

Helping patients with localized prostate cancer reach treatment decisions

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Mr Jones, a 66-year-old man you sent to a urologist because of elevated prostate-specific antigen levels and abnormal findings from digital rectal examination, has come to see you with the news that he indeed has prostate cancer. The note from the urologist indicates that Mr Jones has early prostate cancer and that he has been given 5 treatment options: active surveillance, radical prostatectomy, external beam radiotherapy, brachytherapy, and cryotherapy. Mr Jones says that he has no idea which route to choose and has come to you for guidance.

In Canada from 2002 to 2004, the 5-year relative survival ratio for prostate cancer was 95%,¹ indicating that a large proportion of survivors are living for years with this disease and its treatment sequelae. While treatment options are typically weighted for the best medical outcome, prostate cancer patients are faced with a difficult choice between several medically equivalent treatments. The decision is further confounded by conflicting recommendations from specialists, such as urologists, radiation oncologists, and medical oncologists; various media sources; and family and friends. Patients also commonly report feeling distress while making this treatment decision, and they worry about the appropriateness of their choices.² Beyond its medical appropriateness, a good treatment decision is one that is ultimately characterized by minimal decision-related regret.³

Reported rates of decisional regret among patients with localized prostate cancer range from 4% to 19%, with higher rates reported with increased time since treatment.^{2,4-7} The unique relationships that family physicians have with their patients can play a key role in good treatment decisions. Family physicians might see patients more regularly than specialists do, and many men will continue to turn to their family physicians for ongoing follow-up and management of treatment side effects.⁸ There are several

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Cet article a fait l'objet d'une révision par des pairs.

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Abstract

OBJECTIVE To highlight the role of psychosocial variables in treatment decision making for patients with localized prostate cancer and how family physicians can be of most help to such patients in facilitating good treatment choices.

QUALITY OF EVIDENCE PubMed was searched, and articles relevant to the psychosocial aspects of localized prostate cancer treatment decision making were included. Articles were excluded when they clearly specified inclusion of men with metastatic disease. This is not a systematic review, and recommendations made are drawn from studies of level II or III evidence.

MAIN MESSAGE The optimal strategy for managing localized prostate cancer has not been established and currently includes a number of potential options: active surveillance, radical prostatectomy, external beam radiotherapy, brachytherapy, and cryoablation. Consequently, men often struggle during the decision-making process, and some later regret their decisions. With an increased awareness of the psychosocial aspects of patient decision making, family physicians can help patients make better decisions.

CONCLUSION Family physicians can help minimize the decisional regret experienced by patients after treatment by encouraging patients to consider their values and social supports, as well as the accuracy and appropriateness of the information used in the decision-making process.

Résumé

OBJECTIF Décrire les variables psychosociales qui influencent la décision du choix de traitement pour un cancer prostatique in situ et montrer comment le médecin de famille peut aider le patient à choisir un traitement approprié.

QUALITÉ DES PREUVES On a consulté PubMed et retenu les articles traitant des aspects psychosociaux de la prise de décision concernant le traitement d'un cancer prostatique in situ. Les articles qui indiquaient clairement comprendre des patients avec une maladie métastatique ont été exclus. Il ne s'agit pas d'une revue systématique, et les recommandations émises proviennent d'études dont les preuves sont de niveau II ou III.

PRINCIPAL MESSAGE La stratégie thérapeutique optimale pour un cancer prostatique in situ n'a pas encore été établie, les options actuelles incluant: surveillance active, prostatectomie radicale, thérapie externe, brachythérapie et cryoablation. Les patients ont donc souvent de la difficulté à faire un choix et plus tard, certains regrettent leur décision. Avec une meilleure connaissance des facteurs psychosociaux qui influencent la décision du patient, le médecin de famille peut l'aider à faire un choix plus éclairé.

CONCLUSION Le médecin de famille peut minimiser les regrets qu'éprouvent les patients après avoir reçu le traitement de leur choix en les encourageant à tenir compte de leurs valeurs personnelles et de leurs supports sociaux, mais aussi de la justesse et de la pertinence des informations utilisées dans le processus décisionnel.

crucial ways for family physicians to facilitate good treatment decisions: 1) ensure that the patient's treatment decision is based on accurate and appropriate information; 2) help the patient to clarify his values and ensure that they are taken into consideration; and 3) address the influence of the patient's social support system in treatment decision making.

