Sources of Information for Learning and Decision-Making in Men With Localized Prostate Cancer

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Abstract

Information seeking is essential for effective patient-centered decision-making. However, prostate cancer patients report a gap between information needed and information received. The importance of different information sources for treatment decision remains unclear. Thus, using the Comprehensive Model of Health Information (CMIS) framework, we assessed the antecedent factors, information carrier factors, and information-seeking activities in localized prostate cancer patients. Data were collected via semistructured one-on-one, interviews and structured survey. Men with localized prostate cancer were recruited from two urban health-care centers. Following the interview, participants completed a survey about sources that were helpful in learning about prostate cancer treatment and decision-making. The interviews were audio-recorded, transcribed, and subjected to a thematic analysis using NVivo 10. Fifty localized prostate cancer survivors completed the interviews and surveys. Important antecedent factors that were observed were age, marital status, uncertainty, anxiety, caregiver burden, and out-of-pocket expenses. We identified complexity, magnitude, and reliability as information carrier characteristics. Preferred sources for information were health providers, medical websites, and pamphlets from the doctor's office. These sources were also perceived as most helpful for decision-making. Urologists, urological oncologists, and radiation/radiation oncologists were important sources of information and helpful in decision-making. Prostate cancer patients obtained information from multiple sources. Most prostate cancer patients make patient-centered choices by incorporating personal factors and medical information. By considering factors that influence patients' treatment decisions, health-care providers can enhance the patient-centeredness of care. Multiple strategies and interventions are necessary for disseminating valid, reliable, and unbiased information to prostate cancer patients to facilitate informed decisions.

Keywords

localized prostate cancer, shared decision-making, information seeking, sources of information, patient interviews

Patient involvement in decision-making is an essential component of patient-centered care (Barry & Edgman-Levitan, 2012). Decision-making is, in turn, facilitated by the availability of and access to health information (Davison & Breckon, 2012). Health information-seeking behavior has key implications for shared decision-making. Understanding how people seek and make use of health information, the channels they use to obtain health information, and the factors that inhibit or encourage health information use has been facilitated by the study of personality in psychology, consumer behavior, innovation research, health communication studies, and organizational decision-making (Ikoja-Odongo & Mostert, 2006;

Lambert & Loiselle, 2007; Wang et al., 2013; Wilson, 1999).

Process of Information Seeking

Information seeking is a complex process that involves multiple disciplines of social, communicative, and interactive behavior and can be defined as "patient's or caregiver's constructive effort to derive meaning from information in order to extend their state of knowledge on a particular health issue or topic" (Ikoja-Odongo & Mostert, 2006; Kuhlthau, 1993). Health information seeking is a way to address "shortcomings," which can viewed as shortage,

uncertainty, or unclear attributes of health-care intervention. Thus, health information seeking is a method for coping with a stressful life event, such as a prostate cancer diagnosis. Many factors, including personal characteristics, perception of the situation, and time, influence the quantity and details of health information that a person seeks and is able to absorb (Davison & Breckon, 2012; McCaughan & McKenna, 2007).

Models of Information Seeking

Most research related to health information communication has focused on senders (e.g., professional medical sources) and the way in which they can use communication to influence individuals. Research focused on the receiver (e.g., patient) as an active information seeker and processor is relatively scant (Johnson & Meischke, 1993). Also, while health behavior models such as the health belief model usually downplay the role of communication, the models of channel and media usage tend to ignore the health-related motivations that can have strong implications for a person's use of specific information carriers (Johnson & Meischke, 1993). The Comprehensive Model of Information Seeking (CMIS) addresses these issues by focusing on the perspective of the information seeker or receiver. The CMIS was developed in the context of information seeking among cancer patients and is the result of the synthesis of three theoretical research streams: the health belief model, uses and gratifications research, and a model of media exposure and appraisal (Johnson, 1997). The CMIS model consists of three categories of factors: antecedent factors, information carrier factors, and information-seeking actions. Antecedent factors are those that motivate a person to seek information (e.g., demographics, personal beliefs); information carrier factors relate to the characteristics and utility of the information source; and information-seeking actions involve choosing among sources as well as an array of other behavioral and cognitive elements. In recent years, several studies related to cancer have adopted the CMIS framework (Han et al., 2010; Johnson et al., 2001; Kim et al., 2017; Ruppel, 2016; Van Stee & Yang, 2018).

