

Information that affects patients' treatment choices for early stage prostate cancer: a review

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Introduction: We conducted a systematic review of primary evidence to clarify what information influences treatment selection by patients with early stage prostate cancer.

Materials and methods: We conducted a systematic review of the Web of Knowledge, using the ALL DATABASES option. Papers were then triaged out on the basis of the title and/or abstract, leaving 120 papers. Reviewing the full papers resulted in a final corpus of 21 papers.

Results: The data suggest that patients typically balance potential benefits against potential side effects but in a complex way with large variation across patients. For some patients, potential benefits relate to chances of survival but,

for others, relate to control over cancer spread. The most common potential harm is effect on bladder functioning but even that is not a concern of all patients. Similarly, potential impact on bowel and on sexual functioning affects some patients' decisions but not others. Patient decisions are also affected by information not typically identified as affecting this decision. These include aspects of treatment and decision processes, competencies, and others' opinions, again, with wide variation across patients. The patient's view of which information items affect his decision may also change over time, consistent with a dynamic decision-making process.

Conclusions: Decision support interventions are needed to optimally tailor information for decision-making to the individual patient, and should be designed to accommodate the illustrated variation in patients' needs.

Key Words: prostate cancer, treatment decision making, patient preferences, patient education

Introduction

Making a decision about treatment for early stage prostate cancer is often a complicated and challenging process for patients. Currently, widely available therapies include radical prostatectomy, external beam radiation, brachytherapy and watchful waiting (instituting palliative treatment if required) or active surveillance (instituting radical treatment only if specific indications appear). Continuous research and development results in frequent changes in procedures and in the expected outcomes of currently offered treatments, but also results in new treatments being developed, such a cryosurgery or high-frequency

ultrasound. The situation is further complicated by the long natural history of the disease and, hence, limited Level I evidence that clarifies the comparative outcomes of the current treatment options.

The purpose of this paper is to review the literature on the information that affects patients' decisions about which treatment they prefer for their early stage prostate cancer, and to assess the implications of these findings for the provision of effective decision support for patients considering one or more treatment option. By "information", we are referring to facts and opinions that may affect a patient's choice. Understanding which pieces of information affect the decisions clarifies the information that should be provided to the patients, for them to be able to make informed decisions consistent with their values. Our endeavor is to update previous reviews of this literature¹⁻³ and to put the literature into the broader context of decision science, thereby helping to resolve previously identified apparent inconsistencies. While several other factors are known to possibly influence patients' decisions (e.g., anxiety

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or distress), this review focuses only on the information items identified in the literature as affecting the decision as a means for ensuring the patients are provided with appropriate information to ensure their decisions are well informed.

To help organize the evidence, we begin with a common clinical paradigm used by clinicians considering this decision, namely, the balance between chances of cure against the risks to bladder, bowel, and sexual function. It is this approach that is typified by decision analytic models of the decision.^{4,8} We then expand this consideration to show that the relevant information related to the balance between potential benefits and side effects is more complex than is apparent in this common paradigm, and further, that there is information beyond the classic benefit-risks paradigm that is commonly deemed by patients as being important to their decisions. Finally, we apply our theoretical understanding of the decision processes to resolve apparent inconsistencies previously identified in the literature regarding information needs.

Materials and methods

We conducted a systematic review of the Web of Knowledge, using ALL DATABASES option with the following MESH headings: Title = (prostat* and (cancer or carcinoma)) AND Title = (decid* or decision or choice or choose or choosing or chose or select* or option*) NOT Title = (screen* or metastat* or detect*).

This search yielded 992 publications. Using Web of Knowledge "results analysis", we excluded papers whose primary subject area is "biochemistry or molecular biology"; this left 798 titles. Using titles and abstracts, this group was then restricted to decision making for early stage prostate cancer, leaving 120 titles. Finally, reviewing the full papers led to a corpus of 21 papers that provide primary evidence on which factors affect actual patients' choices. We deemed papers that identified associates (e.g., demographic or psychological factors) of particular choices, those studying hypothetical choices, and those addressing information needs of the patients for reasons other than decision making (e.g., to understand, to plan, etc) as not relevant to this particular analysis. Table 1 lists the qualitative studies and Table 2 lists the quantitative studies that we found that provide relevant evidence.