Quality of evidence

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Ensure the accuracy and appropriateness of information

Overall, patients do not appear to obtain, understand, or comprehensively use all information pertinent to their treatment decision making.^{9,10} Large information gaps have been identified between what patients deem important in making treatment decisions and their level of knowledge about those issues. The largest gaps relate to having knowledge of all treatment choices available; details regarding specific treatments; the risks and benefits associated with each possible treatment; and personal considerations, such as recovery time after treatment.¹⁰ Furthermore, patient treatment choices might be more influenced by the information patients receive than by their fundamental preferences.¹¹

Most patients with localized prostate cancer seek information about their disease from a multitude of sources beyond their physicians, including the Internet, other media sources, and family and friends^{2,9,12-14}; however, many of these sources provide inaccurate or inappropriate information. This information can also be misinterpreted, owing to false beliefs about causes and treatments of cancer.^{9,15} Family physicians should assess the credibility of the information patients are using.

Patients appear to hold pervasive views regarding the benefits and risks of prostate cancer treatments, particularly that radical prostatectomy is always the best treatment.^{9,16} Those in favour of surgery state that it is the most certain and the most expeditious, and that it provides the most tangible knowledge about the cancer. Those against surgery express concerns about the risks of the procedure itself. Radiation is considered to be a less concrete treatment,^{9,15} and brachytherapy is believed to be less invasive, the least painful, and the most convenient, and to promise the fewest side effects.² Watchful waiting or active surveillance is often not considered to be a serious option, as it is misunderstood as "doing nothing."¹⁷ Men who do choose this option are often anxious to avoid treatment side

effects.¹⁸ When making treatment decisions, reliance on anecdotal information, as well as misconceptions and misbeliefs held by patients, often leads to inappropriate use of health information and uninformed decision making.^{9,15} Family physicians can help by correcting treatment misconceptions.

Patients vary in the degree to which they wish to be involved in making treatment decisions. These preferences influence their tendency to seek and make use of treatment-related information. While most patients with localized prostate cancer prefer to take collaborative or leading roles in the decision-making process,^{5,19,20} a considerable proportion of patients do prefer to follow their specialists' treatment recommendations.^{2,5,9,19} Patients who prefer a passive role in decision making cite a lack of technical competence; not wanting to be viewed as disrespectful; or anxieties about taking responsibility for treatment outcomes.²¹ These patients might be less likely to seek information and thus might require additional help accessing information. Passive participation is associated with higher levels of decisional regret 1 year following treatment.⁶ Conversely, patients preferring an active or collaborative role in decision making might be more likely to seek additional treatment information, thereby increasing their risk of using inaccurate information in treatment decisions.²⁰ Thus, family physicians should try to understand patients' desired level of involvement and address risks and benefits.

While a second opinion is often a useful source of additional information, research indicates that more than half of patients have no intention of seeking one. This is largely the result of common misconceptions, including the belief that a second opinion is merely confirmation of the cancer diagnosis and is an expression of distrust in the diagnosing physician.¹⁶ Other reasons for declining a second opinion include a desire to avoid treatment delay for fear that the cancer will become untreatable; wanting to reduce information overload; and unease with prolonged decisional uncertainty.¹⁵ This avoidance can lead to heavy reliance on the opinions of urologists, as they are often the first to discuss treatment options with patients.¹³ Urologists, like other specialists, are most likely to recommend treatment options that fit with their area of expertise.^{11,21-23}

This extant knowledge gap provides a unique opportunity for family physicians, who are often seen as unbiased but credible sources of information. While patients do rely heavily on information provided to them by their specialists,^{13,24} it is still important for family physicians to inquire about patients' sources of information in order to ensure the accuracy and appropriateness of that information.^{12,24} Additionally, family physicians can recommend sources of information to address any gaps in patients' knowledge. Whenever possible, family physicians should encourage active or collaborative participation in the decision-making process. Family

physicians can also play a role in correcting misconceptions about the purpose and possible benefits of second opinions and, if appropriate, reassure patients that there is no urgency for treatment and that there is time to seek second opinions.