Information Seeking Among Prostate Cancer Patients

Prostate cancer is the most common cancer among men in the United States. It is estimated that, in 2020, there will be 191,930 new cases of prostate cancer and 33,330 deaths due to this cancer (Siegel et al., 2020). Prostate cancer diagnosis creates a situation where patients and their support person(s) must familiarize themselves with medical jargon, participate in decision-making to the extent they are comfortable with, and bring about lifestyle changes. Due to the availability of multiple treatment choices and no one superior treatment option, prostate cancer treatment decision-making is a complex task (Davison & Breckon, 2012). Prostate cancer patients have reported the use of resources such as physicians, spouses, family and friends, and different media to make informed decisions (Cox & Amling, 2008; Gwede et al., 2005; Steginga et al., 2002; Walsh et al., 2010). At the same time, a study of early-stage prostate cancer patients reported a gap between what information patients need to know and what information they actually receive (Snow et al., 2007). In addition, the relative importance of the different information sources for treatment decision remains unclear. Therefore, in this paper, we pose the following research question: What are the antecedent factors, information carrier factors, and information-seeking activities among patients with localized prostate cancer? We plan to address this question using the CMIS framework.

Materials and Methods

Study Sample and Recruitment

Our overall study was a large, multicenter, two-phase study. We developed a preference assessment instrument for localized prostate cancer patients in Phase 1, and tested its effectiveness in a randomized controlled study in Phase 2. The details of the study are presented elsewhere (Chhatre et al., 2018; Jayadevappa et al., 2015, 2017, 2019). As part of the Phase 1 of the study, from the urology and radiation outpatient offices of two urban health-care centers, we recruited 50 men who had undergone radical prostatectomy, radiation therapy, or hormone therapy treatment for localized prostate cancer or were on active surveillance.

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Active surveillance is a management option for localized prostate cancer where period checks are done to check if the cancer is growing, with intent to intervene if needed.

Participants were interviewed over the telephone, except one that was conducted in person. The interviewer asked about the participants' experiences with prostate cancer and its treatment, especially about how men make decisions about which treatment they will use. Participants were asked which aspects of the prostate cancer treatment they feel are most important, and would want to share with other men who are making treatment decisions. The average length of the interview was 30 min. On average, the participants were 65.8 years of age (*SD* = 7.9 years), and had survived 3.8 years after prostate cancer diagnosis (*SD* = 3.7 years). More than two-thirds of the participants were White (68.1%) and 29.8% were African American. Sixty-five percent had radical prostatectomy, 25% had radiation, and 10% were on active surveillance.

Interview Procedure

Interviews were conducted by facilitators who were neither physicians nor associated with the study. Informed consent and verbal consent to record the discussion were obtained prior to interviews. The questions for the interview were based on a review of the literature (Jayadevappa et al., 2017); the interview was semi-structured (Given, 2008) and, whilst ensuring that all relevant topics were covered in each session, was flexible enough to allow for the introduction and discussion of new topics, if necessary (Given, 2008; Morgan, 1997). Participants shared their views on the experience of illness (i.e., prostate cancer), information seeking, treatment decision-making, role of providers and family members, barriers and facilitators, and external and internal sources of information. Sociodemographic data were obtained via a brief questionnaire and were de-identified. Recruitment for interviews continued until no new themes emerged from additional interviews (Morgan, 1997).

