

Prostate Cancer Information Available in Health-Care Provider Offices: An Analysis of Content, Readability, and Cultural Sensitivity

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Abstract

Prostate cancer (PrCA) is the most common cancer affecting men in the United States, and African American men have the highest incidence among men in the United States. Little is known about the PrCA-related educational materials being provided to patients in health-care settings. Content, readability, and cultural sensitivity of materials available in providers' practices in South Carolina were examined. A total of 44 educational materials about PrCA and associated sexual dysfunction was collected from 16 general and specialty practices. The content of the materials was coded, and cultural sensitivity was assessed using the Cultural Sensitivity Assessment Tool. Flesch Reading Ease, Flesch-Kincaid Grade Level, and the Simple Measure of Gobbledygook were used to assess readability. Communication with health-care providers (52.3%), side effects of PrCA treatment (40.9%), sexual dysfunction and its treatment (38.6%), and treatment options (34.1%) were frequently presented. All materials had acceptable cultural sensitivity scores; however, 2.3% and 15.9% of materials demonstrated unacceptable cultural sensitivity regarding format and visual messages, respectively. Readability of the materials varied. More than half of the materials were written above a high-school reading level. PrCA-related materials available in health-care practices may not meet patients' needs regarding content, cultural sensitivity, and readability. A wide range of educational materials that address various aspects of PrCA, including treatment options and side effects, should be presented in plain language and be culturally sensitive.

Keywords

prostate health, African Americans, health literacy, content analysis

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Prostate cancer (PrCA) is the most commonly diagnosed cancer among American men (Siegel, Miller, & Jemal, 2018). African American (AA) men have higher

incidence and mortality rates of PrCA than White men do (Chornokur, Dalton, Borysova, & Kumar, 2011; Siegel et al., 2018). Despite high incidence, the 5-year survival

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rate is 99% (Siegel et al., 2018); thus, as patients seek better quality of life after diagnosis, patient understanding of the multidimensionality of treatment outcomes and side effects is crucial.

PrCA patients often experience negative physical and psychosocial health outcomes due to diagnosis and treatment side effects including urinary or bowel incontinence and sexual dysfunction. These issues place stress on social relations, and knowledge of these potential future problems may influence patients' decisions about treatment or information seeking (Harvey & Alston, 2011; Imm et al., 2017; Pearce et al., 2015; Rivas et al., 2016). AA patients, who report more symptoms of urinary or sexual dysfunction than Whites do (Puri, Gbadebo-Goyea, Barker, & Bailey, 2009), may be more vulnerable to emotional distress following treatment (Imm et al., 2017; Jenkins et al., 2004).

Given that PrCA is generally slow growing and patients are presented with various treatment options that are often associated with negative health outcomes, PrCA patients and survivors need clear, easy-to-understand information about the disease, treatment options, potential side effects of treatment, and the physical, psychosocial, and psychosexual implications of treatment. Previous studies have reported that PrCA patient materials are often written above high-school level (Colaco, Svider, Agarwal, Eloy, & Jackson, 2013; Ellimoottil, Polcari, Kadlec, & Gupta, 2012); thus patients may not be able to understand the information. PrCA patients with low satisfaction levels regarding their understanding of treatment side effects reported significantly higher levels of treatment regret with the unexpected impact of side effects (Morris et al., 2015). Patient materials need to be accessible (e.g., written at a 7th–8th grade level), provided in a variety of formats, use nontechnical terms and graphics, and be amenable to being reviewed with the assistance of one's spouse and/or support personnel to improve comprehension (Morris et al., 2015; National Library of Medicine, 2017).

Recent studies have examined the readability of PrCA/urological cancer online information (Colaco et al., 2013; Ellimoottil et al., 2012); however, previous studies did not focus on the content or cultural appropriateness. In addition, the most recent study evaluating content, readability, and cultural appropriateness of printed PrCA materials was conducted in 2004 (Weintraub, Maliski, Fink, Choe, & Litwin, 2004). The purpose of this study was to determine the current resources that are being provided to patients that address PrCA and treatment side effects.