Help patients clarify their values

Increased patient involvement in treatment decision making can help patients to clarify what they consider important in making treatment choices. This is important given the large individual differences in both the number of items and the specific individual items that patients rate as important considerations. Demographics, such as age, marital status, and education, have not been shown to be helpful for predicting necessary considerations to address,^{25,26} and decision models based on average preferences lead to sub-optimal treatment decisions for by far most patients.²⁷ Decision models can be helpful for guiding decision-making discussions, but should not be considered comprehensive for all patients. Considerable variability also exists among physicians' ratings of important considerations and questions to be addressed with patients before treatment decision making,²⁸ and, when examined concurrently, show poor agreement with what patients consider to be important.^{29,30} There is substantial interphysician variability in the content and amount of information provided to patients; information is also subject to the physicians' personal values and preferences.^{10,28} Overall, there is inconsistency in what considerations patients deem necessary, and physicians' judgments do not necessarily correspond with these considerations. Follow the individual patient's lead when determining what factors are important in treatment decision making.

Further, patient rankings of the importance of various factors in treatment decision making are not stable over time.²⁶ With the initial shock of receiving a cancer diagnosis, patients are more focused on survival and cancer eradication than on the realities of living with particular side effects for many years.¹¹ It should be noted, however, that treatment side effects do play a substantial role in treatment decision making¹¹ and that some men, even at the time of diagnosis, are not willing to sacrifice physical and sexual function for greater life expectancy.³¹ As patients transition into survivorship, and as the threat to life lessens, quality-of-life issues become more important. This is when some men begin to question their treatment choices, particularly if their recovery expectations are not met. Family physicians can help reduce the likelihood of this possibility by encouraging patients to think beyond cancer control and into survivorship before making treatment decisions.

The side effects patients experience are largely predictive of treatment-decision regret.³ Summaries of main side effects (by treatment modality and with the

respective percentage of men likely to experience dysfunction) are available,³² and for clarity they should be presented in multiple formats.³¹ One way to help a man consider the potential effects of a specific side effect is to distinguish between *dysfunction* (the objective physical effects) and *bother* (the subjective experience associated with the symptoms), as they can affect individual men differently.^{3,31} Although they cannot necessarily change the physical effects, patients are able to minimize the amount of bother that symptoms produce.

Family physicians can help minimize patients' distress and decisional regret by ensuring that patients understand the possible side effects of treatment, their own side effect risk probabilities, the timing of side effect occurrence, the permanence of side effects, and the potential disruptions to their lives.³¹ Patients should be encouraged to consider long-term side effects early on in the treatment decision-making process and not as an afterthought once the success of treatment has been determined. Individualizing information for patients has been shown to increase their satisfaction with the type, amount, and method of information provided, as well as their role in the decision-making process.³³ Patients might also benefit from knowing how other men have adjusted following treatment, and can be referred to appropriate readings on symptoms such as urinary incontinence or erectile dysfunction.^{34,35}

Resources

- Pickles T. What's a man to do? Treatment options for localized prostate cancer. *Can Fam Physician* 2004;50:65-72.
- Gray R. *Prostate tales: men's experience with prostate cancer*. Harriman, TN: Men's Studies Press; 2003.
- Alterowitz R, Alterowitz B. *Intimacy with impotence: the couple's guide to better sex after prostate disease*. Cambridge, MA: De Capo Press; 2004.

Address the influence of social supports

Friends and family members can be very influential in treatment decision making, as by far most patients consult with their spouses or close supports before making treatment choices.^{34,35} Spouses and partners often provide emotional support and are involved in gathering information^{12,36}; however, partners seek information from informal sources similar to those identified by patients and are similarly swayed by inaccurate information, anecdotal information, and misconceptions.³⁶ Partners tend to play active roles in treatment decision making for patients in equal partnerships, although some men do exclude their spouses from providing informational or emotional support.^{12,24} It is beneficial for family physicians to understand the role and influence of spouses, family members, and other supports.

