



# Patient preference and the impact of decision-making aids on prostate cancer treatment choices and post-intervention regret

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## ABSTRACT

The number of prostate cancer survivors is rapidly growing in the Western world. As a result of better oncologic outcomes, more patients are living longer with the adverse effects of treatment, which can be both functional and psychological. Clinicians, in an era of shared decision-making, must not only cure the cancer, but also ensure that, after treatment, their patients experience the best quality of life and minimal post-treatment decisional regret. To participate in the decision-making process, men and their involved partners and family need to fully understand the relative benefits and harms of prostate cancer treatments.

Patient preference studies indicate that men with prostate cancer are not well informed. Decision-making aids are a positive treatment adjunct both to convey information and to allow patients to explore their own beliefs and values during the decision-making process. The evidence suggests that decision-making aids better prepare patients for involvement in treatment decisions, but further studies are required to investigate the relationship between the use of decision-making aids and post-treatment decisional regret in prostate cancer.

## KEY WORDS

Prostate cancer, patient preferences, partners, decision-making aids, decisional regret

## 1. INTRODUCTION

Although it is the most common cancer in North American men<sup>1</sup>, prostate cancer is in most cases diagnosed when it is still localized and curable. There are a number of treatment options with comparably good oncologic outcomes, but with particular side-effect profiles. Men treated for prostate cancer embark on a journey with many decision points or “forks in the road” where they must manage uncertainty and ultimately their personal fear of a cancer death.

Today, most men who have localized prostate cancer at diagnosis and who undergo either active surveillance or curative treatment can expect to have a disease-specific survival of at least 10 years<sup>2-4</sup>. Even men with metastatic disease can expect increased survival as new therapeutic agents become available and alternative regimes for existing treatments are tried<sup>5,6</sup>. Those facts, combined with an overall life expectancy predicted to reach 81.9 years by 2031<sup>7</sup>, result in the reality of long exposure to the ramifications of prostate cancer treatments for patients and their families alike.

The traditional oncologic outcomes of margin status, biochemical recurrence, disease-free survival, and overall survival are no longer sufficient measures of treatment success. The adverse effects of treatment, which can be both functional and psychological, must also be considered. The potential impacts of treatment side effects on quality of life for patients and their partners have to be considered in the informed decision-making process<sup>8</sup>. Thus, the quality of information received by patients and their decision-making before treatment, as well as post-treatment regret, must be studied carefully. As such, this previously informal and subjective area of cancer care is now an evolving research field. In the modern era of shared decision-making, the onus is now on specialists not only to cure the cancer, but also to ensure that patients receive the best quality of life after treatment. The present article examines the treatment preferences of prostate cancer patients, the role of decision-making aids (DMAs), and the effect of the use of such aids on post-treatment regret.

## 2. PATIENT PREFERENCES

Today's patients have health-related preferences that go beyond simply being cured of cancer. Understanding those preferences is essential if caregivers are to provide holistic quality of life after treatment. Knowing a patient's particular preferences provides insight into how that patient will approach making treatment

decisions after a localized prostate cancer diagnosis. Those preferences are particularly cogent in situations in which several choices of optimal therapy are available. Eliciting preferences and translating them into cancer care is, however, challenging.

The first challenge has to do with basic patient education. Randomized and observational studies investigating patient perceptions of prostate cancer have identified that patients are not well informed about the natural history of prostate cancer, the predictive value of the prostate-specific antigen (PSA) blood test, the controversies about PSA screening, and the benefits and risks of treatment at all stages<sup>9–12</sup>. Men who do not receive education about the PSA test and its possible sequelae are disturbingly more likely to elect active treatment over observation if prostate cancer is detected by a screening PSA test<sup>9</sup>. Furthermore in a survey of men over 50 years of age who had undergone prostate cancer screening, although respondents recalled discussing screening and feeling informed about the rationale, fewer than half could accurately answer one knowledge question about screening<sup>10</sup>. A similar lack of knowledge about treatment side effects has been documented for patients with advanced disease commencing androgen deprivation therapy<sup>13,14</sup>.

