

Using a web-based decision support intervention to facilitate patient-physician communication at prostate cancer treatment discussions

by B. Joyce Davison, Michael Szafron, Carl Gutwin, and Kishore Visvanathan

Abstract

Purpose: To measure the preferences and values of men newly diagnosed with prostate cancer (PC) using a web-based decision support technology—the Decision Support Intervention-Prostate Cancer (DSI-PC).

Methods: Health information seeking behaviour, factors having an influence on the treatment decision, decision control, and preferred treatment were recorded by the DSI-PC program prior to the treatment consultation. A summary page of responses was provided to each patient to use at treatment discussions. Measures of decision control and decision conflict were measured prior to the treatment discussion, and following a treatment decision. Patient satisfaction was measured after a treatment decision had been made.

Results: Forty-nine men completed the DSI-PC program prior to their treatment discussion. Sixty-one per cent shared the summary sheet with their physician/s when discussing treatment options. The majority (63%) of patients wanted access to in-depth or detailed information. Impact of treatment on survival, urinary function, bowel function, and physician's treatment recommendation were the four factors having the most influence on patients' treatment decisions. Patients reported high levels of satisfaction with their treatment decision, and involvement in treatment decision making (TDM). Levels of decision conflict were significantly lower ($p < 0.001$) after a treatment decision was made, and men reported assuming a significantly more active role in TDM than originally preferred ($p = 0.038$).

Conclusions: Results suggest that the DSI-PC intervention may be a useful tool to help patients identify and communicate their values and preferences to physicians at the time of treatment discussions.

Key words: prostate cancer, patient-physician communication, decision support intervention

Introduction

Prostate cancer (PC) remains the most commonly diagnosed non-skin malignancy and third most common cause of male cancer-related deaths in North America (American Cancer Society, 2013; Canadian Cancer Society, 2014). Several treatment options are currently available for PC, but there is a lack of evidence available to guide patient's and clinician's decision making regarding the optimal treatment. Patients continue to make their treatment choices based on the impact of potential side effects on their quality of life (Gwede et al., 2005; Holmboe & Concato, 2000) and cancer control (Gwede et al., 2005; Hall, Boyd, Lippert, & Theodorescu, 2003). The complexity of choosing a treatment option often contributes to patients experiencing conflict over which treatment is right for them (Berry et al., 2011; Davison, Goldenberg, Wiens, & Gleave, 2007).

The majority of men newly diagnosed with PC want to be informed (Davison & Breckon, 2012a; Davison, Degner, & Morgan, 1995; Davison et al., 2002; Wong et al., 2000) and involved in medical decision making (Davison & Breckon, 2012a, Davison & Breckon 2012b; Davison & Degner, 1997; Feldman-Stewart et al., 1998). Unfortunately, the majority of health care professionals do not assess how patients wish to participate in treatment decision making (TDM) (Stalmeier et al., 2007), or the type and amount of information they wish to access (Auvinen et al., 2004; Feldman-Stewart et al., 1998; Lambert, Loisel, & Macdonald, 2009a; Lambert, Loisel, & Macdonald, 2009b; Snow et al., 2007). Physicians continue to provide information using a standard approach developed through years of clinical practice, even though several studies suggest an individualized approach is optimal (Davison et al., 1995; Davison & Degner, 1997; Davison et al., 2002). The standardized approach used in the majority of consultations misses the goal of providing patient-centred care, and time is often spent offering information that is not consistent with what the patient wants at that particular time. In addition, PC patients often consider their personal characteristics and preferences as more influential than any medical factor when choosing a treatment (Berry et al., 2003; Davison et al., 2002; Diefenbach et al., 2002; Feldman-Stewart, Brundage, Nickel, & MacKillop, 2001; Patel, Mirsadraee, & Emberton, 2003; Steginga, Occhipinti, Gardiner, Yaxley, & Heathcote, 2002).

Currently, treatment discussions are supposed to be patient-centred or based on the information needs and preferences of the patient. However, PC patients continue to have unmet information needs and are not satisfied with their ability to communicate what is important to them during treatment discussions (Cegala et al., 2008). Since helping patients to identify what is important to them has been shown to be positively associated with the extent of satisfaction experienced with treatment decisions (Glass et al., 2012), there is a need to develop strategies that physicians can use to ensure the provision of information and treatment selections are consistent with patients' preferences and values (Müller-Engelmann, Keller, Donner-Banzhoff, & Kronen, 2011; Hoffman, 2012).