Partners recognize side effects as important, but only a very small proportion deem them to be the most

important deciding factor in treatment choice, focusing more on eradication of the cancer.³⁶ Some patients report feeling pressured by family members or other patients to pursue more aggressive treatment, leading to the elimination of active surveillance as an option.¹⁸ Most partners acknowledge that the final decision should be made by the patient, with almost half purposefully trying to avoid influencing the final treatment choice.^{19,36}

Patients' primary sources of support are not always their spouses, and not all patients have key supports. It is important for family physicians to inquire about the support available to patients. There is some evidence that patients who discuss treatment options with their physicians, friends, and family before beginning treatment demonstrate improved emotional adjustment from 1 month up to 6 months following treatment.³⁷ Family physicians should encourage discussion between patients and their families, but additionally can play a role in helping patients balance their own values and considerations with those of others when making treatment choices. Support from other health professionals (eg, psychologists, social workers, pharmacists) is also often available to patients through local cancer centres; family physicians can play an important role by ensuring that patients are aware of these services.

Key recommendations for helping newly diagnosed prostate cancer patients make treatment decisions

Ensure the accuracy and appropriateness of information

- Assess the credibility of information sources
- Correct treatment misconceptions
- Address reliance on anecdotal information
- Consider the degree to which the patient wishes to be involved in decision making when addressing information needs
- Encourage patients to seek second opinions by explaining the purpose of such opinions

Help patients clarify their values

- Do not presume to know what the patient considers important
- Encourage patients to think beyond cancer control and into survivorship
- Help patients understand side effect risk probabilities
- Help patients consider the dysfunction and bother that particular side effects will cause in their lives

Address the influence of social supports

- Understand the role and influence of spouses, family members, and other supports
- Help patients to balance family members' opinions with their own values

EDITOR'S KEY POINTS

- Without support in treatment decision making, men are often influenced more by anecdote than by credible information. Reported rates of decisional regret among patients with localized prostate cancer range from 4% to 19%, with higher rates reported with increased time since treatment.
- Whenever possible, family physicians should encourage active or collaborative participation in the decision-making process. Increased patient participation in treatment decision making minimizes decisional regret by addressing information needs, facilitating values clarification around treatment choice, and helping patients to understand any potential side effects.
- Patients should be encouraged to take time to decide about treatment, as their frame of mind will shift as the initial shock of the diagnosis diminishes.
- Family physicians provide unique support, as they can focus more neutrally than treatment specialists or family members on the best treatment choices considering patients' circumstances and values.

POINTS DE REPÈRE DU RÉDACTEUR

- Sans support pour choisir un traitement, les hommes ont tendance à être davantage influencés par des données anecdotiques plutôt que par des données crédibles. On rapporte qu'entre 4 et 19% des patients regrettent leur décision en rapport avec un cancer prostatique in situ, un taux qui augmente avec le temps écoulé depuis le traitement.
- Autant que possible, le médecin de famille devrait promouvoir une participation active ou en collaboration au processus décisionnel. Une participation accrue du patient à la décision entraîne moins de regret à l'égard du traitement choisi, clarifie les valeurs conditionnant le choix d'un traitement et permet au patient de mieux comprendre les effets indésirables éventuels.
- On devrait encourager le patient à ne pas précipiter sa décision de traitement puisque son état d'esprit risque de changer à mesure que le choc initial du diagnostic s'atténue.
- Le médecin de famille est une source de support irremplaçable puisqu'il peut, de façon plus neutre que les spécialistes ou les membres de la famille, envisager les meilleurs choix de traitement compte tenu des circonstances et des valeurs du patient.

Conclusion

Good treatment decisions should be based primarily on medical appropriateness; however, when treatments are deemed medically equivalent there are several steps that can be taken to help patients make good treatment choices, characterized by minimal decisional regret.

Addressing the information needs and biases of patients is a critical first step in ensuring the accuracy and appropriateness of information being used to reach treatment decisions. Patients need help applying information to their own circumstances, while also looking beyond the immediate distress of the cancer diagnosis to long-term side effects. The influence and role of family and friends in the decision-making process must be considered. Of all the medical professionals encountered by patients during the decision-making process, family physicians are uniquely situated to facilitate effective treatment decision making.

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Contributors

Both authors contributed to the literature search and preparation of the article for submission.

Competing interests

None declared

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