Studies on patient perception and knowledge about medical choices are commonly biased toward well-educated, affluent, white populations. Unsurprisingly, prostate cancer knowledge is particularly poor in less privileged minority groups<sup>15,16</sup>. Patient comprehension of cancer terminology and treatment options has historically been demonstrated to be poor<sup>17,18</sup>. Increasing awareness of this situation on the part of health care professionals has led to a proliferation of “patient friendly” flyers, booklets, videos, and Web sites. Unfortunately, the information accessed by patients at many sources has little, if any, quality control and may be neither verified nor accurate. Additionally, patients may misinterpret the information presented<sup>19</sup>, and there is little evidence that the abundance of accessible information has had any positive impact in improving treatment selection or reducing treatment regret.

The reality is that patients repeatedly cite their health care providers as their most important source of information, and they rely on their specialist to inform them about management options<sup>10,20</sup>. Patient preferences for the communication of an initial diagnosis rely on the “honesty and expertise” of their doctors. How the diagnosis is communicated has been rated as less important<sup>21</sup>. However, once aware of their diagnosis, most patients prefer to take an active or collaborative role with their physician in decision-making. The key information preferences identified by patients to bolster their participation in the decision process are prognosis, stage of disease, treatment options, and side effects<sup>22</sup>.

Treatment advice given by urologists and radiation oncologists about options for prostate cancer

therapy tends to be weighted (even biased) toward the specialist’s own realm of expertise<sup>23,24</sup>. During selection of a primary treatment, shared decision-making between physician and patient can be stressful and problematic for the patient because there is little evidence to favour one treatment over another<sup>25</sup>. Ideally, an individual’s choice of treatment should reflect an evaluation of the benefits, harms, costs, and inconveniences compared with the available alternatives. In reality, such decisions are often subjective, and a lack of information may affect the patient’s ability to understand the tradeoffs. Age, the family physician’s opinion, current health, level of sexual function, and personal contact with family or friends diagnosed with prostate cancer all significantly affect a patient’s treatment choice<sup>25–27</sup>.

Patients have preconceptions and, often, unrealistic expectations of treatment outcomes despite receiving information about risks and benefits<sup>19</sup>. Although providing more resources and taking extra time to support and intensively counsel patients may intuitively seem to be appropriate, recent evidence suggests that this approach alone does not eliminate unrealistic expectations<sup>28</sup>. And so, given that the strongest predictor of treatment choice remains the type of physician seen at enrolment<sup>29</sup>, the physician should not necessarily be considered to be the one biasing the treatment; rather, patients may be choosing to see a specialist who favours their preconceptions and expectations.

In the literature, many studies of patient preference report high levels of patient satisfaction with prostate cancer treatment choices<sup>26,30,31</sup>. There are, however, potential sources of bias in those studies. In particular, patients who respond to such surveys are likely to be well-motivated and educated. Respondents are similarly likely to have had a satisfactory response to treatment and thus to respond positively to retrospective questions concerning treatment regret. Patients may speak positively about a treatment outcome when they have nothing to compare it with. The concept of cognitive conflict explains the reality that they do not know what would have happened if they had chosen another treatment. Caregivers must be aware that this uncertainty may result in deferred psychological distress that may manifest some time after treatment.

Patients can be biased toward novel treatments, even when there are no randomized controlled trial data to support the new option. The perception that medicine is advancing and “new must be better” can be difficult to dispel. Robot-assisted laparoscopic prostatectomy is an example of how the high preoperative expectations of patients about a new treatment can lead to dissatisfaction with actual postoperative outcomes<sup>32</sup>.

The information priorities of patients are highly individual, and although most patients wish to participate in their treatment decision, there is wide

variation with respect to needs both between and within countries<sup>33</sup>. The literature is dominated by pre- and post-treatment questionnaire studies. Such studies are easy for patients to comprehend, and they provide an overview of trends. However, they fail to examine the true decision-making “tradeoff process” in choosing a cancer treatment. Objective methods of assessing that decision-making process are available (Table 1 summarizes research methods for determining patient preference), and it is likely that those methods will be increasingly used in future studies.

Patient preference and selection of a treatment does not occur in isolation: partners and other family members play influential roles<sup>35</sup>. Those parties are involved in information gathering and may take active roles in decision-making<sup>19</sup>. The patient’s partner has been demonstrated to be more able than the specialist responsible for the patient’s care to accurately identify the patient’s quality-of-life preferences<sup>36</sup>. It is increasingly recognized that the side effects of treatment burden partners (sometimes more than the patients themselves), particularly side effects relating to urinary and sexual function<sup>37</sup>.