This study was conducted to assess the utility of using the web-based Decision Support Intervention-Prostate Cancer (DSI-PC) to assist PC patients to communicate their values and preferences to physicians at the time of the treatment consultation.

About the authors



B. Joyce Davison, PhD, RN, College of Nursing, University of Saskatchewan, Saskatoon, Saskatchewan

Michael Szafron, PhD, School of Public Health, University of Saskatchewan, Saskatoon, Saskatchewan

Carl Gutwin, PhD, Department of Computer Sciences, University of Saskatchewan, Saskatoon, Saskatchewan

Kishore Visvanathan, MD, FRCSC, FACS, College of Medicine, Division of Urology, University of Saskatchewan, Saskatoon, Saskatchewan

Address for correspondence: B. Joyce Davison (Corresponding author), Room 4222- 104 Clinic Place, University of Saskatchewan, Saskatoon, SK S7N 2Z4

Telephone: 306-966-8379; Fax: 306-966-6621; E-mail: joyce.davison@usask.ca

Methods

Design and patient sample

This one-arm quasi-experimental study was approved by the local ethics committees before data collection. Between February 2012 and March 2013, all men newly diagnosed with localized prostate cancer (PC) at one urology outpatient clinic in Western Canada were invited to use the DSI-PC web-based decision support technology prior to their initial treatment discussion with their urologist. Exclusion criteria included the inability to speak and read English.

Procedure

The nurse educator at the clinic provided all newly diagnosed PC patients meeting the study criteria with a letter of invitation to participate in this study, after she had provided them with an education session on available treatment options for localized prostate cancer. Names of interested patients were provided to the study coordinator. Patients were contacted by the study coordinator within one week of referral. Patients who agreed to be in the study were provided with a password and user name to access the DSI-PC program from their home. Patients who did not have access to a computer were able to access a computer at the education centre. Patients used the DSI-PC program to produce a summary page (see Appendix A) that was used to identify: their personal preferences regarding the degree to which they wanted to participate in TDM with their physician (decision control); the type and amount of information they wished to access (educational resources and health information seeking behaviour); the factors influencing their decision; and their preliminary treatment choice. The program instructed patients to share a copy of the summary page with their physician at the time of their treatment consultation. The physicians (urologists and radiation oncologists) were instructed on how to incorporate the information from the summary sheet into their discussions.

The study coordinator contacted the study participants again at approximately two months (after a treatment decision had been made). Patients used the DSI-PC program to complete measures of decision control, decision conflict, patient satisfaction, chosen treatment, and type of health care professional with whom the summary sheet was shared. Patients were contacted up to two times to complete the measures at each time point.

Description of DSI-PC program. The three-part DSI-PC program was based on a paper survey that was administered to 150 newly diagnosed PC patients (Davison & Breckon, 2012a). *Part one* measured health information-seeking behaviour using the five patterns recently used by Davison et al. (Davison & Breckon, 2012a) with PC patients at the time of diagnosis: 1. intense—in-depth or detailed information; 2. complementary—general information; 3. fortuitous—getting information mainly from others with PC; 4. minimal—limited interest in receiving information; and 5. guarded—avoidance of information. Patients selected the description of the pattern that best described the amount of information they wished to access when making a treatment decision. The choices were presented in random order to eliminate any bias associated with a fixed order presentation. Patients then selected the types of information resources they wanted to access (for example, decision aid, journal articles, internet sites, brochures, etc.). *Part two* asked patients to identify the role they would like to play in medical decision making, and their preferred treatment choice.