At the end of the one-on-one interview, each participant completed a structured survey. As part of the survey, from a list of resources and provider entities, participants were asked to select all resources that were helpful in learning about prostate cancer treatment options and in making treatment decisions, and all provider entities who were helpful in communicating about treatment options and in making treatment decisions. Each participant was offered a US$20 gift card as a token of appreciation. The study was approved by the University of Pennsylvania Institutional Review Board.

Analysis

All interviews were transcribed verbatim and the transcripts were used to perform a qualitative data analysis.

Data analysis comprised of four steps: immersion in the data, coding, creating categories, and identification of themes (Green et al., 2007; Morgan, 1997). Data collection and analysis occurred simultaneously, and we stopped data collection once data saturation was observed (Green et al., 2007; Morgan, 1997; Morse, 1995). Qualitative data software package NVivo 10 (QSR International) was used for analyzing the interview data. The survey data were analyzed using SAS software, Version 9.4 (SAS Institute, Cary, NC). Thematic analysis, a method of "identifying, analyzing, and reporting patterns (themes) within data" (Braun & Clarke, 2006), was the methodological framework within which we analyzed the data from the interviews. It is a descriptive method that facilitates data reduction in a flexible manner (Vaismoradi et al., 2013). The five steps of our thematic analysis were data organization and familiarization; initial broad code generation; applying broad codes to data; identifying attributes within coded text; and naming attributes. All members (JG, MW, RJ, and SC) participated in the thematic analysis and also verified the intercoder agreement. Any discrepancies in coding were resolved via discussion (Jayadevappa et al., 2019).

Results

As we observed from our one-on-one interviews, "information source" emerged as a complex and multifaceted construct. Prostate cancer patients provided detailed and articulate descriptions of their disease experience, and often referred to the notions of "decision making," "balance," and "trusted sources" in their discussions. (Jayadevappa et al., 2019). Within the CMIS framework, we used the information from one-on-one interviews, and the survey results to identify the antecedent factors, information carrier factors, and information-seeking activities (Table 1) among our cohort of localized prostate cancer patients.

Antecedent Factors

All participants were localized prostate cancer survivors and thus had direct experience of the disease under discussion. Participants recognized the association between age and treatment type, as was revealed from the discussion with participants ID25, ID116, and ID122.

"She explained everything to me, what I would be going through and they also told me because of my age the options are less." (ID25, age 75, received radiation therapy)

"We – his belief was that the radical probably would, because of my age and my physical condition at the point that we were making the decision, I think he felt like that might be the best alternative." (ID116, age 67, received prostatectomy and radiation therapy)

Table 1. Components of the Comprehensive Model of Information Seeking (CMIS)* Among Prostate Cancer Patients (*n* = 50).

Antecedent factors	Information carrier factor	Information seeking actions
Demographics characteristics: age, marital status Direct experience: prostate cancer Salience: worry, uncertainty, anxiety, caregiver's burden, out-of-pocket expenses, desire to address the issue Beliefs: availability of appropriate treatment option	Content characteristics: complexity, magnitude, reliability Utility: preferred sources for information—health providers, scientific/academic websites, pamphlets from the doctor's office Sources most helpful for decision-making: health providers, scientific/academic websites, pamphlets from the doctor's office Preferred providers as source of information: urologist, urological oncologist, radiation/radiation oncologist Providers most helpful for decision-making: urologist, urological oncologist, radiation/radiation oncologist	Method of search (channel): number and types of information sources used—television, Internet, pamphlets from the doctor's office, scientific website, other patients, friends with prostate cancer, spouse/partner, support groups Scope: treatment options, side effects, symptoms, risk factors

*Source: Johnson (1997).

"You know, I guess when you're a certain age, maybe they don't want to do surgery or somebody else has health issues." (ID122, age 70, received robotic prostatectomy)

Several participants noted active involvement of the spouse following the diagnosis of prostate cancer. For example, participants ID100, ID116, and ID126 made the following observations regarding the roles of spouses in decision-making or information seeking.