A partner experiences their loved one’s illness vicariously, and thus her or his beliefs are likely to exert a significant influence on the patient’s adjustment after treatment. In certain circumstances the partner may, in fact, be better able (or perhaps more willing) than the patient himself to identify or articulate the

relevant trade-off issues in treatment selection. Patients with spouses who have high treatment control beliefs and who anticipate that the patient will recover quickly from treatment have been shown to report a better quality of life after treatment<sup>38</sup>. That finding affirms the influence not just of the patient’s beliefs, but those of his partner, in the ultimate well-being of the patient. Little research has addressed the issue of decision regret for partners.

### 3. DECISION-MAKING AIDS

Decision-making aids prepare patients to participate in decisions that involve risks and benefits. A good decision will be made with confidence, will be compatible with the patient’s (and, where appropriate, the partner’s) beliefs and values, and will result in minimal regret at the time of the decision and in the future.

Decision-making aids are subtly different from educational tools, nomograms, or risk calculators. Educational tools are preparatory in nature and are used in anticipation of a decision that has already been, or yet to be, made. Clinicians treating patients with prostate cancer may use nomograms or risk calculators in their practice; the Prostate Cancer Prevention Trial Prostate Cancer Risk Calculator is one such example<sup>39</sup>. Although useful in the outpatient clinic to give patients an absolute percentage risk of

TABLE 1 Summary of research methods used to determine patient preferences<sup>34</sup>

Name	Method Description	Involves	
		Uncertainty?	Trade-off between health states?
Ranking or weighting	Individuals rank or rate a preference for a set of alternative cancer treatments on a scale.	No	No
Standard gamble	Individuals choose to gamble between perfect health (for a given time) and immediate death or a certainty of living in an intermediate health state between perfect health and certain death (for the same given time)	Yes	Yes
Time trade-off	Individuals choose between either an intermediate health state for a time, followed by death or perfect health for a variably less time, followed by death	No	Yes
Visual analogue scale	Individuals choose a preference for a health state on a line with anchors at either end for perfect health and death respectively.	No	No
Discrete choice experiment	Cancer treatments are broken down into key attributes. Individuals then choose between scenarios that describe a health state using varying levels of those attributes. The treatment preference is evaluated by how an individual rates the attributes.	No	Yes
Multi-attribute utility instrument	Individuals complete a generic health-related quality-of-life instrument. Population preference values are then used to convert the scores into a utility score.	No	No

an outcome; risk calculators fail to provide insight into the complexities of the decision the patient must make. Decision-making aids make explicit the decision that is being considered, with a personalized focus on options and outcomes to foster an informed decision. They help patients when there is more than one reasonable option, each with its own unique benefits, risks, and side effects. The International Patient Decision Aid Standards (IPDAS) collaboration defines criteria to evaluate the content and quality of DMAS (Table II describes the IPDAS checklist)<sup>40</sup>, and the Informed Medical Decisions Foundation in Boston is developing and evaluating several programs for American men (Table III describes examples).

Decision-making aids improve knowledge at all stages of a patient's journey, minimize anxiety, and reduce decisional conflict attributable to feeling uninformed<sup>41,42</sup>. Studies comparing patient management with and without DMAS have consistently demonstrated that DMAS increase the involvement of patients in their decision and facilitate a realistic perception of outcomes without apparent adverse effects<sup>42</sup>.

Decision-making aids for prostate cancer patients are available in written, video, and Internet-based formats to cater to diverse patient needs. The growth of the Internet since the early 2000s has led to a proliferation of DMAS on the Web (Table III provides examples of prostate cancer DMAS available online) and enabled patients to share material about their diagnosis with family and friends. The Internet is advantageous, in that it is easily accessible to patients, relatives, and supporters at a convenient time, and material can be regularly updated, facilitating the shared decision-making process<sup>43</sup>.

Compared with simpler DMAS, more detailed DMAS seem to confer a small but significant improvement in knowledge gained by patients<sup>42</sup>. However, highly detailed or complex DMAS may not be applicable to a broad population with varying literacy standards. Plain-language DMAS with multicultural photos engage patients across diverse ethnicities, cultures, educational levels, and socioeconomic groups in the shared decision-making process. Decision-making aids in this format increase knowledge about prostate cancer treatment options without being perceived as being “dumbed down”<sup>43</sup>. Decision aids that express the probabilities of various decision sequelae in numbers rather than words lead to more accurate risk perceptions by patients in general<sup>41,42</sup>.