Part three asked patients to rate the importance of nine factors having an influence on their treatment choice. The nine categories included: impact of treatment on survival; impact of treatment on urinary function; impact of treatment on sexual function; impact of treatment on bowel function; impact of treatment on work and leisure activities; the invasiveness of treatment options; the impact of a friend's or acquaintance's experience with a specific treatment; the doctor's treatment recommendation; and a spouse or family member's opinion. The nine items were arranged in subsets of two using

Ross's matrix of optimal ordering (Ross, 1974) to provide 36 pairs. Patients were asked to select out of each pair the statement corresponding to the factor having the most influence on their treatment decision at that time. Ross's method ensures that the maximum spacing between the maximum numbers of items is obtained to avoid selection bias. This methodology was chosen to eliminate the "ceiling effect" that is often associated with the use of Likert scales.

Instruments

Four outcome measures were used to evaluate the utility of the intervention, and were completed, as part of the DSI-PC program. The first outcome consisted of three statements used to measure the degree of decision control men wished to have in making a treatment choice with their physician (Henrikson, Davison, & Berry, 2011). The three statements included: 1. I prefer to make the final treatment choice after seriously considering my doctor's opinion about which treatment would be best for me (active); 2. I prefer that my doctor and I make the decision together (collaborative or shared); and 3. I prefer that my doctor decides what would be the best treatment for me after s/he seriously considers my opinion (passive). Following the treatment decision, these same three statements were presented in the past tense. The three statements were randomized at both measurement times.

O'Connor's 10-item low-literacy version of the *decision conflict* scale was used to measure levels of decision conflict patients experience before and after a treatment decision is made (O'Connor, 1995). The items correspond to the original longer version and measure the following factors: uncertainty and the factors contributing to uncertainty; feeling uninformed; feeling unclear about values; and feeling unsupported in decision making. Internal consistency values for this scale as measured by Cronbach's alpha pre-test 0.85; post-test 0.75 have previously been reported by Davison et al. (2007) with newly diagnosed PC patients. Statements were presented to patients in the past tense following the treatment decision.

A five-item questionnaire with a five-point Likert scale (1 = Strongly Disagree to 5 = Strongly Agree) was used to measure satisfaction with the amount, type, and way information was received to make a treatment decision; one's involvement in decision making with the physician; and an individual's treatment choice. Higher scores on this scale indicate higher levels of satisfaction. Internal consistency values of this scale as measured by Cronbach's alpha (0.89) had previously been reported by Davison et al. (2007) with newly diagnosed PC patients.

A 10-item questionnaire with a five-point Likert Scale (1 = Not at all to 5 = A great deal) was used to evaluate the decision processes relating to patients' preparedness for decision making and discussions with their doctor at the time of the treatment consultation based on their use of the summary page (O'Connor et al., 2000). Using newly diagnosed PC patients, Davison et al. (Davison et al., 2007) previously estimated the internal consistency of this scale was 0.93 using Cronbach's alpha.

Demographic information on age, education, marital status, and ethnicity were also collected online. Patient disease characteristics (prostate specific antigen, clinical stage and Gleason score) were obtained from patients' clinical records.

Statistical analysis

All anonymous coded data from the DSI-PC program was stored on a secured mainframe. The Statistical Analysis System (SAS) version 9.3 was used to perform all statistical analyses. Descriptive statistics (frequency tables, means and standard deviations) were used in the analyses of demographic data. The decision conflict and satisfaction with preparation in decision-making scales were analyzed as per authors' instructions. Student t-tests were used to compare levels of decision conflict between measurement times. Kruskal Wallis Analysis of Variance was used to compare the total satisfaction

levels of patients. A Chi Square test was used to compare levels of decision control pre- and post-treatment decision. The Likert scales of the satisfaction questionnaires were analyzed assuming an interval level of data. A 0.05 critical P-value was used to determine statistical significance for all analyses.

Kendall's Zeta Coefficient of Agreement was calculated for each patient as a measure of the internal consistency of the patient's responses. This analysis indicated that the responses for each patient were consistent. Hence, all the patients' responses were used to determine the importance of the nine factors in treatment decision making. The Thurstone Case III modelling technique was used to study how different patient personal and disease attributes were affected by the factors influencing TDM (Mackay & Chaib, 1982). A Thurstone score greater than zero indicates more than 50% of the patients identified the factor as having an influence in their decision making whereas, a score less than zero indicated that more than 50% of the patients identified the factor as not having an influence on their decision making. Gulliksen's and Tukey's index of scalability R-squared was used to measure how well the model fit (variability in the patient's individual responses) using Thurstone's Case III technique. Mosteller's test for a significance difference between the expected and observed proportions was then used to determine the statistical significance of the model fit (Mosteller, 1951).