Methods

Material Collection

General and specialty practices that may provide PrCA educational information to patients, including urology,

oncology, internal medicine, family medicine, community health centers, and preventive medicine located in three cities in a southeastern U.S. state were selected. An invitation letter explaining the purpose of the study was mailed to practice managers 2 weeks prior to visiting the practices. Two members of the research team visited 31 practices during March and April 2017 to collect materials related to PrCA and sexual dysfunction. All materials (including magazines, flyers, brochures [1–4 pages], pamphlets [5+ pages], hard copy newsletters, and printed website articles), in the reception, front desk, and waiting areas of practices were collected and manually searched for relevant content. If the material had PrCA and/or related side effects content, then the material was collected or relevant pages were photographed upon the practice's permission.

Three practices (2 oncology and 1 internal medicine) refused material collection and 12 practices (1 urology, 2 family medicine, 6 internal medicine, 3 primary care) did not have any relevant materials. From the 16 remaining practices (8 urology, 2 oncology, 5 internal medicine, 1 library located within a cancer center), a total of 78 materials was collected. Fourteen materials were located in multiple practices. After excluding 5 materials that had only contact information for related organizations/websites, 16 advertisements, and 13 duplicates, 44 materials were included in the final sample. Study protocols were reviewed and approved by the institutional review board at the University of South Carolina.

Coding

One article from each of the collected materials was coded. If there were multiple articles related to PrCA and/or related side effects within a single material, then a featured article on the cover was selected for coding, assuming that featured articles have content that the publisher wants to highlight or focus readers on. If there was not a featured article, then we randomly selected one article for coding.

A codebook was developed based on previous content analysis studies (Friedman et al., 2014; Friedman, Laditka, Laditka, & Mathews, 2010). The first author tested the codebook with five randomly selected materials and revised as needed. Variables coded included general characteristics, intended audience, graphics, persons quoted, format, content, and cultural sensitivity. Material characteristics included type of material (pamphlet, flyer, etc.), year of publication, distributor, and mobilizing information (e.g., contact for more information). For the intended audience variable, whether the material was for a specific race, sex, persons with a certain condition (e.g., PrCA patient), or specific role (e.g., health-care provider) was examined. Whether the material contained any

graphics including photos and illustrations was examined. If the material had a graphical component, then content of the graphics featured and the tone (e.g., positive: people are smiling, active; negative: frowning face; neutral: medicine bottles) were examined. When role and race of people featured in the graphic were examined, males who were not health-care providers in the graphic were considered as patients. Persons quoted in the text were coded based on the person's condition/role (e.g., PrCA survivor, current patient, health-care provider). Format of the text was categorized into explanatory (informational or educational information), anecdotal (personal stories), promotional (stories including commercial elements), news, and event driven (e.g., charity walk, donation).

Cultural sensitivity was assessed using the Cultural Sensitivity Assessment Tool (CSAT), which was originally developed to assess cultural sensitivity of printed cancer materials for AAs (Guidry & Walker, 1999), and has since been used to evaluate cancer educational materials for diverse racial/ethnic groups (Friedman & Hoffman-Goetz, 2006a; Friedman & Kao, 2008; Thomson & Hoffman-Goetz, 2007; Tofthagen et al., 2014). Three categories of CSAT—format (3 items), written message (11 items), and visual message (16 items)—were assessed using a 4-point Likert scale (4 = *strongly agree*; 3 = *agree*; 2 = *disagree*; 1 = *strongly disagree*). The mean score of each category was calculated. The overall CSAT score was calculated as a mean score of the three categories. Higher scores (>2.5) indicate the information is more culturally acceptable.

To assess the readability of materials, Flesch Reading Ease (FRE; Flesch, 1948), Flesch-Kincaid Grade Level (Kincaid, Fishburn, Rogers, & Chissom, 1975), and the Simple Measure of Gobbledygook (SMOG; Friedman & Hoffman-Goetz, 2006b; Mc Laughlin, 1969) were used. All readability measures were calculated based on the number of words per sentence and the number of syllables per word. While higher scores of FRE indicate the information is easier to read, higher Flesch-Kincaid Grade Levels and SMOG indicate more difficult readability. Excluding unrelated text (e.g., heading, disclaimer, author information, hyperlinks, copyright) and incomplete sentences, up to 30 sentences were selected from each material for the readability assessment as per SMOG guidelines (Mc Laughlin, 1969). If materials had more than 30 sentences, 10 sentences each from the first, middle, and the last sections of the materials were selected (Mc Laughlin, 1969). Microsoft Word 2016 was used to assess FRE and Flesch-Kincaid Grade Level and an online readability calculator (<https://www.webpagefx.com/tools/read-able/>) was used to calculate SMOG.