“Explicit values clarification” is a beneficial concept that has recently been included in DMAS. Values clarification aims to assist patients to combine their beliefs with their values by helping them either discover that they have particular values or learn the relative impact of competing values. “Explicit values clarification” describes the process of a patient performing an action—such as moving a bar or typing numbers—to reflect the relative impact of particular values on their decision. Randomized controlled trial

data suggest that, when used as part of a DMA, values clarification exercises better prepare the patient for decision-making and lessen regret after the decision is made. The inclusion of explicit values clarification into a DMA results in even more patients achieving decisions that are informed and consistent with their own values<sup>44</sup>.

Although DMAS are associated with improved patient–doctor communication and patient satisfaction<sup>42</sup>, the most appropriate time and manner for introducing DMAS to patients has not been rigorously established. Decision-making aids have been demonstrated to have a variable effect on physician consultation length. A Cochrane review indicated that a median of 2.5 minutes (range: –8 minutes to +24 minutes) might be added to consultation time<sup>42</sup>. However, if the patient is overwhelmed by the impact of a new cancer diagnosis, an early consultation may be an inappropriate occasion to introduce a DMA and encourage its use. At that point, a patient is unlikely to be able to make an informed decision or to formulate the information presented with or without assistance. Decision-making aids have demonstrated their greatest impact in undecided patients after diagnosis and the first consultation with a physician<sup>45</sup>. It therefore seems prudent to advise patients (and their partners, if they are involved) to use DMAS after (rather than at) the consultation during which they are informed of a prostate cancer diagnosis. However, that approach requires a follow-up appointment with either the specialist or a qualified multidisciplinary team member to discuss the final treatment choice.

The Personal Patient Profile–Prostate (P3P) is a tailored decision-support tool available on the Web for patients diagnosed with localized prostate cancer. It was developed by a North American team and has transitioned from the pilot phase to a multicentre randomized controlled trial in American men<sup>46,47</sup>. The DMAS includes all of the applicable dimensions of the IPDAS instrument. When the P3P was evaluated in a multicentre randomized controlled trial, the tool was highly rated for acceptability and usefulness. It reduced decisional conflict and facilitated selection of prostate cancer treatment consistent with the values and preferences of patients<sup>47</sup>.

#### 4. DECISION REGRET

In the period immediately after a diagnosis of prostate cancer, patients are focused on survival and cancer eradication<sup>48</sup>, and decision regret therefore usually manifests only after treatment has commenced or been completed. Up to one third of patients express some regret<sup>14,25,30</sup>. Post-treatment decision regret has been correlated with passive involvement in the decision-making process and also subsequent changes in role and functioning in society, spirituality, financial difficulty, and pain<sup>30,49,50</sup>.

TABLE II The IPDAS checklist

*Content*

- 1 The decision aid describes the condition (health or other) related to the decision.
- 2 The decision aid describes the decision that needs to be considered (the index decision).
- 3 The decision aid lists the options (health care or other).
- 4 The decision aid describes what happens in the natural course of the condition (health or other) if no action is taken.
- 5 The decision aid has information about the procedures involved (for example, what is done before, during, and after the health care option).
- 6 The decision aid has information about the positive features of the options (for example, benefits, advantages).
- 7 The decision aid has information about negative features of the options (for example, harms, side effects, disadvantages).
- 8 The information about outcomes of options (positive and negative) includes the chances that they may happen.
- 9 The decision aid has information about what a test is designed to measure.
- 10 The decision aid describes possible next steps based on the test results.
- 11 The decision aid has information about the chances of disease being found with and without screening.
- 12 The decision aid has information about the detection and treatment of disease that would never have caused problems if screening had not been done.
- 13 The decision aid presents probabilities using event rates in a defined group of people for a specified time.
- 14 The decision aid compares probabilities (for example, chance of a disease, benefit, harm, or side effect) of options using the same denominator.
- 15 The decision aid compares probabilities of options over the same period of time.
- 16 The decision aid uses the same scales in diagrams comparing options.
- 17 The decision aid asks people to think about which positive and negative features of the options matter most to them.
- 18 The decision aid makes it possible to compare the positive and negative features of the available options.
- 19 The decision aid shows the negative and positive features of the options with equal detail.

