partners consulted a large number of information sources in researching treatment options for local-stage prostate cancer and the types of sources accessed varied by race/ethnicity and educational attainment. Additional resources to promote selection of high-quality non-

Compliance with Ethical Standards

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Disclaimer The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

provider information sources are warranted to enable partners to better aid patients in their treatment decision-making process.

Keywords

Prostate cancer; Information sources; Partner information needs

Introduction

Common treatment options for local-stage prostate cancer include active surveillance, radical prostatectomy, brachytherapy, external beam radiation, and hormone therapy. While the 5-year survival rate for local-stage prostate cancer exceeds 99% [1], many men experience long-term, adverse effects as a result of treatment [2]. Despite the prevalence of prostate cancer, there is limited comparative data on treatment efficacy and no consensus on what primary treatment constitutes the optimal treatment strategy for patients diagnosed with local-stage disease [3–5]. Partners may play a key role in collecting and processing information on management options for patients and evaluating the treatment-related side effects [6, 7].

Partners of newly diagnosed prostate cancer patients are often encouraged to engage in a shared decision-making approach with the patient and provider to determine the optimal treatment for the patient. Although the information needs of men diagnosed with prostate cancer have been previously reported [8, 9], there is limited literature on the information needs of partners [10]. Previous studies have shown that partners often pursue a more active coping strategy in the pretreatment phase than patients who may still be in a state of shock following their prostate cancer diagnosis [11]. Men who are distressed by the need to make a treatment decision report being unable to engage in active coping strategies such as information seeking and may be more reliant on their partner for sharing information and initiating the treatment discussion [12, 13].

Little is also known about the types of information sources partners use, whether they perceived this information as useful, and of the role that these information sources played in partner's satisfaction with the treatment process, particularly when their spouse experienced adverse outcomes (e.g., urinary incontinence, sexual dysfunction) following treatment. The literature on cancer survivors provides strong evidence that access to information facilitates treatment decision-making and provides a host of benefits to both the patient and partner [14]. Although these benefits are not as well characterized in partners, in patients, access to information leads to a more active coping strategy [15], decreased anxiety and distress [16], improved communication with family members [17, 18], and increased satisfaction with treatment choice [19, 20]. In this study, we evaluated the idea that the relationship between information sources, perceived usefulness, and satisfaction for patients is similar for partners.

In the current study, we evaluated (1) information sources used by partners to understand prostate cancer management options and possible treatment-related outcomes, (2) perceived usefulness of information sources 12 months after diagnosis, and (3) the relationship

between number of information sources used and satisfaction with treatment experience. We hypothesized that high ratings of usefulness at baseline and follow-up were associated with higher levels of satisfaction at follow-up, even for partners of men who experienced side effects of therapy.

Materials

Study Design

We conducted a longitudinal study using data from the Family And Cancer Therapy Selection (FACTS) study, evaluating partner survey responses at baseline (at time of patient diagnosis) and 12-month follow-up. Recruitment procedures and patient eligibility have been described elsewhere [21]. In brief, newly diagnosed prostate cancer patients were recruited from academic urology clinics in CA, SC, and TX. Eligible patients included those diagnosed with incident localized prostate cancer (American Joint Cancer Committee stages I–III, TNM stages T1–T2, N0, M0, PSA < 50) that had not initiated treatment other than hormone therapy at the time of approach.

Study coordinators conducted patient and partner recruitment at clinic sites at the end of the patient's treatment consultation visit. Patients enrolled to the study were asked to nominate a family member to participate in the associated partner study. Of the family members identified by the patient, 93% were female spouses or partners [21]. As a result, we chose to restrict the linked study to female partners only for this analysis. Patients and partners who opted to participate signed consent forms and received a baseline take-home survey to return by mail in a self-addressed stamped envelope. Partners who did not attend the initial consultation were mailed a study approach letter, consent form, and baseline survey.

Study staff mailed out follow-up surveys to patients and partners 12 months from enrollment in the study and conducted follow-up phone calls to maximize survey response at this follow-up survey time point. Participants received \$25 after completing the baseline survey and after completing the follow-up survey.

The study protocol and materials were approved by the institutional review board at each recruitment center, the coordinating center at the Fred Hutchinson Cancer Research Center in Seattle, WA, and the human subjects review committee at the Centers for Disease Control and Prevention.