Two research team members—a cancer researcher and a public health major undergraduate student—independently

coded the same seven materials (15.9%) and interrater reliability was calculated. Cohen's Kappa (Cohen, 1960) was calculated for categorical variables, and intraclass correlation (ICC) was calculated for each CSAT subcategory. Most variables had 100% agreement between the two coders; Kappa scores ranged from 0.59 to 1.00. ICC values of CSAT scores ranged from 0.73 to 0.84. Discrepancies between the two coders were discussed and then they each independently coded half of the remaining materials. For readability assessment, one coder recorded FRE and Flesch-Kincaid Grade Level and another coder recorded SMOG.

Analysis

Descriptive statistics were used to present frequencies and percentages of material characteristics, intended audience, graphical content, persons quoted in the text, format, content, and mean and standard deviation (*SD*) of CSAT scores and readability. χ^2 tests, Fisher's exact tests, and one-way analysis of variance were used to compare characteristics, CSAT scores, and readability of materials by characteristics of the material or practice as needed. All analyses were conducted using SAS 9.4 with statistical significance set at $p < .05$.

Results

Characteristics of Educational Materials

Among the 44 materials collected, magazines were the most common ($n = 20$, 45.5%), followed by pamphlets ($n = 15$, 34.1%), flyers ($n = 3$, 6.8%), brochures ($n = 3$, 6.8%), printed web page articles ($n = 2$, 4.5%), and hard copy newsletters ($n = 1$, 2.3%; Table 1). About half of the materials ($n = 23$, 52.3%) were published within 2 years of data collection. The rest of the materials were published between 2003 and 2015 ($n = 18$, 40.9%) or did not indicate the published year ($n = 3$, 6.8%).

Most materials ($n = 42$, 95.5%) listed a distributor. Health-related publishers (e.g., Men's Health, WebMD) distributed the plurality of the educational materials reviewed ($n = 11$, 25.0%), followed by pharmaceutical companies ($n = 9$, 20.5%), organizations/associations related to cancer research (e.g., American Association for Cancer Research; $n = 7$, 15.9%), nonprofit organizations (e.g., American Cancer Society [ACS]; $n = 5$, 11.4%), government organizations (e.g., National Cancer Institute; $n = 2$, 4.5%), and patient educational material developers ($n = 2$, 4.5%). Two materials ($n = 2$, 4.5%) did not contain distributor information. About half of the materials had an organizational logo on the material ($n = 24$, 54.5%). Websites ($n = 26$, 59.1%) were most often provided as contact information, followed by the name of a contact person/organization ($n = 20$, 45.5%) and phone number ($n = 16$,

Table 1. Characteristics of Educational Materials Related to Prostate Cancer and Sexual Dysfunction ($n = 44$).

	Frequency	%
Material type		
Magazine	20	45.5
Pamphlet/guide (5+ pages)	15	34.1
Flyer	3	6.8
Brochure (1–4 pages)	3	6.8
Printed web page article	2	4.5
Hard copy newsletter	1	2.3
Distributor		
Health-related publisher	11	25.0
Pharmaceutical company	9	20.5
Organization/association related to cancer research	7	15.9
Nonprofit organization	5	11.4
Government organization	2	4.5
Company developing patient education materials	2	4.5
Hospital/clinic	1	2.3
Health-care provider association	1	2.3
Other	4	9.1
Not listed	2	4.5
Mobilizing information		
Website	26	59.1
Name of contact person/organization	20	45.5
Phone	16	36.4
Physical address	6	13.6
E-mail address	1	2.3
Social media	0	0.0
Intended audience—race		
Applicable to all race or not specified	42	95.5
African American	2	4.5
Intended audience—sex		
Male	34	77.3
Both male and female	10	22.7
Intended audience—condition/job		
Prostate cancer patient	24	54.5
All men	23	52.3
Men having prostate-related condition	16	36.4
Men with family history of prostate cancer	12	27.3
Prostate cancer survivor	8	18.2
Men having sexual dysfunction	7	15.9
Urologist	2	4.5
Other health-care provider	2	4.5
Caregiver/family member	2	4.5
Graphical content		
Photo	41	93.2
Illustration (e.g., animated figure)	34	77.3
Data chart/table	21	47.7
	4	9.1