*Development process*

- 20 Users (people who have already faced the decision) are asked about what they need to prepare them to discuss a specific decision.
- 21 The decision aid is reviewed by people who previously faced the decision and who were not involved in its development and field testing.
- 22 People facing the decision field-tested the decision aid.
- 23 Field-testing shows that the decision aid is acceptable to users (the general public and practitioners).
- 24 Field-testing shows that people who were undecided felt that the information was presented in a balanced way.
- 25 The decision aid provides references to the scientific evidence used.
- 26 The decision aid reports the date of its last revision.
- 27 The decision aid reports whether the authors or their affiliations stand to gain or lose by the choices people make after using the decision aid.
- 28 The decision aid (or available technical document) reports readability levels.

*Effectiveness*

- 29 There is evidence that the decision aid (or an aid based on the same template) helps people learn about the available options and their features.
- 30 There is evidence that the decision aid (or one based on the same template) improves the match between the features that matter most to the informed person and the option that is chosen.

TABLE III Examples of decision-making aids for prostate cancer that are available on the Web<sup>a</sup>

Type	Decision aid Name (Web locator)	Developer
Screening	Deciding if the PSA Test is Right for You ( <a href="http://informedmedicaldecisions.org/imdf_decision_aid/deciding-if-the-psa-test-is-right-for-you/">http://informedmedicaldecisions.org/imdf_decision_aid/deciding-if-the-psa-test-is-right-for-you/</a> )	Informed Medical Decisions Foundation
Screening	Prostate Cancer Screening with PSA Testing ( <a href="http://www.asco.org/ASCOv2/Department%20Content/Cancer%20Policy%20and%20Clinical%20Affairs/Downloads/Guideline%20Tools%20and%20Resources/PSA/PSA%20PCO%20Decision%20Aid%207.16.12.pdf">http://www.asco.org/ASCOv2/Department%20Content/Cancer%20Policy%20and%20Clinical%20Affairs/Downloads/Guideline%20Tools%20and%20Resources/PSA/PSA%20PCO%20Decision%20Aid%207.16.12.pdf</a> )	American Society of Clinical Oncology
Screening	Welcome to PROSDEx, Which Can Help You Decide Whether or Not to Have a PSA Test ( <a href="http://www.prosdex.com/index_content.htm">http://www.prosdex.com/index_content.htm</a> )	University of Cardiff
Treatment	Treatment Choices for Prostate Cancer ( <a href="http://informedmedicaldecisions.org/imdf_decision_aid/treatment-choices-for-prostate-cancer/">http://informedmedicaldecisions.org/imdf_decision_aid/treatment-choices-for-prostate-cancer/</a> )	Informed Medical Decisions Foundation
Treatment	Treating Prostate Cancer: A Guide for Men with Localized Prostate Cancer ( <a href="http://www.effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?pageaction=displayproduct&amp;productID=98">http://www.effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?pageaction=displayproduct&amp;productID=98</a> )	U.S. Agency for Healthcare Research and Quality
Treatment	Treatment Choices for Men with Early-Stage Prostate Cancer ( <a href="http://www.cancer.gov/cancertopics/treatment/prostate/understanding-prostate-cancer-treatment">http://www.cancer.gov/cancertopics/treatment/prostate/understanding-prostate-cancer-treatment</a> )	U.S. National Cancer Institute

<sup>a</sup> All last accessed October 1, 2012.

Decision regret is recognized to increase significantly with time since treatment. That trend has been associated with limitations in activity because of incontinence and changes in sexual dysfunction—symptoms that occur in prostate cancer patients, particularly after radical prostatectomy<sup>51</sup>.