The internal consistency values of the decision conflict and satisfaction measurements as measured by Cronbach alpha were as follows: 1) decision conflict (pre-test 0.89; post-test 0.85); 2) five-item satisfaction measure (0.90); and 3) 10-item satisfaction measure (0.96).

Results

Fifty-three patients were referred to the study coordinator by the nurse educator, and 49 agreed to participate in this study. A total of 46 patients completed measures prior to the treatment consultation and again after a treatment decision had been made. It took approximately 20 minutes for patients to complete the DSI-PC program prior to the treatment discussion (including on-line consent), and approximately six minutes to complete the measures after a treatment decision had been made.

The mean age of patients was 60.5 (SD = 6.7) years. The majority of participants were Caucasian (96%), married (87.8%), rural (57.1%), and had a high school education or less (51%). Brachytherapy was chosen as the definitive treatment by 39% of patients, radical prostatectomy 20%, active surveillance 22%, and external beam radiation 12%. Patient personal and disease specifics are categorized in Table 1.

A total of 30 (61%) patients shared the summary sheet with a physician who was involved in their care. Of these patients, 35% shared the summary sheet with the urologist, 14% with the radiation oncologist and 12% with their family doctor. In addition, 47% of patients reported discussing the summary sheet with the nurse educator.

A significant proportion of patients reported assuming a more active role in treatment decision making than originally preferred ($\chi^2 = 4.33, p = 0.038$). Prior to the treatment consultation, 59.2% of patient had a preference for a collaborative or shared role in medical decision making, and 38.8% had a preference for an active role. One patient had a preference to play a passive role in decision making. After a treatment decision had been made, 63.3% of patients reported playing an active role in treatment decision making, 28.6% a collaborative role, and one a passive role. No differences in preferred or assumed role were found based on age and education level.

The majority (63%) of patients wanted access to in-depth or detailed information followed by those who wanted general information (20%). Eight percent of patients wanted to pick up information about PC "as they went along", and 8% of patients wanted little or no information about PC. Patients who wanted in-depth information wanted access to a higher number of education resources compared to the other categories. Over 50% of patients wished to access the following types of information resources: list of reliable internet

sites (84%), talking with other patients who had had a particular procedure (55%), written brochures (53%), and access to group education sessions (53%).

Patients reported that the impact of treatment on survival, urinary function, bowel function; and physician's treatment recommendation were the four factors having the most influence on their treatment decisions. These four priorities were the same based on age (<60 versus >61years), level of education (< high school versus >high school), marital status (single versus partnered), preferred role in decision making, and health information seeking behaviour (how much information they wanted) category.

Total levels of decision conflict and the four subscores (uncertainty, informed, values clarity, and support) were all significantly lower ($p < 0.001$) following the treatment decision, compared to the pre-treatment medical consultation (Table 2).

Variable	N (%)
Age (yr):	
≤60	25 (51.0)
61-70	23 (46.9)
>70	1 (2.1)
Educational attainment:	
≤ HS	25 (51.0)
Trade/community	15 (30.6)
College/University	9 (18.4)
Marital status:	
Married/cohabitating	43 (87.8)
Single	6 (12.2)
Residence	
Rural	28 (57.1)
Urban	21 (42.9)
Ethnicity:	
Caucasian	47 (96.0)
Black	1 (2.0)
Other	1 (2.0)
PSA:	
<10	39 (79.6)
10-20	10 (20.4)
Gleason Score:	
6	20 (40.8)
7	29 (59.2)
Clinical stage:	
T1C	37 (75.5)
T2A	12 (24.5)

The five-item satisfaction questionnaire (Table 3) showed that the majority of patients were satisfied with the amount and type of information they received and the way they received this information. The mean score of the five items was 4.34 (SD = 0.663). They were also highly satisfied with their involvement in treatment decision making with their physician and their final treatment choice. The scores did not differ significantly according to their preferred role in decision making, age or education.