(continued)

Table 1. (continued)

	Frequency	%
Patients' race in the photo/illustration		
Non-Hispanic White	25	75.8
Non-Hispanic African American	21	63.6
Hispanic	3	9.1
Asian	5	15.1
Health-care providers' race in the photo/illustration		
Non-Hispanic White	8	61.5
Non-Hispanic African American	5	38.5
Hispanic	3	23.1
Unknown (only back is shown)	1	7.7
Caregivers' race in the photo/illustration		
Non-Hispanic White	15	62.5
Non-Hispanic African American	13	54.2
Hispanic	3	12.5
Asian	2	8.3
Tone of photo/illustration		
Positive (people are smiling, active, etc.)	31	75.6
Negative (frowning face, fatigued)	3	7.3
Neutral (medicine bottles, etc.)	23	56.1
Format		
Explanatory (informational or educational information)	39	88.6
Anecdotal (personal story related to prostate health/cancer)	9	20.5
Promotional (story that includes a commercial element)	5	11.4
News (e.g., new research results, new diagnosis tool)	2	4.5
Event driven (e.g., charity run/walk)	1	2.3
Material encourages men talking to health-care providers	29	65.9

36.4%). Only one material ($n = 1$, 2.3%) listed an e-mail address, and none of the materials listed social media.

Most materials were applicable to all races or did not have a specific race as their intended audience ($n = 42$, 95.5%). Only two materials (4.5%) specifically mentioned that the content was for AAs. About 77.3% of materials ($n = 34$) were exclusively for males, while 22.7% of the materials ($n = 10$) were for both males and females. Most materials targeted PrCA patients in general ($n = 24$, 54.5%), followed by men with prostate-related conditions ($n = 16$, 36.4%), men with a family history of PrCA ($n = 12$, 27.3%), PrCA survivors ($n = 8$, 18.2%), and men with sexual dysfunction ($n = 7$, 15.9%). Materials for urologists, other health-care providers, or caregiver/family members of PrCA patients were less common ($n = 2$, 4.5% each).

Most materials ($n = 41$, 93.2%) had graphics. Photographs were most commonly used ($n = 34$, 77.3%) and about half of the materials had illustrations ($n = 21$, 47.7%). Only four materials (9.1%) had data charts or tables. Of materials with graphics ($n = 41$), patients appeared in the graphic most with their family, friend, or caregiver ($n = 24$, 58.5%), alone ($n = 16$, 39.0%), or with a health-care provider (22.0%). Active lifestyles ($n = 9$, 22.0%) and healthy diets ($n = 3$, 7.3%) also were presented. Some materials included graphics that could help audiences understand the materials such as an image of the prostate ($n = 8$, 19.5%), a medical procedure ($n = 7$, 17.1%), other body parts ($n = 3$, 7.3%), or cancer staging ($n = 2$, 4.9%). Among the 33 materials with images of patients, 75.8% of the materials ($n = 25$) featured non-Hispanic White patients, 63.6% ($n = 21$) had non-Hispanic AAs, 15.1% ($n = 5$) had Asians, and 9.1% ($n = 3$) portrayed Hispanics. Among the 13 materials with a graphic of health-care providers, 61.5% of them ($n = 8$) showed non-Hispanic White providers, 38.5% ($n = 5$) showed non-Hispanic AAs, and 23.1% ($n = 3$) showed Hispanics. Among the 24 materials with a graphic of caregivers, non-Hispanic Whites were featured on the materials most often ($n = 15$, 62.5%), followed by non-Hispanic AAs ($n = 13$, 54.2%), Hispanics ($n = 3$, 12.5%), and Asians ($n = 2$, 8.3%). The two materials specifically for AA men had graphics of AAs. Most graphics had a positive ($n = 31$, 75.6%) or neutral ($n = 23$, 56.1%) tone. Only a few graphics had a negative tone ($n = 3$, 7.3%). Half of the materials ($n = 22$, 50.0%) reviewed had quotes. Among the materials with quotes, PrCA survivor ($n = 10$, 45.5%) and physician ($n = 9$, 40.9%) quotes were the most commonly presented. Five materials (22.7%) had quotes from celebrities who were PrCA survivors and one material (4.5%) each had quotes from a current patient or supporter of a PrCA-related organization. The format of the materials was mostly explanatory ($n = 39$, 88.6%). About 20.5% of the materials ($n = 9$) were anecdotal, while few materials were promotional ($n = 5$, 11.4%), news related ($n = 2$, 4.5%), or event driven ($n = 1$, 2.3%).