The effect of DMAS on post-treatment regret is poorly defined. In the largest randomized controlled trial evaluating the use of the P3P DMA in American men, use of the aid did not predict decision regret<sup>52</sup>. Conversely, in a smaller randomized controlled trial in Scotland, investigators did find lower regret scores 6 months after treatment in the group that used the DMA compared with a control group that did not<sup>53</sup>. Another multicentric randomized controlled trial compared two versions of a decision aid, one with structured information and one with values clarification exercises, on subsequent decision regret. Patients were reviewed immediately after reaching their decision, 3 months post treatment, and more than 1 year later. In both groups decisional conflict decreased after the DMA was used, but the values clarification group reported better preparation for decision-making. Decision regret did not differ between the groups at the 3-month follow-up, but regret was lower for the values clarification exercises group at more than 1 year after follow-up<sup>44</sup>. Further research is required to truly ascertain the effect of DMAS on treatment regret.

## 5. SUMMARY

Shared decision-making for prostate cancer treatment must involve both the patient and his partner. A patient's knowledge and understanding of his diagnosis and treatment options should not be assumed to be adequate after a consultation during which he is informed of both. Although educational aids are useful, comprehension and interpretation by patients of the information contained in the material may differ from what a health care professional expects. As a treatment adjunct, DMAS permit patients (and their partners and family members, if they are involved) to explore their values and beliefs about treatment in a non-pressured environment. Decision-making aids meeting IPDAS standards should be offered to all patients after their diagnosis and before a final treatment decision is made, especially when the patients seem undecided at the consultation after diagnosis. Health care professionals must recognize that treatment regret may manifest despite fully informed consent, and they must have appropriate strategies in place within their organizations for dealing with that regret.

## 6. CONFLICT OF INTEREST DISCLOSURES

The authors declare that no financial conflicts of interest exist.