The total mean score on the 10-item satisfaction questionnaire that measured the usefulness of the DSI-PC intervention summary page was 65.82 (SD = 22.71). Responses to the individual items can be found in Table 4. Patients who showed the summary sheet to their urologist ($\chi^2 = 8.37, p = 0.004$) and the nurse educator ($\chi^2 = 13.01, p = 0.001$) had significantly higher total levels of satisfaction compared to those patients who did not share the summary sheet with a health care professional.

Table 2: Decision conflict scores

	Time 1 ^a X (SD)	Time 2 ^b X (SD)	t-stat	p-value
Total score	21.09 (21.91)	3.91(10.43)	5.375	< 0.001
Subscores:				
Uncertainty	35.87 (34.42)	6.52 (17.82)	5.491	< 0.001
Informed	15.94 (23.82)	3.62 (14.45)	3.284	0.001
Values clarity	15.22 (24.43)	1.63 (8.17)	3.939	< 0.001
Support	20.29 (21.06)	3.99 (12.26)	5.438	< 0.001

^aN= 49, ^bN= 46

Table 3: Satisfaction (N = 45)

Item	Not at all/a little N (%)	Somewhat N (%)	Quite a bit/great deal N (%)
Amount of information provided	1 (2%)	1 (2%)	43 (96%)
Type of information provided	1 (2%)	2 (4%)	42 (93%)
Way information provided	1 (2%)	4 (9%)	40 (89%)
Involvement in decision making with doctor	0 (0%)	4 (9%)	41 (91%)
Treatment choice	1 (2%)	1(2%)	43 (96%)

Table 4: Satisfaction with preparation in treatment decision-making (N=46)

<i>Did the information from the summary page help you to get the information you needed to...</i>	Not at all/a little N (%)	Somewhat N (%)	Quite a bit/a great deal N (%)
Identify your treatment options?	9 (19.6)	13 (28.3)	24 (52.2)
Prepare you to make a better decision?	6 (13.0)	17 (37.0)	23 (50.0)
Help you think about the pros and cons of each treatment option?	3 (6.5)	18 (39.1)	25 (54.3)
Help you think about which pros and cons were most important to you?	4 (8.7)	15 (32.6)	27 (58.7)
Help you know that the decision depended on what mattered most to you?	3 (6.5)	15 (32.6)	28 (60.9)
Help you organize your own thoughts about the decision?	5 (10.9)	12 (26.1)	29 (63.0)
Help you think about how involved you wanted to be in this decision?	5 (10.9)	8 (17.4)	33 (71.7)
Help you identify questions you wanted to ask your doctor?	7 (15.2)	12 (26.1)	27 (58.7)
Prepare you to talk to your doctor about what matters most to you?	4 (8.7)	14 (30.4)	28 (60.9)
Prepare you for a treatment consultation with your doctor?	5 (10.9)	14 (30.4)	27 (58.7)

Discussion

This study highlights the potential of newly diagnosed PC patients using the DSI-PC program to facilitate patient-centred communication at the time of medical treatment discussions. Our results suggest that patients who used this program were highly satisfied with the information they received to make a treatment decision and the degree to which they were involved in TDM.

Our current model of health care supports patient involvement in health care. However, patient education and patient-centred communication is required for this to happen (Epstein & Street, 2007). Martinez et al. (2009) reported patient-clinician engagement helps patients to feel informed, which in turn predicts treatment decision satisfaction. Our results suggest that facilitating patient-physician communication at the time of the medical treatment consultation does result in high levels of patient satisfaction with regards to the type, amount and way information was provided; involvement in TDM with the physician; and treatment choice. Satisfaction with preparation in decision making was also high for items relating to the communication aspects of the consultation. One explanation for this finding may be attributed to the fact that the majority of patients wanted to be informed and actively involved in their treatment decision. A second explanation is that 61% of patients shared the summary page from the DSI-PC program with their physicians at the time of the treatment consultation so that the physicians were aware of the patient's values and preferences.

The impact of treatment on survival, urinary function, bowel function and physician's treatment recommendation were identified as the four factors having the most influence on the overall group's treatment decisions. These four factors were similar to results recently reported by Davison et al. (Davison & Breckon, 2012). Survival (Zeliadt et al., 2006) and the specialist's opinion (Cohen & Britten, 2003) continue to play a significant role in how patients make treatment decisions at the time of diagnosis.