Content

The most frequently presented content was how to work with health-care providers (e.g., list of questions to ask providers; $n = 23$, 52.3%), followed by side effects of treatment options ($n = 18$, 40.9%), sexual dysfunction due to PrCA and its treatment ($n = 17$, 38.6%), PrCA treatment options ($n = 15$, 34.1%), PrCA screening ($n = 14$, 31.8%), PrCA diagnosis ($n = 14$, 31.8%), and solutions for side effects of PrCA treatment ($n = 13$, 29.5%). While PrCA treatment options and side effects were frequently

presented, few materials included the duration of side effects ($n = 6$, 13.6%) and benefits of treatment options ($n = 4$, 9.1%). PrCA prevention ($n = 8$, 18.2%) and symptoms ($n = 5$, 11.4%) were presented less often than treatment options, screening, and diagnosis. About two thirds of materials ($n = 29$, 65.9%) encouraged men to talk to their health-care providers about prostate health and PrCA. Material content did not significantly differ by type of practice, except regarding side effects of PrCA treatment options. About 48.7% of materials in urology practices ($n = 18$) covered side effects of PrCA treatment options, while none of the materials from other practices included side effect content ($p = .008$; Fisher's exact test).

Cultural Sensitivity and Readability

The overall mean CSAT score was 3.4 (SD : 0.3). CSAT score for format was the highest (3.9 ± 0.4), followed by written message (3.3 ± 0.4) and visual message (3.1 ± 0.6). The five materials with the highest overall cultural sensitivity included two materials distributed by a pharmaceutical company and the ACS each, and one material distributed by a health-care provider association. When the total CSAT or each category score over 2.5 was considered acceptable, one material (2.3%) distributed by a pharmaceutical company did not have acceptable cultural sensitivity for format. Seven materials (15.9%)—three by a health-related publisher, two by an organization/association related to cancer research, and one each by a pharmaceutical company and other distributor—did not have acceptable cultural sensitivity for visual message.

Readability of the materials varied. The mean FRE was 55.9 (range: 14.5–82.1), a score considered “fairly difficult to read.” The mean Flesch-Kincaid grade level was 9.6 (range: 4.6–21.4) and SMOG grade level was 8.5 (range: 4.2–16.3). Based on the FRE, Flesch-Kincaid grade level, and SMOG grade level, five materials written at the easiest reading levels included two materials distributed by a governmental organization and one material each distributed by a company developing patient educational materials, the ACS, and a pharmaceutical company. The five most technical materials written at high reading levels included three materials distributed by an organization/association related to cancer research and one each from a health-related publisher and health-care provider association.

Discussion

PrCA patients, caregivers, and men who are at elevated risk of PrCA need accessible information from medical practices they visit. The majority of materials reviewed in this study had acceptable cultural sensitivity; however,

some materials may be too difficult to understand or are not relevant to the unique concerns of AA men who are at the highest risk for PrCA.

As advances are made in PrCA research, guidelines for PrCA screening and treatment recommendations have changed, making the timeliness of educational information imperative. Promisingly, half of the materials collected were produced within the past 2 years. A large portion of materials, however, was outdated and had old contact information. This finding suggests that providers are not actively selecting material. Practices may have limited knowledge about the availability of best practice educational materials for patients. This has negative implications for patients with low levels of literacy or low information-seeking behavior. These patients may not further investigate or compare the information that they encounter in a physician's office, trusting that it is relevant and static.