Survey Items

Baseline partner surveys included sociodemographic characteristics, type of information sources used in treatment decision-making, treatment options considered, treatments recommended by the physician, and the treatment outcomes that may be important to partners of a prostate cancer patient. The partner baseline survey also collected information on the partner's role in the information gathering and treatment decision-making process. The information sources listed in the survey included (1) type of provider seen based on treatment received (e.g., doctor who performed biopsy, surgery, radiation therapy); (2) literature provided by physicians (pamphlets, videos, lectures) and medical journals; (3) friends or family members diagnosed with prostate cancer; (4) online websites (e.g.,

hospital, national cancer organizations, or other websites); (5) books about prostate cancer; (6) traditional media (e.g., newspaper, magazines, television, or radio); and (7) support groups (in-person or on the Internet). Patients and partners were asked to rate how helpful each information source was on a 5-point Likert scale ranging from not helpful to very helpful. The 12-month follow-up partner survey assessed the impact of cancer on the patient's life, the treatment-related side effects, and the utility of the information source, defined as whether they would recommend the information source to family members of patients with local-stage prostate cancer. Finally, we included questions asking partners to rate their satisfaction with the patient's doctor and the treatment outcome. Survey questions were generated for the purposes of this study.

Analysis

A total of 179 partner-patient pairs completed the baseline survey. We tabulated summary statistics of partner sociodemographic characteristics and the number and type of information sources consulted at the time of the baseline survey.

For each information source, we explored partner characteristics associated with using that particular source. A separate multivariate logistic regression model was fit for each source. The outcome was whether the source was used at baseline and the predictors included partner age, race/ethnicity (non-Hispanic white vs all other), and education.

Next, among those who completed both baseline and follow-up surveys, we assessed whether the partners' perception of helpfulness of each information source changed between baseline and 12 months (determined by whether the partner would recommend the source at 12 months). A separate multivariate logistic regression model was fit for each source, among partners who used that source at baseline. We used robust variance estimation to account for the correlation due to repeated measurements on the same partners.

Finally, we assessed the relationship between number of information sources used at baseline and satisfaction with care at 12-month follow-up. We fit two separate multivariate logistic regression models using the following dependent variables: (1) partners' overall level of satisfaction with the patients' prostate cancer doctors and (2) partners' satisfaction with the treatment outcome, reflecting the partners' responses to the following questions:

- Please rate your overall level of satisfaction with your loved one's prostate cancer doctors
- How do you feel your loved one's treatment (or watchful waiting) has worked out?

Responses were recorded on a 5-point Likert scale with the following categories: completely satisfied, very satisfied, somewhat satisfied, not at all satisfied, and not sure. For this analysis, the dependent variable was recorded as a 1 if the response was "completely" or "very" satisfied and 0 otherwise. We adjusted for partner age, partner race/ethnicity, partner education, and recruitment site.

Statistical analyses were performed using R statistical software (version 3.2.1). Reported *p* values are two-sided and significance of test was considered when $p < 0.05$.

Results

A total of 315 family members were approached for participation at the time of patient diagnosis. Of the family members approached, 122 were excluded from the analyses for the following reasons: non-response to the baseline survey ($n = 83$), ineligible due to patient identified by the partner not participating in a companion survey ($n = 27$), and refusal to participate or not interested ($n = 12$). We removed an additional 14 family members from the analysis who reported not being the wife or female partner of the patient. Of the 179 partners who returned the baseline survey, 93 (52%) completed a 12-month follow-up survey.

Table 1 summarizes baseline partner demographic characteristics and information use. Among partners who completed the baseline survey, the average age (range 40–84 years) was 59.1 (SD 8.7), 69% were <65 years of age, 70% were non-Hispanic white, and 48% were college graduates. At baseline, partners consulted an average of 4.6 (SD 1.5) information sources to inform treatment decision-making. Partners reported providers as the most commonly used information source (99%), followed by the literature (80%), friends or family members diagnosed with prostate cancer (78%), and online sites (65%).

Table 2 shows the associations between partner characteristics and use of information sources other than doctors at baseline. Non-Hispanic white partners were more likely than others to use friends and family diagnosed with prostate cancer as an information source (OR = 2.44, 95% CI (1.04, 5.56)). Partners who were more educated were less likely to use face-to-face or Internet support groups as an information source (OR = 0.31, 95% CI (0.14, 0.71) than partners with lower levels of education.

Table 3 compares partners' views of helpfulness of information sources at baseline and at 12-month follow-up, among those who completed both surveys. Partners at baseline rated providers as the most helpful information source (97% of partners), followed by literature (92%), friends or family members (92%), and Internet websites (90%) as the most helpful information sources. At baseline, 84% reported they had received enough information to understand the issues involved in making a treatment decision. Among partners who completed the 12-month follow-up survey, the proportions of those who would recommend the same information sources at 12 months generally declined or remained the same with the exception of Internet or face-to-face support groups (Table 3). We note that 12-month data on providers were not available, as they were not listed as an information source in the 12-month survey. There was a statistically significant decline in books viewed as a helpful information source at 12-month follow-up compared to baseline (OR 0.23; 95% CI (0.11, 0.49)). Traditional media was also viewed as less helpful at 12-month follow-up compared to baseline, although this association was not statistically significant (OR 0.51; 95% CI (0.25, 1.02)).