Results

Data on what information affects early stage prostate cancer patients' treatment decisions come from different types of studies, including qualitative and

quantitative, prospective and retrospective studies. Capitalizing on the strengths of each type of study such as combining the depth of understanding gleaned from the qualitative studies with the prevalence estimates from the quantitative studies, leads us to conclude that the information that affects many of these patients' treatment decisions extends well beyond that accounted for by the common medical paradigm.

Consistent with the common medical paradigm and with observations made in previous reviews, the evidence suggests that patients are motivated to have treatment to eradicate the cancer and that many patients consider the treatments' potential impact on bladder functioning, on bowel functioning, and on sexual functioning. Tables 1 and 2 identify the qualitative and quantitative studies, respectively, that provide this evidence, and list selected examples of information items identified in each study. As can be seen, all studies provide evidence consistent with the paradigm except the two papers that were devoted to determining why men refuse all standard treatments.^{9,10} The evidence, however, also suggests that there is wide variability amongst patients in exactly what information within the categories affects their decisions. Only quantitative studies can establish extent of variability and, as can be seen in Table 2, all of the studies (except one that studied the sensitivity of the decision to one piece of information) provide evidence of high variability. We will first discuss the evidence related to potential benefits, then the evidence related to potential side effects.

While most patients report being motivated to have treatment in order to eradicate the disease, as Zeliadt et al² suggest in their review, there appears to be a disconnect between what patients say is important and what actually influences their decisions: patients appear to say that particular potential outcomes affect their decisions but, in the end, what actually seems to affect their choice is different. This disconnect seems to occur particularly when considering the impact of potential efficacy of treatments on the decision: once patients learn that efficacy does not differ greatly amongst the active treatments, for many patients, relative treatment efficacy recedes as being a factor that affects the choice.¹¹ However, for other patients small differences in efficacy are important: a sensitivity assessment shows that an absolute difference as small as 1% in the chances of survival at 10 years would affect some patients' decisions.¹² In addition to the chances of survival, some patients see potential benefits of treatment to include control over cancer spread outside the prostate. But, there is variability in which aspect of the control it is that affects the decision: some patients

TABLE 1. Qualitative studies

Papers	Factors related to: cure rate, bladder, bowel and sexual functioning	Additional factors		
		Process	Competencies	Opinions
Berry et al ^{31,62}	Yes	Urgency to get treatment		Doctor Friends Family Business partners Celebrities
Chapple et al ²¹	Yes	Desire for rapid treatment Daily trip for RT Do something active		Family members Doctors Support groups
Davison et al ³⁰	Yes	Decision control		Doctor Family Friends
Denberg et al ²⁵	Yes	Desire for rapid treatment Length of treatment time	Competency of doctor	
Henrikson et al ¹⁶	Yes	Reversibility of treatment Decision timing		
O'Rourke ²⁸	Yes	Timing Withholding physician information Busy docs	Trust in physician	Doctor
O'Rourke ¹⁵	Yes	Do nothing/ do something	Trust in physician Renown facility Urologist's competency	Urologist Family doctor
Verhoef et al ⁹	n/a	Whole-person care		
White & Verhoef ¹⁰	n/a	Control over timing		
White et al ²⁴	n/a	Control over decision making, healing approach		Family doctor Family

consider the chances that cancer will spread^{11,13,14} to be important while others consider where the cancer is likely to spread as most important (for example, wanting to avoid potential brain metastases).¹⁴ In addition, some patients perceive a benefit of surgery to be having a second-line treatment available should the first fail.^{11,15,16} Thus, across patients, the important information related to potential benefit is more complex than simply the goal of eradicating disease.