More than half of the materials collected contained content focused on improving patient-provider communication. This type of information is necessary for preparing patients to both engage effectively with their provider and become active participants in their own health care. Better relationships between patient and provider could lead to improved health-related quality of life (Li, Matthews, Dossaji, & Fullam, 2017), as patients may be able to gain a better understanding of their treatment options and relevant side effects. Side effects for PrCA treatment options and treatment-related sexual dysfunction were also frequently presented. Both PrCA treatment decision-making and treatment regret are influenced heavily by the side effects of treatment, especially sexual function (Mahal et al., 2015).

While all practices need to ensure that patients have enough information to make an informed decision, among the practices sampled, content on the side effects of PrCA treatment was only available at urology practices. Patients who visit other practices also may need information on side effects to make a more informed treatment decision. In addition, there is a need for educational materials targeted at spouses or partners to improve their involvement in decision-making, level of "preparedness," and adjustment needs to potential changes in their relationships and roles. There were only a few materials that targeted caregivers/family members. Diverse content should be made available at each practice so that patients and their caregivers have a comprehensive understanding of the various dimensions of treatment and outcomes.

Cultural sensitivity of most materials reviewed was considered acceptable, and the CSAT scores were higher than previously reported for cancer-related materials (Friedman & Hoffman-Goetz, 2006a; Friedman & Kao, 2008; Guidry, Fagan, & Walker, 1998). While graphics in the materials were fairly representative of AAs, there was

less AA than White representation. Racially sensitive visual information may be an important factor in determining whether a source will be utilized or trusted by the target audiences. Given that AA men are at higher risk for PrCA, comprehensive and tailored education materials for this population may encourage better treatment outcomes.

Most materials reviewed were written in technical language at a high reading grade level. The readability level of materials in this study was easier than reported for printed or web-based cancer- or urology-related materials in some previous studies (Colaco et al., 2013; Ellimootil et al., 2012; Friedman & Kao, 2008; Guidry et al., 1998). However, it was more difficult than reported readability of online PrCA information in a recent study (Borgmann et al., 2017). Given that literacy impacts a patient's ability to understand and utilize health information, educational materials need to be written in plain language to accommodate all levels of literacy (Friedman & Hoffman-Goetz, 2006b). Most materials collected included graphical content, which was explanatory or assistive in nature. Graphical content could improve patient understanding of the material regardless of literacy. Due to the complexity and heterogeneity of PrCA, graphics that show relationships between staging, treatment options, side effects, and survival rates may be valuable as decision aids for patients considering treatment options.

This study had limitations. Materials were collected from a relatively small number of practices located in one Southeastern state. Materials located in other types of practices in other parts of the country may have different information. Most materials in this study, however, were distributed by national organizations such as national publishers or federal government organizations, which may also be available in other states and practices. Further studies assessing materials from a larger sample of practices would be beneficial to understand the scope of information provided to patients. Some of the articles reviewed might have been published for marketing purposes rather than for providing educational information about PrCA. This study did not gather information on how patients used the materials available in the practices or examine who accessed the materials and whether the materials were intentionally selected by each practice. Future research should poll patients regarding the use, preferences, and needs of PrCA information they receive in medical settings.

PrCA patients and their caregivers need information before, upon, and after diagnosis, but they may not have the ability to seek and/or understand relevant information. Materials reviewed in this study had better readability and cultural sensitivity compared to those in previous studies; however, there is still room for improvement. Given recent changes in PrCA screening guidelines,

various PrCA treatment options, and the unique physical and psychological impacts of PrCA, providing comprehensive PrCA information to patients and caregivers and improving patient-provider communication about PrCA are imperative. Health-care providers should be aware of the information that is being displayed in their practices. The information should be the most current, accurate, and relevant to patients' situations. Providers also need to be willing to discuss educational information with patients to ensure that patients understand the information. A wide range of educational materials that address various aspects of PrCA, including treatment options, side effects, and solutions to side effects, should be presented in culturally sensitive and easily understandable ways to reduce treatment regret and promote a higher quality of life through survivorship.

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