"None of the folks at XXX were trying to direct me in any way. They were sort of presenting the facts and making me know many times over that this is not their decision, this is my decision, or my wife and I decision." (ID100, age 66, received robotic prostatectomy)

"And it just came down to, when he explained it and he explained the risks associated with all three, I think my wife and I just decided that if we were gonna do something, we wanted to make sure that we got it done in one get-go." (ID116, age 67, received prostatectomy and radiation therapy)

"But he said to me – and my wife was obviously in attendance at all these meetings and full sharing of information and joint decision making and all that." (ID126, age 69, received radiation therapy)

Anxiety or worry about the disease prognosis, the desire to minimize caregivers' burden as well as out-of-pocket costs of care, and the desire to address the issue head-on were some of the factors that prompted information seeking as indicated by some participants (ID005, ID008, ID011, ID012, and ID123).

"I'm prone to anxiety attacks anyway and when he told me he believed it was cancer I was basically having anxiety attacks every time my mind wasn't engulfed in something." (ID005, age 58, received robotic prostatectomy treatment)

"I needed a cure, to have it cured at once, you know. Taking it out and be done with it and not have to worry about it." (ID008, age 51, received prostatectomy treatment)

"I wasn't gonna worry about insurance, but he found cancer so I had to get insurance, but it's costing me a fortune." (ID123, age 47, received robotic prostatectomy treatment)

"And I was anxious – I was anxious because, you know, I'm like okay I got this, am I gonna be all right, you know, then I start reading on it and I felt a little better." (ID011, age 63, received robotic prostatectomy treatment)

"I'm the kind of person that wants to attend to things when it happens so I don't have to worry about it or think about it, so it fit my personality to do it this way." (ID012, age 79, received radiation therapy)

In addition, almost all participants indicted that they were reasonably well aware of the available treatment options for localized prostate cancer. These rich insights from the interviews enabled us to identify antecedent factors of demographics characteristics (age, marital status), direct experience (patients were prostate cancer survivors), salience (uncertainty, anxiety, caregivers burden, out-of-pocket expenses, and the desire to address the health condition), and beliefs (knowledge about availability of appropriate treatment options) as presented in Table 1.

Information Carrier Factors

The two types of information carrier factors are characteristics and utility. During our semistructured, one-on-one interviews, participants observed that the cancer-related information (treatment options, effectiveness of different treatment options, potential side effects) was vast and complex in nature. At the same time, participants also voiced concerns regarding the reliability of certain sources of information.

Table 2. Source of Information for Learning and Decision-Making Among Localized Prostate Cancer Patients (*n* = 50).

	Television	Internet	Pamphlets from the doctor's office	Website such as NCI, ACS, AUA	Other patients	Friends with prostate cancer	Discussion with spouse /partner	Support group	Other
After prostate cancer diagnosis, how helpful were these resources for you to learn about prostate cancer treatment?									
Very helpful	3	12	17	21	10	10	21	3	5
n, (%)	(6.4)	(25.5)	(36.2)	(44.7)	(21.3)	(21.3)	(44.7)	(6.4)	(10.6)
After prostate cancer diagnosis, how helpful were these resource(s) to you in making a decision about treatment?									
Very helpful	2	10	15	21	9	10	22	2	5
n, (%)	(4.3)	(21.3)	(31.9)	(44.7)	(19.1)	(21.3)	(46.8)	(4.3)	(10.6)

Note. NCI = National Cancer Institute; ACS = American Cancer Society; AUA = American Urologic Association.