However, variation in these factors does exist among patients so it is therefore helpful to use a program such as the DSI-PC to ensure the values and preferences of individual patients are recognized and incorporated into the medical consultation.

Most patients and physicians report that shared decision making (SDM) is desirable (Floer et al., 2004; Janz et al., 2004). However, there is evidence that SDM might not be appropriate for all patient groups (Joosten et al., 2008; Deber, Kraetschmer, Urowitz, & Sharpe, 2007; Edwards et al., 2005). Twenty-four percent of patients in our study reported assuming a more active role than originally preferred, with the majority (63%) of men reporting they had made the final treatment decision after considering the physician's recommendation. Similarly, Davison and colleagues have demonstrated that using different methodologies to provide information to newly diagnosed PC patients does result in patient's assuming a more active role in TDM than originally intended (Davison et al., 2002; Davison, Goldenberg, Gleave, & Degner, 2003; Davison, Parker, & Goldenberg, 2004; Davison et al., 2007). The DSI-PC program provides clinicians with a simple way to assess how patients wish to participate in treatment decision making.

Decision conflict is defined as personal uncertainty about which course of action to take when each treatment option has significant advantages and disadvantages (such as is the case for PC). The goal of most decision support interventions is to increase the likelihood that treatment choices are based on adequate knowledge as well as realistic expectations of outcomes and personal values, thus reducing decision conflict (O'Connor & Rostom, 1999). Although patients in our study reported having significantly lower levels of decision conflict following the treatment decision, it is unknown if this conflict remains the same following treatment (Clark, Bokhour, Inui, Silliman, & Talcott, 2003; Steginga, Occhipinti, Gardiner, Yaxley, & Heathcote, 2004). Further longitudinal studies are required to determine the impact of improved patient-physician communication on levels of decision conflict following the definitive treatment.

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There were several limitations to this study. The small sample size prohibits any generalizations of results to this patient population. However, we wanted to determine if changes were required to the DSI-PC program before further implementation at other clinical sites. A second limitation is that we were not able to use a randomized control study design in this clinical setting to establish causality. Therefore, the impact of extraneous variables on the study outcomes cannot be determined within the scope of this study. Although the patients and physicians who participated in this study found the DSI-PC program useful, further testing is required to determine the acceptability of this intervention in larger centres with diverse PC patient populations. A multi-site randomized study is therefore required to address these limitations.

Conclusions

In conclusion, this preliminary study suggests that the DSI-PC is an acceptable decision support aid that can be utilized by patients in either a home or clinical setting. The program assists men with localized PC to identify the factors having an influence on their treatment decision and provides a means for these men to share these preferences and values with their physician at the time of treatment discussions. This simple tool also could easily be incorporated into clinical practice to guide treatment discussions provided by oncology nurses to this group of patients. ❏

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Conflicts of interest

The authors have no potential conflicts of interest.

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Last Name

First Name

Appendix A: Summary page

Profiling Prostate Cancer Patients' Preferences to Facilitate Treatment Decision Making

How to Use this Summary Page

Please give a copy of this summary page to your nurse and/or doctor when you discuss treatment options. It will help them to provide you with the information that is important to you as you make a treatment decision.

PATIENT REPORTED

PSA: 5.6 Gleason Score: 4+3 Clinical Stage: Unknown

PATIENT PREFERENCES

How I would like to receive information:

- I am the type of person that is committed to get thorough, in-depth information.

Sources of information I would like to access:

- General brochures on prostate cancer, Internet sites, Prostate Support Group meetings (dates, locations), Education session on treatment decision making, Audio tape of treatment consultation, and Decision aid (a booklet and/or DVD that will provide you with the advantages & disadvantages of each treatment option available to you)

How I want to be involved in making a treatment decision with my doctor:

- I prefer that my doctor and I make the treatment decision together.

Main factors having an influence on my treatment decision:

- Impact of treatment on survival.
- Impact of doctor's treatment recommendation. Impact of treatment on bowel function.
- Impact of treatment on urinary function.

My treatment preference at this time is:

- Prostatectomy (surgery)

At this time, I am sure about this decision:

Yes No