Evidence on patients' desire to avoid side effects also shows wide variability across patients. One indicator suggesting wide variability is the fact that, in groups of patients, very few factors affect the decisions of even

half the patients: the papers all suggest that the most prevalent risk that patients want to avoid is treatment's effect on bladder functioning^{11,17-19} but no paper suggests that it is a universally important factor. Risk of impact on bowel functioning and on sexual functioning, each, are the most important factor to some patients but not at all important to others.²⁰ The variability is further demonstrated by the evidence that, although it is a very rare side effect, the chance of the treatment causing death is very important to some patients.¹¹ Studies that detail the decision-relevant information show that many patients define their side effect concerns in terms of the treatments' impact on their quality of life.^{13,21}

TABLE 2. Quantitative studies

Papers	Factors related to: cure rate, bladder, bowel and sexual functioning	Additional factors			High inter patient variability
		Process	Competencies	Opinions	
Berry et al ²²	Yes			Doctor Friends Family Famous people	Didn't report
Brundage et al ¹²	Yes	n/a			Yes
Crawford et al ¹³	Yes	Cost			Didn't report
Demark- Wahnefried et al ²³	Yes	Cost		Doctors Family Friends	Didn't report
Diefenbach et al ²⁹	Yes	Convenience Invasiveness		Doctors Family Friends	Didn't report
Feldman- Stewart et al ¹⁴	Yes	Length of time to complete entire treatment	Doctor's experience	Doctor	Yes
Feldman- Stewart et al ¹⁸ (replication of 2001 study a decade later)		Need for escort to and from treatment	Experience of non-physician staff		
Feldman- Stewart et al ¹¹	Yes	Time to recover When treatment can start	Doctor's experience	Other patients Doctor	Yes
Feldman- Stewart et al ⁶²	Yes	How long can I safely take to make up my mind When treatment can start	Equipment up to date Doctor's experience		Yes
Gwede et al ²⁶	Yes	Invasiveness			Didn't report
Hall et al ²⁰	Yes	Recovery time		Doctor	Yes
Holmboe & Concato ¹⁷	Yes	Duration of treatment		Doctor Family	Yes
Steginga et al ¹⁹	Yes	Anticipated regret Hospital stay		Doctor	Yes

This impact is articulated by some men as “impact on discomfort”,¹¹ by others as impact on activities of daily life,^{11,15,22} impact on recreation²² and by others as impact on their ability to work.¹¹ For yet others, their concern is focused more broadly to include all aspects of impact on their family¹¹ and/or finances.^{13,14,23} Longitudinal effects are evident in what information relating to side effects affects the decisions but, rather than being systematic as seen with efficacy, the changes over time related to side effects appear to be random. A large proportion of

patients appear to demonstrate shifts in the information that affect their decisions over time.¹¹ We will return to this shortly.

Summarizing the above findings, many men do seem to make this treatment decision by weighing benefits such as cure but also cancer control against side effects. The high variability among patients, the particular details of the decision-relevant information that are important, and the shifts over time make the simple weighing of three primary potential side effects

against one benefit considered in the simple clinical paradigm to be inadequate in capturing what affects most patients' decisions.

Beyond weighing the potential benefits of treatment against their potential side effects, evidence suggests that many patients also weigh other types of information. Tables 1 and 2 identify which studies provide that evidence and, as can be seen, almost every primary study identified information beyond conventional benefits and risks. We have grouped the additional details into three categories; the category labels, emerging from the details they were intended to capture, were chosen by the authors.

The first additional category of information can be conceptualized as "process issues" around having the various treatments, that is, actions or steps taken in order to achieve a particular end. Such information includes the travelling required to get to treatment,^{19,21} how to know if the treatment was effective,¹¹ the location where the treatment would be provided,¹¹ timing of treatment (e.g., relative to work schedule or other important events),^{11,24} the total length of time required for the treatment,^{15,17,25} and time to recover.^{11,20} Other process issues relate to the procedures of the treatment itself, such as surgery's cutting out the tumor (sometimes a pro, sometimes a con)^{11,17,25} or, more generally, wanting the least invasive treatment,^{26,27} and what can be done to alleviate particular side effects.¹⁰ Finally other process issues relate specifically to decision making such as being able to get a second opinion¹¹ or wanting to have more personal control than is being offered,⁹ including more control over timing¹⁶ or better communication with the doctor.⁹

A second additional category relates to the competency of the system caring for them, that is, the ability of the healthcare system to provide their care successfully or efficiently. These factors include the experience of the doctor,¹¹ the experience of the non-physician staff,¹⁴ and whether the equipment is up-to-date.¹⁴