"I got a couple books from Dr. XX down here and I spent a lot of time on the internet watching – I mean reading and trying to learn about what the options were and what kind of is the most prominent treatment." (ID005, age 58, received robotic prostatectomy)

"I'd say primarily it was my urologist in XX, told me stories about nameless other patients and people that chose different routes." (ID006, age 48, prostatectomy)

"Well actually my fiancé went online and she printed off some papers on different websites but I'm not sure what websites. The American Cancer Society was one." (ID123, age 47, received robotic prostatectomy)

Thus, as shown in Table 1, we identified complexity of information, magnitude of information, and its reliability as information carrier characteristics. The utility of the information carrier was evident by the identification of preferred sources for information; sources most helpful for decision-making; providers as source of information; and providers most helpful for decision-making. As presented in Table 2, the top three resources for learning about prostate cancer were websites (45%) of the National Cancer Institute (NCI), the American Cancer Society (ACS), and the American Urologic Association (AUA); discussions with spouse or partner (45%); and pamphlets from the doctor's office (36%). These three resources were also reported as being most helpful in making a treatment decision (45%, 47%, and 32%, respectively). This was also evident during one-on-one interviews, where participants observed that medical sites were often a popular source of information. Additionally, spouses were reported to be active seekers of information from medical sites, which lead to a common information base and facilitated shared decision-making.

Next, we determined who among the providers was considered to be most helpful in communicating about treatment options (Table 3). Sixty-two percent of the participants said that urologists were most helpful in communicating to the patient about treatment options,

followed by radiation oncologists (53%) and urologic oncologists (40%). Patients also considered these provider entities to be most helpful for making treatment decisions (53%, 51%, and 40%, respectively). Similar observations were made in the one-on-one interviews. For example, participants often said that their doctors were the primary source of information. Participants reported trust in their doctors and found them to be helpful in treatment decision-making.

Information-Seeking Actions

Information-seeking actions can be described in terms of the method of search (channel) and scope of the search. Participants reported using a range of methods of search (channel) such as television, internet, materials from the doctor's office, medical websites, other patients/friends with prostate cancer, spouse/partner, and support groups. The scope of the information-seeking action was observed to be broad, as participants reported having sought information regarding treatment options, symptoms, outcomes of care, and side effects.

"Nothing other than the little pamphlet that I had got from XXX Hospital, other than that, and you know, going on the little websites that they had listed in the back of the pamphlet." (ID002, age 53, received radiation therapy)

"Yeah, I went on – I can't remember the sites at this point, but I remember going on the sites for cancer and radiology and got as much information as I could out of that." (ID100, age 66, received robotic prostatectomy)

Discussion

Our results can be viewed within the broad context of the CMIS model, especially as they relate to the "information carrier factors" of the model. Information carrier factors are the characteristics and utility of a source, for example, the credibility and ease of access that determine if a person will use that source. In our study, we found that men

Table 3. Providers as Source of Information and Decision-Making Among Localized Prostate Cancer Patients.

	Urologist	Urological oncologist	Radiation/ radiation oncologist	Oncologist	Primary physician /geriatrician	Nurse practitioner	Other
Who was helpful in communicating with you about your treatment options?							
Very helpful	29	19	25	7	14	15	5
n (%)	(61.7)	(40.4)	(53.2)	(14.9)	(29.8)	(31.9)	(10.6)
Who was helpful to you in making a decision?							
Very helpful	24	19	24	6	13	15	5
n (%)	(51.1)	(40.4)	(51.1)	(12.8)	(27.7)	(31.9)	(10.6)

with localized prostate cancer had obtained information from multiple sources to learn about the diagnosis, treatment options, and side effects. Each source had varying degrees of ease of access, accuracy, and quality. Medical websites, spouse/partner, and materials from doctors were the most helpful sources of information. Additionally, these sources were also identified as most helpful for making a treatment decision. Only a small proportion of the participants identified television and support groups as helpful sources for obtaining information or for making treatment decision. While all providers, including primary, specialist, and nurse practitioners, were considered to be helpful in learning about the treatment options or making treatment decisions, specialist providers were reported to be the most influential.

