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Evaluation of a widely available patient decision aid for the treatment of prostate cancer

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ABSTRACT

Background: The effectiveness of patient decision aids (PtDA) is rarely evaluated in the “real world” where patients vary in their preferences related to decision support.

Purpose: To determine how Canadian patients use and evaluate our widely available PtDA for early-stage prostate cancer treatment with its 8 components.

Methods: Google Analytics and online tracking provided usage information. A Usability Assessment (UA) following the PtDA provided evaluation data; main outcomes [scale: 1 (strongly disagree) to 5 (strongly agree)] were (a) the aid was helpful, and (b) I would recommend it to other patients.

Results: Usage data were from 993 users, and UAs from 168 of them. Mean “helpfulness” score was 4.1(5 max); mean “recommend” score was 4.2 (5 max). For each PtDA component, there was no significant difference on each main outcome, between those who used it and those who did not.

Conclusion: Overall, patients who completed the UA rated the PtDA as helpful and would recommend it to other patients. The widely available PtDA accommodated expected variation in decision support desired, and helpfulness was not associated with variation in components used.

Practice implication: The internet can be an effective medium for making appropriately designed decision support widely available to prostate cancer patients.

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1. Introduction

Decision support for men diagnosed with prostate cancer and facing their treatment decision is challenging in a number of different dimensions. The incidence of prostate cancer is high, and primary treatment decisions are often made by urologists who have also provided the diagnosis. Previous research shows that men vary widely in their information needs [1], in how much decision support they desire [2], at what time it would be most useful [3], and in what medium (written or web-based) they would prefer they receive it [3].

In an effort to address these challenges, we developed a patient decision aid (PtDA) that could be integrated into usual clinical care at the time of initial diagnosis, and that could accommodate variation in information and decision support needs of patients [4]. The aid was shown to be efficacious in a randomized controlled trial (RCT), in that patients who used the PtDA felt better prepared to make their decisions with their doctor, and experienced less regret one year after

the decision was made, than did patients who just received information without decision support exercises [5]. Given these findings, we sought to disseminate the decision aid more widely, to understand how it would be used, and to evaluate its usefulness on a broader scale outside of the context of a controlled trial.

Little is known about how to make decision aids widely available: we could find no guidance from published reports of decision aids being made widely available or being used in routine clinical practice. In a 2013 review of PtDAs on the internet, the authors noted gaps in empirical evidence which included lack of tests of different dissemination and implementation strategies [6]. A comparison of a more- to a less- intensive program focussed on engaging providers in the use of breast cancer decision aids concluded that the extra effort of the more intensive program did not improve the proportion of providers who maintained use of the intervention [7]. One of the most common requests to facilitate implementation from those providers was to have web-based versions of the PtDAs available on the internet. We had developed an internet version of our PtDA, which allowed wide access and also allowed it to be used by the patient outside the consultation when he is ready to do so (then return to his doctor to make his treatment decision). Further, 85% of prostate cancer patients in a recent population survey expressed interest in using decision support [3].

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The evaluation of a decision aid once it is widely disseminated is also very challenging. It is not clear how efficacy of the aid demonstrated in an RCT translates to effectiveness at a societal level when used more broadly. This is primarily because the RCT trial outcomes cannot be determined at the population level: the validated measures used for these outcomes [8,9] are not collected in routine care, thus, cannot be analyzed using administrative databases [10].

The objectives of this study were to determine the usage and the usability of our PtDA once widely available, considering that

patients vary widely in the level of decision support they want [5] and our need to rely on pragmatic measures of its helpfulness.

2. Method

2.1. Usage

Website visit information was derived from Google Analytics data. The information included number of visits to the site at any

TREATMENT DETAILS

- How the treatment works
- When can the treatment start
- How to know if treatment is working

POSSIBLE BENEFITS OF TREATMENTS

- Chances of PSA control (avoiding further treatment)
- Reducing the chances of cancer causing symptoms
- Reducing the chances of dying from cancer
- Effect on how long I will live

POSSIBLE HARMS OF TREATMENTS

- Chances of dying from treatment
- Effects of treatment on sexual function
- Effects of treatment on bladder function
- Effects of treatment on bowel function

OPTIONS IF CANCER IS NOT CURED

- Options if cancer gets worse without treatment
- Options if cancer remains after treatment
- Options if cancer returns later on

WHAT OTHERS CHOOSE

- Choices other patients make
- Choices doctors make

WANT MORE INFORMATION?

If you would like additional information to help with your decision making, you may search for information below. Type a search phrase or some keywords in the text field below and click the **SEARCH** button to the right. If you do not need any additional information, skip the search below and continue to the next page.

We found the following topic(s) related to "partner". Click on the topic tabs below to view the information.

- [Sex and my partner's health](#)
- [Sex and prostate cancer treatment](#)
- [Treatment and being radioactive](#)

Fig. 1. Information component of the decision aid.

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