A final additional category of information relates to the fact that the treatment decision is complicated, driving some patients to want assistance with the decision process by using the opinions of those they consider "expert", in other words using "decision assistance". For example, a prevalent factor in this category is that some patients' choices are affected by the opinion of their doctors^{15,28-31} but also of other patients.¹¹ We suggest that these opinions are different for the decision-making patients from those of their family members and friends; these would not necessarily be seen as expert opinion but are valued by many patients,²⁹ in part, because the decision is so

difficult. Alternatively, some patients use anecdotes of the experience of others (often without being clear about whether it is appropriate to generalize from these anecdotal situations³²).

One further note on the extent of variability: while variability estimates can only come from quantitative studies, the most accurate assessments would come from studies of the decision as it happens. One study of 60 patients using a decision aid found that 33 different information details affected the 60 decisions, and each of 18 different pieces of information was someone's "most important" issue affecting their decision.¹¹ In that group, again only one piece of information affected the decisions of more than 50% of the patients: the impact of the treatment on their bladder functioning. These data corroborate the findings of high variability across other studies reviewed.

Discussion

We were motivated to identify the information that affects the treatment choices of early stage prostate cancer patients in order to help identify the information that should be provided to patients so that they can make decisions consistent with their values. Our review has led to an extensive list of information items. The evidence leads us to conclude that three key themes underlie what makes the list complex: (1) there is high variability amongst patients in what affects their decisions, (2) the variability results in a wide scope of information being potentially important, and emphasizes the importance of particular details of information within this scope to individual patients, and (3) the decision-making process is protracted in time. It is by looking at the detail that we gain insight into what is important to individuals and into how widely the important information differs from one patient to the next. Understanding that the decision process is protracted in time leads us to examine if and how these factors change with time, and to examine when change is systematic across people and when it is not.

As we noted, high variability is illustrated by the fact that no information (other than impact on bladder functioning) appears prevalent enough to affect the decisions of more than half of the patients. It is worth asking if the apparent variability is due to the design of the studies that identified the information. For example, inappropriate variability could arise because some studies include prostate cancer patients who don't have early stage disease.^{13,23} Estimates of variability might also be spuriously high in retrospective studies wherein the information

actually provided to the patients before they made their decisions limits what they can consider to be important. That information likely varies considerably across doctors since treatment patterns show high geographic variation in care³³ and evidence suggests that the information provided to patients is often slanted toward the physician's preference.³⁴ That the variability was still evident even when the information provided was the same across patients, as in decision aid studies, suggests that study design is not the cause of the variability seen. We also note that high inter-patient variability in what information affects decisions has been noted in other medical decisions.³⁵⁻³⁷

An important observation in these studies is that the specific information that patients deem affects their decision can change over time. We suggest these changes occur because, in fact, the decision-making process is protracted in time. For many of these patients, this decision is "incomparable with any other life decisions" they had faced previously¹⁵ in terms of complexity, seriousness, or both. New decisions demand particular cognitive processes, and understanding the processes can help clarify why the decision takes time and why the specific information affecting the decision can change. We noted above that many of the shifts over time appear random. With new information, patients can change their attitudes, as their understanding of the options improves, and as they become clear about what they prefer. That is, in new decisions, people often need to discover which of their values are relevant and can discover that they have values that are in conflict with one another --- for example, the values for quantity but also for quality of life. We note, for example, that over three-quarters of the patients in one decision aid study changed either which information they thought affected the selection of their most preferred option or the information's relative importance during their use of the decision aid (all had previously discussed their diagnosis and treatment options with both a urologist and a radiation oncologist).¹¹ These shifts are consistent with Svenson's descriptive theory of how people make decisions. In his theory, the shifts reflect a systematic process (called "differentiation") that eventually results in the decision maker having a single preferred option.³⁸ Thus, each study that looks at information affecting treatment decisions at just one point in time, is only getting one snapshot in a process that can be quite extended and include many shifts. Although the shifts may appear to be random when looking across patients, for each individual patient the shift is part of a systematic process that is inherent to arriving at a single preferred choice.