The internet is an increasingly important source of information for prostate cancer patients. One study of 119 patients reported that 40% of participants used the internet for information and was the most common external source of information, as we have observed as well (Steginga et al., 2002). We too found that almost half the responders identified the internet, including specific websites, as being very helpful for learning about prostate cancer treatments and for making treatment decisions. However, one important finding of our research is that participants also acknowledged the limitations due to the possibility that information may be incomplete, inappropriate, or biased. Thus, while ease of access and availability of information are important features of the internet as a source of information, patients also are mindful about its potential lack of accuracy. At the same time, one study reported that cancer patients who had obtained information via internet were more engaged with their physician during the visit and were active in decision-making (Bass et al., 2006). Research has shown that spouses and other family members can take an active role in seeking information and influence treatment decision (Bansal et al., 2018; Gwede et al., 2005; Srirangam et al., 2003; Zeliadt et al., 2006). Our participants also reported that in addition to influencing the decision, spouses were active in seeking information from the internet as well as from the physician.

Diagnosis of prostate cancer is a stressful life experience for patients and their family members. The nature of the prostate cancer diagnosis requires patients to learn about the illness, make difficult treatment decisions, and cope with the short-term and long-term consequences of the illness. A review of the decision-making literature suggests that there is considerable variation in treatment decisions, which does not appear to be truly reflective of patient preferences, but rather attributable to differences in both the content and the methods by which patients perceive and receive information (Zeliadt et al., 2006).

Many prostate cancer patients have negative experiences when searching for information, and lower income and less education were related to negative information-seeking experiences (Bernat et al., 2016). Social determinants that are mediated by sociodemographic factors (e.g., age and gender) can lead to variations in health communication, resulting in difficulties with access, seeking, processing, and use of health information, and ultimately contributing to disparities in health outcomes. Health-care providers, friends and family, mass media, internet or print, and support groups were recognized as the sources of information (Blanch-Hartigan & Viswanath, 2015). Prostate cancer patients who use support of their networks may experience improved psychosocial outcomes (Brown et al., 2016).

In our study, providers were reported to be helpful in communicating about the treatment options and in decision-making. Specifically, urologists were the most helpful communicators of treatment options. Also, half of the participants identified both the urologist and radiation oncologist as most helpful for decision-making. Studies have shown that in 95%–100% of men with prostate cancer, urologists are an important source of information (Gwede et al., 2005; Hall et al., 2003; Steginga et al., 2002).

One study found that almost two-thirds of the patients desired an active role in the treatment decision-making, and nearly one-third preferred joint collaboration with their physicians (Gwede et al., 2005). It is also reported that among patients, a transition from a passive to a more

active role is emerging (Zeliadt et al., 2006). Two separate studies were conducted 5 years apart, but they used the same questionnaire. The proportion of men who wanted the physician to make the final decision dropped from 58% to 32% (Davison & Degner, 1997; Davison et al., 1995). In another study, only 23% of the patients with localized prostate cancer reported that they relied on their physician's opinion while making a decision (Berry et al., 2003).

Limitations

We note some limitations to this research. While data on age, race/ethnicity, type of prostate cancer treatment, and survival time were obtained, we did not gather data on education, income, and employment. Interviews and surveys required participants to think back in time, and thus there is a potential for recollection bias. Nevertheless, our research makes an important contribution to the areas of health information and decision-making in localized prostate cancer using the CMIS framework.

Conclusions

Our results have important implications for effective dissemination of information to localized prostate cancer patients. It is evident that a variety of sources contribute to the patients' need for information and influence the treatment decision. Physician, spouse/partner, and medical websites were observed to be the most frequent sources sought by patients and also the most influential in treatment decision. Notwithstanding the slow but steady move away from the "paternalistic" model of patient–physician relationship, patients in our study reported that the physician was a trusted source of information and influential in reaching treatment decision. At the same time, while participants identified the internet as an important source of information, there was acknowledgement of its imitations and the need for unbiased information.

In conclusion, our research shows that when a patient and his spouse/partner are equipped with appropriate information, a comprehensive and open patient–physician dialogue can take place, leading to shared decision-making. Most prostate cancer patients make patient-centered choices by incorporating personal factors and medical information. By considering factors that can potentially influence a patient's treatment decisions, health-care providers can enhance the patient-centeredness of care.

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