## 7. REFERENCES

- Canadian Cancer Society's Steering Committee on Cancer Statistics. *Canadian Cancer Statistics 2012*. Toronto, ON: Canadian Cancer Society; 2012. [Available online at: [http://www.cancer.ca/Canada-wide/About%20cancer/~/\\_media/CCS/Canada%20wide/Files%20List/English%20files%20heading/PDF%20-%20Policy%20-%20Canadian%20Cancer%20Statistics%20-%20English/Canadian%20Cancer%20Statistics%202012%20-%20English.ashx](http://www.cancer.ca/Canada-wide/About%20cancer/~/_media/CCS/Canada%20wide/Files%20List/English%20files%20heading/PDF%20-%20Policy%20-%20Canadian%20Cancer%20Statistics%20-%20English/Canadian%20Cancer%20Statistics%202012%20-%20English.ashx); cited September 19, 2012]
- Eggener SE, Scardino PT, Walsh PC, *et al*. Predicting 15-year prostate cancer specific mortality after radical prostatectomy. *J Urol* 2011;185:869–75.
- Warde P, Mason M, Ding K, *et al*. Combined androgen deprivation therapy and radiation therapy for locally advanced prostate cancer: a randomised, phase 3 trial. *Lancet* 2011;378:2104–11.
- Klotz L, Zhang L, Lam A, Nam R, Mamedov A, Loblaw A. Clinical results of long-term follow-up of a large, active surveillance cohort with localized prostate cancer. *J Clin Oncol* 2010;28:126–31.
- de Bono JS, Logothetis CJ, Molina A, *et al*. Abiraterone and increased survival in metastatic prostate cancer. *N Eng J Med* 2011;364:1995–2005.
- Crook JM, O'Callaghan CJ, Duncan G, *et al*. Intermittent androgen suppression for rising PSA level after radiotherapy. *N Eng J Med* 2012;367:895–903.
- Statistics Canada. *Canadian Demographics at a Glance*. Catalogue 91-003. Ottawa, ON; Statistics Canada; 2008. [Available online at: <http://www.statcan.gc.ca/pub/91-003-x/91-003-x2007001-eng.pdf>; cited September 19, 2012]
- Siegel R, DeSantis C, Virgo K, *et al*. Cancer treatment and survivorship statistics, 2012. *CA Cancer J Clin* 2012;62:220–41.
- Flood AB, Wennberg JE, Nease RF Jr, Fowler FJ Jr, Ding J, Hynes LM. The importance of patient preference in the decision to screen for prostate cancer. Prostate Patient Outcomes Research Team. *J Gen Intern Med* 1996;11:342–9.
- Hoffman RM, Couper MP, Zikmund-Fisher BJ, *et al*. Prostate cancer screening decisions: results from the national survey of medical decisions (DECISIONS study). *Arch Intern Med* 2009;169:1611–18.
- Steginga SK, Occhipinti S, Gardiner RA, Yaxley J, Heathcote P. Making decisions about treatment for localized prostate cancer. *BJU Int* 2002;89:255–60.
- Snow SL, Panton RL, Butler LJ, *et al*. Incomplete and inconsistent information provided to men making decisions for treatment of early-stage prostate cancer. *Urology* 2007;69:941–5.
- Walker LM, Tran S, Wassersug RJ, Thomas B, Robinson JW. Patients and partners lack knowledge of androgen deprivation therapy side effects. *Urol Oncol* 2012;:[Epub ahead of print].
- Soeyonggo T, Warde P, Fleschner N, Timilshina N, Alibhai SM. Information needs of men on androgen deprivation therapy. *BJU Int* 2012;109:1503–9.
- Deibert CM, Maliski S, Kwan L, Fink A, Connor SE, Litwin MS. Prostate cancer knowledge among low income minority men. *J Urol* 2007;177:1851–5.
- Agho AO, Lewis MA. Correlates of actual and perceived knowledge of prostate cancer among African Americans. *Cancer Nurs* 2001;24:165–71.
- Chapman K, Abraham C, Jenkins V, Fallowfield L. Lay understanding of terms used in cancer consultations. *Psychooncology* 2003;12:557–66.
- Rot I, Ogah I, Wassersug RJ. The language of prostate cancer treatments and implications for informed decision making by patients. *Eur J Cancer Care (Engl)* 2012;21:766–75.
- Denberg TD, Melhado TV, Steiner JF. Patient treatment preferences in localized prostate carcinoma: the influence of emotion, misconception, and anecdote. *Cancer* 2006;107:620–30.
- Schulman C. Assessing the attitudes to prostate cancer treatment among European male patients. *BJU Int* 2007;100(Suppl 1):6–11.
- Davison BJ, Parker PA, Goldenberg SL. Patients' preferences for communicating a prostate cancer diagnosis and participating in medical decision-making. *BJU Int* 2004;93:47–51.
- Davison BJ, Gleave ME, Goldenberg SL, Degner LF, Hoffart D, Berkowitz J. Assessing information and decision preferences of men with prostate cancer and their partners. *Cancer Nurs* 2002;25:42–9.
- Fowler FJ Jr, McNaughton Collins M, Albertsen PC, Zietman A, Elliott DB, Barry MJ. Comparison of recommendations by urologists and radiation oncologists for treatment of clinically localized prostate cancer. *JAMA* 2000;283:3217–22.
- Pearce A, Newcomb C, Husain S. Recommendations by Canadian urologists and radiation oncologists for the treatment of clinically localized prostate cancer. *Can Urol Assoc J* 2008;2:197–203.
- Gwede CK, Pow-Sang J, Seigne J, *et al*. Treatment decision-making strategies and influences in patients with localized prostate carcinoma. *Cancer* 2005;104:1381–90.
- Sidana A, Hernandez DJ, Feng Z, *et al*. Treatment decision-making for localized prostate cancer: what younger men choose and why. *Prostate* 2012;72:58–64.
- Davison BJ, Goldenberg SL. Patient acceptance of active surveillance as a treatment option for low-risk prostate cancer. *BJU Int* 2011;108:1787–93.
- Wittmann D, He C, Coelho M, Hollenbeck B, Montie JE, Wood DP Jr. Patient preoperative expectations of urinary, bowel, hormonal and sexual functioning do not match actual outcomes 1 year after radical prostatectomy. *J Urol* 2011;186:494–9.
- Sommers BD, Beard CJ, D'Amico AV, Kaplan I, Richie JP, Zeckhauser RJ. Predictors of patient preferences and treatment choices for localized prostate cancer. *Cancer* 2008;113:2058–67.
- Davison BJ, So AI, Goldenberg SL. Quality of life, sexual function and decisional regret at 1 year after surgical treatment for localized prostate cancer. *BJU Int* 2007;100:780–5.
- Hoffman RM, Hunt WC, Gilliland FD, Stephenson RA, Potosky AL. Patient satisfaction with treatment decisions for clinically localized prostate carcinoma. Results from the Prostate Cancer Outcomes Study. *Cancer* 2003;97:1653–62.
- Schroek FR, Krupski TL, Sun L, *et al*. Satisfaction and regret after open retropubic or robot-assisted laparoscopic radical prostatectomy. *Eur Urol* 2008;54:785–93.
- Feldman-Stewart D, Capirci C, Brennenstuhl S, *et al*. Information for decision making by patients with early stage prostate cancer: a comparison across 9 countries. *Med Decis Making* 2011;31:754–66.