Finally, among partners who completed both surveys, no association was found between number of information sources used at baseline and satisfaction with care at 12-month follow-up. For partners' overall level of satisfaction with the patients' prostate cancer doctors, we estimated an adjusted odds ratio of 1.19 (95% CI (0.78, 1.80)). For partners'

satisfaction with the treatment outcome, we estimated an adjusted odds ratio of 0.84 (95% CI (0.56, 1.26)).

Discussion and Conclusion

Discussion

Although many partners play an active role in prostate cancer patients' decisions regarding their care, there is limited literature on the informational needs of partners and how they perceive the usefulness of information that they access over time. This prospective, multi-site survey provides some useful insights about baseline and 12-month assessments of perceived helpfulness of information sources. Partners accessed a relatively large number of information sources around the time of their loved one's diagnosis and the types of sources accessed varied by race/ethnicity and educational attainment. Books and traditional media were seen as less helpful in retrospect compared to the time nearest the patient's diagnosis. By comparison, however, Internet or face-to-face support groups were more likely to be recommended by partners at 12 months than at baseline. Satisfaction with the treatment experience was not associated with information sources accessed.

Partners often have the responsibility of gathering information about diagnosis and treatment options, as well as a role in treatment decision-making. A previous study by Rim et al. using the FACTS cohort evaluated how family members (partners) viewed their role in treatment decision-making [6]. In this study, 97% of family members "strongly agreed" that their role was to listen and provide emotional support, while 82% of partners "strongly agreed" that their role was to help collect information about cancer and treatment options. These findings suggest that partners play an active role in gathering information, presumably so they can provide informed support to the patient and assist the patient in his treatment decision-making. In this survey, the great majority of partners (84%) felt that they received enough information to understand the issues involved in making a treatment decision, suggesting that as a whole, there is sufficient accessible information to support partners in their perceived roles.

There is a growing body of evidence to suggest that partners engage in a process of information seeking that is often more active than patients, in part, because partners may seek a broader understanding of the entire cancer experience compared to men with more focused information needs [22]. Furthermore, partners are more likely to exhibit high information-seeking behavior and collect disease and treatment information on behalf of the patient as an active coping strategy [7]. Partners' primary motivations for seeking information include reducing feelings of anxiety and uncertainty, facilitating treatment decision-making, helping to care for the patient, and ensuring their own information needs are met [23]. A pilot study found a significant and positive relationship between participants' information-seeking behavior and their need for information [10]. This finding suggests that both patients and partners benefit from accessing information during the treatment decision-making process. Health care providers can support the needs of the patient and partner by identifying whether they are satisfied with the available information or seek additional information and resources. Accordingly, providers can help the patient

and partner navigate educational materials and resources based on their information needs and preferences.

To our knowledge, no studies have examined the preferences for specific information sources, perceived usefulness, and treatment decision-making needs that exist from a partner perspective. Research examining information seeking and prostate cancer has primarily examined the information sources used by newly diagnosed men and how to address their treatment-related concerns [22, 24]. Relatively few studies have reported on the perceived helpfulness of information sources used by patients or partners.

Our findings indicate that partners are more likely to report Internet or face-to-face support groups as helpful at 12-month follow-up compared to the time period between diagnosis and treatment (baseline). Ramsey et al. surmised that face-to-face support groups are oriented towards helping patients cope with their disease during and after treatment, rather than prior to treatment [25]. Another qualitative study showed that partners desired more emotional support and opportunities to share their experiences [26]. As a result, we might expect that patients and partners are more likely to rate support groups as helpful at 12-month follow-up compared to baseline. More research is needed to understand the useful components of Internet and face-to-face support groups. Importantly, since support groups have not been traditionally designed to address the needs of partners, more studies are needed to inform the development of support groups that incorporate the partner perspective and help couples navigate their treatment options.

A major strength of our study is the geographic representation in the multi-center study design, with study participants recruited from academic medical centers in CA, TX, and SC and recruiting patients early in their treatment decision-making process. Limitations were that study participants were predominantly non-Hispanic white and reported a higher than average education compared to the general population. Results, therefore, may not be representative of samples with greater racial/ethnic and socioeconomic diversity. In addition, patients were recruited through academic medical centers known for excellence in prostate cancer surgery. Hence, our study population may be enriched for men pursuing surgical treatment and may not be representative of all men with newly diagnosed localized prostate cancer. We did not collect data on the different types of information needs partners had and were not able to evaluate the content or quality of information gleaned from each information source.