We note that although the information list we have arrived at in this review is very long with few information details affecting a majority of patient decisions, we suggest that the list is not random. The stability of such data was assessed in a comparison of questions deemed "essential for decision-making" by two different groups of patients separated by 10 years:¹⁸ despite high variation amongst patients in each group, the prevalence of essential questions was highly correlated across the groups. Thus, the information that is most frequently important to patients' decisions appear to be relatively consistent at the group level, despite individual variation.

In the list identified in this review, three categories of information emerged that have not typically been identified as affecting this treatment decision. The categories, however, do coincide with the literature identifying patient concerns affecting other decisions. Related to the first category, process factors, patients in other settings have identified information relating the procedures involved in treatment as affecting their decisions^{39,40} but also to other processes such as office procedures.⁴¹ Related to the second category, competency of the system providing care, patients facing other decisions have identified several competencies of physicians including their therapeutic skills,^{42,36} their communication skills⁴³ and skills at engaging in shared decision making,^{44,45} and also identified competency of the organization⁴⁶ as affecting the patients' decisions. The final additional category, decision assistance including physician recommendation, has been studied specifically in the treatment of prostate cancer and, consistent with our review, has found it was influential in some patients' decisions;⁴⁷ physician recommendation has also been reported as influential in other patient decisions.⁴⁸ Using the experience of previously treated patients to help their decision making has been identified in many settings,^{49,50} and the use of patient stories in patient decision aids is a vibrant point of discussion within efforts to set standards for patient decision aids (IPDAS).⁵¹ Thus, details of the additional categories of information identified in this review have been identified as affecting other patient decisions. We recognize that other systematic ways of categorizing these information items might be also useful for other applications (for example, using a behavioral science framework to evaluate the influence of social support).

Each of the complexities that we have identified has implications both for clinicians and for researchers. The high inter-patient variability means that to cover the needs of the individual patient, either all patients need to receive all information---which risks overwhelming

them---or information provision needs to be tailored to the needs of the individual. We note that efforts at identifying correlates of individuals' needs (e.g. their age or education level)^{18,31,52} have not proved to be very helpful at predicting either the treatment choice or the information that affects the decision, since correlations have been weak even when statistically significant. We recognize that clinicians already frequently tailor their information provision to the individual patient, including altering the complexity of their language and the speed with which information is provided. The challenge in tailoring which pieces of information to provide to individual patients is a particular clinical challenge, as evidence shows that the information priorities of the clinicians often differ from those of their patients.⁵³ The importance of particular details, some of which are unanticipated, increases the complexity of that challenge. The longitudinal nature of the decision processes further adds to that challenge while it also highlights the disservice to patients who are not offered time to decide.³⁴ We suggest that systematic interventions such as patient decision aids can help.

Several patient decision aids have been developed to help early stage prostate cancer patients with this decision.^{11,54-59} They are all systematic approaches to the decision with varying attempts to address the needs of the individual; decision aids can be designed to allow the individual patient to identify the particular information that affects his decision, to clarify his values regarding this information, including information related to process, competency, and decision assistance.¹¹

A recent review of prostate cancer patients' experiences in their care suggests that there is still a need amongst the patients for information related to their treatment options.⁶⁰ And a review of decision aids for this decision suggests that the interventions are effective at helping patients become more informed, while simultaneously reducing their anxiety and distress.⁶¹ Thus, there appears to be a need for decision support and there are interventions that are effective at helping address the need; we suggest their use would help the large proportion of patients with early stage prostate cancer who want to participate in the decision.⁶²

We conclude that while early stage prostate cancer patients appear to be driven to choose their treatment by the desire to eradicate the cancer and the desire to limit unpleasant medical consequences, there is other important information that influences the decisions of many of them. Other information includes that which relates to treatment and decision processes,

to competency of the system, and to help with the decision-making process. Within each of these areas, the precise details that are important vary a great deal from one patient to the next. And, the longitudinal nature of making this complex decision often results in changes within a patient in the information that ultimately affects his decision. It is only by providing patients with well organized information and time to process it all, that the patients have any potential of sorting out what is important to them and of arriving at a preferred treatment choice---a challenge for an unsupported busy clinical practice. □

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