34. Blinman P, King M, Norman R, Viney R, Stockler MR. Preferences for cancer treatments: an overview of methods and applications in oncology. *Ann Oncol* 2012;23:1104–10.
35. Sanda MG, Dunn RL, Michalski J, *et al.* Quality of life and satisfaction with outcome among prostate-cancer survivors. *N Eng J Med* 2008;358:1250–61.
36. Percy R, Waldron D, O’Boyle C, MacDonagh R. Proxy assessment of quality of life in patients with prostate cancer: how accurate are partners and urologists? *J R Soc Med* 2008;101:133–8.
37. Elliot S, Latini DM, Walker LM, Wassersug R, Robinson JW. Androgen deprivation therapy for prostate cancer: recommendations to improve patient and partner quality of life. *J Sex Med* 2010;7:2996–3010.
38. Wu LM, Mohamed NE, Winkel G, Diefenbach MA. Patient and spouse illness beliefs and quality of life in prostate cancer patients. *Psychol Health Med* 2012;:[Epub ahead of print].
39. Thompson IM, Ankerst DP, Chi C, *et al.* Assessing prostate cancer risk: results from the Prostate Cancer Prevention Trial. *J Natl Cancer Inst* 2006;98:529–34.
40. Elwyn G, O’Connor A, Stacey D, *et al.* Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ* 2006;333:417.
41. Volk RJ, Hawley ST, Kneuper S, *et al.* Trials of decision aids for prostate cancer screening: a systematic review. *Am J Prev Med* 2007;33:428–34.
42. Stacey D, Bennett CL, Barry MJ, *et al.* Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2011;10:CD001431.
43. Holmes–Rovner M, Stableford S, Fagerlin A, *et al.* Evidence-based patient choice: a prostate cancer decision aid in plain language. *BMC Med Inform Decis Mak* 2005;5:16.
44. Feldman–Stewart D, Tong C, Siemens R, *et al.* The impact of explicit values clarification exercises in a patient decision aid emerges after the decision is actually made: evidence from a randomized controlled trial. *Med Decis Making* 2012;32:616–26.
45. O’Connor AM, Tugwell P, Wells GA, *et al.* A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Educ Couns* 1998;33:267–79.
46. Berry DL, Halpenny B, Wolpin S, *et al.* Development and evaluation of the personal patient profile-prostate (P3P), a web-based decision support system for men newly diagnosed with localized prostate cancer. *J Med Internet Res* 2010;12:e67.
47. Berry DL, Halpenny B, Hong F, *et al.* The Personal Patient Profile–Prostate decision support for men with localized prostate cancer: a multi-center randomized trial. *Urol Oncol* 2011;:[Epub ahead of print].
48. Zeliadt SB, Ramsey SD, Penson DF, *et al.* Why do men choose one treatment over another? A review of patient decision making for localized prostate cancer. *Cancer* 2006;106:1865–74.
49. Diefenbach M, Mohamed NE, Horwitz E, Pollack A. Longitudinal associations among quality of life and its predictors in patients treated for prostate cancer: the moderating role of age. *Psychol Health Med* 2008;13:146–61.
50. Hu JC, Kwan L, Krupski TL, *et al.* Determinants of treatment regret in low-income, uninsured men with prostate cancer. *Urology* 2008;72:1274–9.
51. Diefenbach MA, Mohamed NE. Regret of treatment decision and its association with disease-specific quality of life following prostate cancer treatment. *Cancer Invest* 2007;25:449–57.
52. Berry DL, Wang Q, Halpenny B, *et al.* Decision preparation, satisfaction and regret in a multi-center sample of men with newly diagnosed localized prostate cancer. *Patient Educ Couns* 2012;88:262–7.
53. Hacking B, Wallace L, Scott S, Kosmala–Anderson J, Belkora J, McNeill A. Testing the feasibility, acceptability and effectiveness of a “decision navigation” intervention for early stage prostate cancer patients in Scotland—a randomized controlled trial. *Psychooncology* 2012;:[Epub ahead of print].

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