Conclusion

Providing partners with balanced and accurate information designed to address their specific information needs is critical. In this survey, we found that partners consulted a large number of information sources in researching treatment options for local-stage prostate cancer, but there was no association between number of information sources used at baseline and satisfaction with care at 12-month follow-up. Some sources were viewed as less helpful to partners in retrospect, suggesting that additional resources to promote selection of high-quality non-provider information sources may enable partners to better aid patients in their treatment decision-making process.

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Table 1

Partner demographic characteristics and information use at baseline

Partner characteristics	Partners completing baseline survey (<i>n</i> = 179)	Partners completing 12-month follow-up survey (<i>n</i> = 93) ^a
Age at diagnosis		
• 40–60	88 (49%)	38 (41%)
• 60–64	36 (20%)	24 (26%)
• 65–69	31 (17%)	20 (22%)
• 70–84	18 (10%)	10 (11%)
• Unknown	6 (3%)	1 (1%)
Race/ethnicity		
• Non-Hispanic white	126 (70%)	72 (77%)
• Non-Hispanic black	21 (12%)	5 (5%)
• Hispanic	15 (8%)	9 (10%)
• Asian/Pacific Islander	12 (7%)	4 (4%)
• Other/unknown	5 (3%)	3 (3%)
Education		
• High school	32 (18%)	12 (13%)
• Some college	61 (34%)	28 (30%)
• College graduate	57 (32%)	38 (41%)
• Graduate degree	28 (16%)	15 (16%)
• Unknown	1 (0%)	0 (0%)
Information source used at baseline		
• Provider	177 (99%)	92 (99%)
• Literature (medical journals)	144 (80%)	75 (81%)
• Friends or family members	144 (78%)	75 (81%)
• Internet websites	116 (65%)	61 (66%)
• Books about prostate cancer	103 (56%)	52 (56%)
• Traditional media (newspaper, magazine, television, radio)	85 (37%)	46 (49%)
• Face-to-face or Internet support group	42 (26%)	15 (16%)

^aPartners completing the follow-up survey (*n* = 97) were a subset of those completing the baseline survey

Table 2

Odds ratios (95% CI) showing associations of partner characteristics with use of each information source at baseline

Partner characteristic	Information source						Face-to-face or Internet support
	Literature	Friends or family members	Internet websites	Books	Traditional media		
Age at diagnosis							
<60	ref	ref	ref	ref	ref	ref	
60	0.89 (0.40, 1.96)	1.77 (0.76, 4.12)	0.72 (0.37, 1.40)	1.02 (0.54, 1.93)	0.87 (0.46, 1.65)	0.65 (0.30, 1.41)	
Race/ethnicity							
Non-Hispanic White	1.27 (0.53, 3.03)	2.44 (1.04, 5.56) ^a	0.89 (0.42, 1.89)	1.37 (0.67, 2.78)	1.47 (0.72, 3.03)	0.79 (0.34, 1.79)	
All Other	ref	ref	ref	ref	ref	ref	
Education							
High school/some college	ref	ref	ref	ref	ref	ref	
College graduate/graduate degree	0.97 (0.43, 2.15)	1.09 (0.47, 2.50)	0.76 (0.38, 1.49)	0.79 (0.41, 1.51)	1.61 (0.85, 3.06)	0.31 (0.14, 0.71) ^a	

Odds ratios are adjusted for study site

^aItalic font indicates statistically significant finding

Table 3

Partner information sources rated as helpful at baseline and rated as recommended in the 12 month follow-up survey, among those who used each resource at baseline

Source	% helpful at baseline ($N_{\text{Helpful}}/N_{\text{Partners}}$)	% recommended at 12 months ($N_{\text{Recommended}}/$ N_{Partners})	Odds ratio (95% CI)	<i>p</i> value
Provider	97% (170/175)	<i>a</i>	<i>a</i>	<i>a</i>
Literature	92% (132/144)	93% (70/75)	1.27 (0.42, 3.84)	0.669
Friends or family members	92% (132/144)	93% (70/75)	1.27 (0.42, 3.83)	0.668
Internet websites	90% (104/116)	82% (50/61)	0.52 (0.22, 1.25)	0.147
Books	87% (90/103)	62% (32/52)	0.23 (0.11, 0.49)	<i><0.001^b</i>
Traditional media	75% (64/85)	61% (28/46)	0.51 (0.25, 1.02)	0.058
Face-to-face or Internet support group	52% (22/42)	87% (13/15)	N/A ^c	N/A ^c

^aProvider was not listed as an information source at 12 months

^bItalic font indicates statistically significant finding

^cThese results were not included due to very small cell counts (2 of 15 partners did not recommend Internet or face-to-face support at 12 months)